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## **2010 Title V Needs Assessment of the Maternal and Child Health Population**

### **1. Process for Conducting Needs Assessment**

#### **Goals and Vision**

The goal of the 2010 Title V Needs Assessment is to identify leading and emerging health issues impacting women, infants, and children (including those with special health care needs) in Louisiana through the engagement of key Maternal and Child Health (MCH) and Children with Special Health Care Needs (CYSHCN) stakeholders. Through the sharing of qualitative and quantitative data and information with stakeholders and MCH and CYSHCN Program staff, MCH will ensure data-driven decision-making for resource allocation to meet the population's identified needs.

The Louisiana MCH and CYSHCN Program's vision for the Needs Assessment is to take the results of the qualitative and quantitative information gathered from MCH and CYSHCN stakeholders in each region of the state and among the MCH and CYSHCN population groups, and to synthesize these findings to establish the priority needs of the MCH and CYSHCN population for the period 2010 – 2015. The consumer and stakeholder findings, along with the most current MCH and CYSHCN data, will be synthesized by MCH and CYSHCN Program leaders to develop a plan to allocate resources in a manner that reflects the concerns of Louisiana citizens and experts, the needs of the MCH and CYSHCN population as expressed in the data, and the capacity of the state to meet these needs.

The purpose of the 2010 Needs Assessment is threefold.

- To engage MCH and CYSHCN stakeholders in the identification and prioritization of health needs and strategies to address the needs of maternal and child population in Louisiana
- To critically review local, regional and state MCH and CYSHCN data and state capacity in order to set objectives, create an MCH and CYSHCN action plan, and allocate resources from MCH Block Grant and other funding sources.
- To monitor and evaluate on an on-going annual basis State Performance Measures, National Performance Measures, Outcome Measures, Health Status Indicators, Health System Capacity Indicators, and progress on the MCH and CYSHCN action plan

The framework that guides the Needs Assessment process reflects the State Title V MCH Program Needs Assessment, Planning and Implementation Process depicted below. By conducting the 5-year Needs Assessment, Louisiana's MCH and CYSHCN programs take the opportunity to engage and check-in with stakeholders in all regions of the state, assess needs, examine strengths and capacity, and set priorities and targets for the MCH and CYSHCN program for the next 5 years. The next step is to develop an action plan, allocate and seek additional resources, monitor progress, and report back to stakeholders on a regular basis.

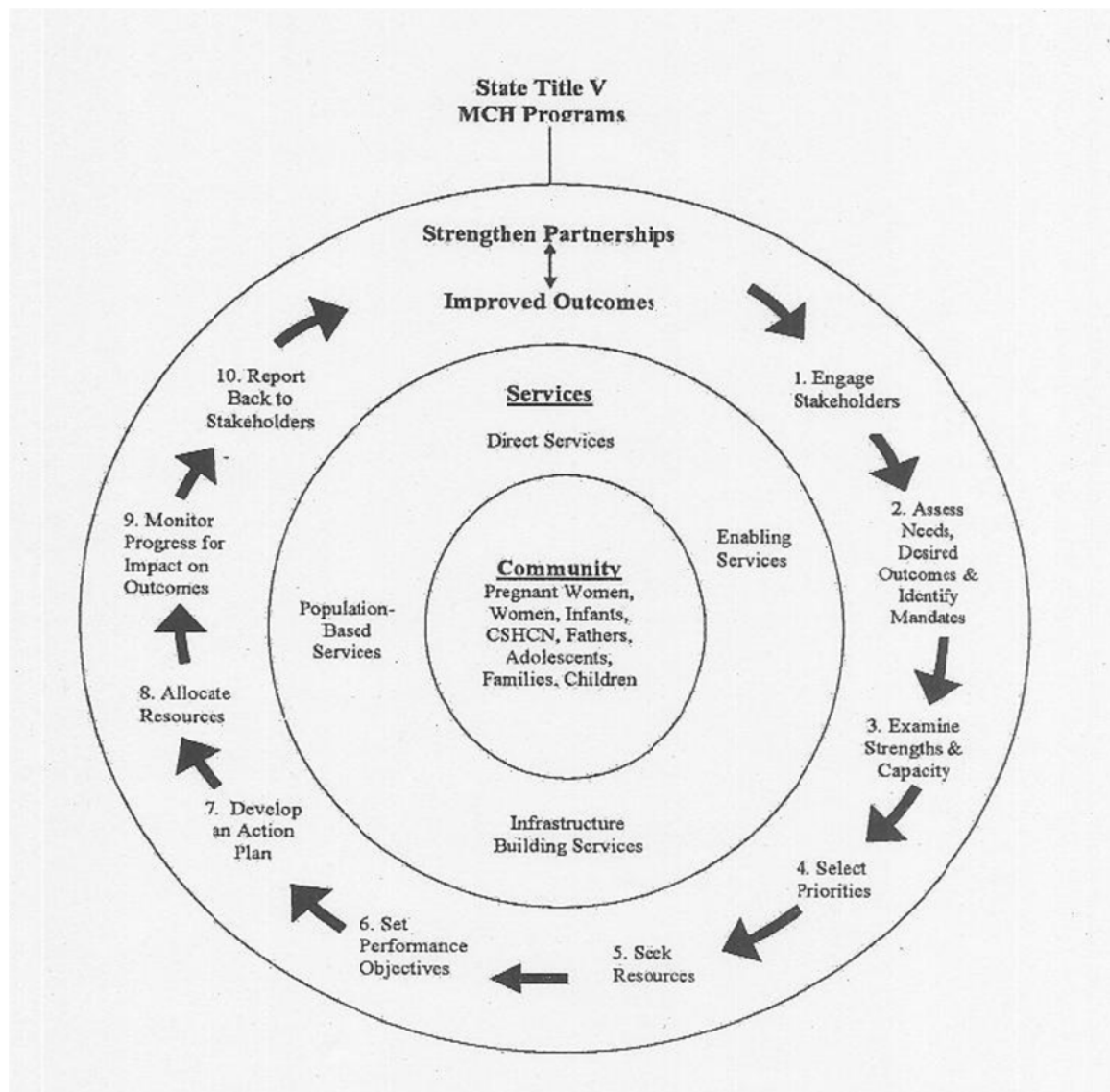


Figure 1: State Title V MCH Program Needs Assessment, Planning and Implementation Process

### **Leadership**

The MCH and CYSHCN Program formed a needs assessment steering committee in mid- 2009 to plan the 2010 Title V Needs Assessment process. The committee consisted of individuals critical to effective planning and implementation of maternal and child health initiatives in Louisiana and included the following: MCH Program Director, Maternal Health Medical Director, Child Health Medical Director, CDC assigned MCH Epidemiologist, Child Health Epidemiologist, Child Safety and State Child Death Review Panel Coordinator, Oral Health Epidemiologist, Adolescent and School Health Program Manager, Needs Assessment Epidemiologist, MCH Health Education and Communications Director, Perinatal Services Director, and Needs Assessment Coordinator. The committee organized the needs assessment process into five subgroups including Perinatal Health, Child Health, Adolescent Health, Oral Health and Children with Special Health Care Needs. The roles and responsibilities of committee members included the provision of strategic direction and oversight for all activities associated with the needs assessment. The committee met at least one to two times monthly to review progress and provide recommendations for

improvement. The Needs Assessment Coordinator, a consultant from the Louisiana Public Health Institute, facilitated and coordinated the MCH Needs Assessment process.

Note: The needs assessment process and results for the Children with Special Health Care Needs subgroup can be found on page 74.

### **Methodology**

Louisiana's Office of Public Health's Maternal and Child Health Program's Needs Assessment methodology consisted of extensive stakeholder input in each region of the state and among each MCH population group. Current MCH data was presented at meetings with the Public Health Directors of each of the 9 regions and in 9 additional community stakeholders meetings that included Fetal Infant Mortality Review (FIMR) Panels and Community Action Team members, and the 9 regional Child Safety/Child Death Review Panels (focusing on child safety). In addition, the Child and Adolescent Health subgroup gathered input from the EMS-C Advisory Council, American Academy of Pediatrics members, Louisiana's Early Childhood Comprehensive Systems Steering Committee, Louisiana Children's Cabinet Advisory Board. The Statewide Oral Health Coalition provided the input for the Oral Health subgroup, and the School-Based Health Center (SBHC) Network provided feedback for the adolescent population. A uniform methodology was used to determine priority needs and recommended strategies.

In an effort to solicit feedback from consumers of MCH related resources and services, MCH launched a survey to assess the public's view of women's health, infant and child health, oral health, adolescent health and access to medical, dental and mental health services. Surveys were mailed to every parish health unit throughout Louisiana over a two month survey period. Patients of parish health units were encouraged to complete the survey and provide additional comments relevant to the needs of women, infants and children. Over 2,500 surveys were analyzed and results presented at each state and regional perinatal, child health, child safety and oral health meeting. These efforts yielded valuable information regarding the public's perspective of the needs of women, infants and children throughout the state.

Data on MCH Block Grant outcome measures, performance measures and health status indicators were vital components to Louisiana's 2010 Title V Needs Assessment data presentations. These data were used as tools to facilitate thorough analysis and foster informed decision making by MCH stakeholders. Through a series of regional and statewide meetings, state MCH leaders received valuable feedback regarding the needs of women, infants and children as well as the local and regional capacity to address the needs.

The 2010 Title V Needs Assessment consisted of 3 major components of collection: secondary data compilation and review, data collection and reporting on federal and state performance measures and health status indicators, and primary data collection from consumers and expert stakeholders. Each subgroup worked with an MCH Epidemiologist to systematically review existing databases, state and national reports, and websites for data and information pertinent to describing the health status of Louisiana's MCH population. Each of the five subgroups utilized distinct processes for performing their respective needs assessments. These processes are outlined further in the following sections.

### **Methods for Assessing the Three MCH Population Groups**

#### **Perinatal**

The quantitative methods used by the perinatal subgroup to assess strengths and needs were based on the regional data presentations that occurred in each of the state's nine administrative regions. The presentations included a detailed set of statistics on a range of health indicators commonly used to assess MCH populations. The presentations were prepared by the Maternity subgroup's lead epidemiologist. The health indicators examined included measures of infant mortality, preterm birth, teen pregnancy, unintended pregnancy, birth weight, birth defects, preconception health, pregnancy spacing, Medicaid paid deliveries, prenatal care entry, adequacy of prenatal care, fetal mortality, perinatal mortality, breastfeeding, gestational diabetes, high blood pressure, SIDS, partner violence, alcohol and tobacco use, sexually transmitted diseases (STDs), and mental health. These data were based on analyses of vital records, Louisiana PRAMS, The Louisiana Birth Defects Monitoring Network, behavioral health data, The Louisiana STD program, the National Immunization Survey, and U.S. census data.

Data from several multivariate analyses were also included in the presentations. An analysis of Louisiana birth cohort data examining factors associated with pregnancy spacing was included. This analysis found a strong association between pregnancy spacing and low birth weight births. In a separate analysis, data from the Louisiana Birth Defects Monitoring Network was analyzed to identify factors associated with birth defects. This analysis assessed whether variables such as preterm birth and birth weight were associated with birth defects. Another analysis examined factors associated with repeat preterm birth using Louisiana vital records data for the years 1999 to 2003. This analysis revealed that having a previous preterm birth and mother's race were associated with having a repeat preterm birth. Lastly, an analysis of 2000 to 2004 Louisiana PRAMS data explored factors associated with moderate preterm birth and very preterm birth. This analysis revealed that measures of hypertension, pregnancy spacing and prenatal care adequacy were each associated with moderate preterm birth and very preterm birth.

The breadth of the data included in the regional presentations allowed for a clear and current assessment of areas where the MCH program has done well in providing access to primary and preventive health care services. The presentations used the infrastructure of the network of regional FIMR's to coordinate the planning of the regional meetings. Since 2003 with initiation of the first FIMR stakeholder meeting, the FIMR's have been a critical component in the coordination and implementation of MCH program initiatives. The regional stakeholder meetings proceeded in two stages. The first stage involved the presentation of the epidemiological data and the data from the consumer survey. The meetings were facilitated by Louisiana Public Health Institute (LPHI) Needs Assessment Coordinator and the Maternal and Child Health Program Needs Assessment Epidemiologist. Each regional meeting began with an overview of the purpose of the Needs Assessment. The LPHI liaison instructed stakeholders to consider three questions as they followed the presentations: What are the priority MCH needs for your region?; What service gaps currently exist in these areas?; and What strategies are needed in these areas? Following this, data was presented from the consumer survey. Coupled with the epidemiologic data presented, the consumer survey offered an additional piece of information with which stakeholders could use to evaluate the needs of their respective region. Following the presentation of the consumer survey data, the Needs Assessment Epidemiologist presented regional, state and U.S. data on the aforementioned health indicators. At the end of this presentation, the LPHI liaison led stakeholders through an exercise to identify the top 10 needs of their region. This process concluded the first needs assessment presentation. After the presentations, stakeholders were invited and encouraged to attend a follow up meeting in which the top 10 preliminary priority needs would be reduced to 5 priority needs and strategies to address those needs would also be identified.

The MCHB prioritization worksheet was the tool used by the Maternity subgroup to qualitatively assess the strengths and needs of our MCH populations. The meeting began with a recap of the top 10 needs identified at the first regional meeting. Following this brief synopsis, the LPHI liaison led stakeholders through an exercise to identify the top 5 priority needs of the region using a worksheet developed by the Maternal and Child Health Bureau (MCHB). The worksheet employed an algorithm to rank the 10 preliminary needs identified at the first regional meeting. This algorithm involved scoring the preliminary needs according to 5 criteria. These criteria were: 1) ranking the extent of the problem, 2) determine whether trends are increasing, 3) identify the severity of consequences, 4) determine the acceptability of the issue, and 5) determine whether resources are available to address the issue. Stakeholders were then asked if the top 5 needs were representative of what they believed to be the top priority needs of their region. Once a consensus was reached, stakeholders were asked to identify strategies to address priority needs.

The MCH program's needs assessment epidemiologist examined the results across all regions to identify the most commonly occurring issues. During this process some issues were collapsed into one category. For example, mental health issues and substance abuse were rolled into one category labeled behavioral health. Once the rankings were completed the needs assessment epidemiologist placed the data into a table that could be used as a reference of the results from the regional presentations.

### *Child Health and Safety*

A child health needs assessment was performed by the child health subgroup, and for the first time, a separate child safety/injury prevention needs assessment was also performed. Child Health subgroup's approach to assessing the health and safety needs of the MCH population was guided by quantitative and qualitative methods of analyses. The quantitative method was based on data analysis using a detailed set of child health and safety indicators for ages 0-19 years. The Child Health subgroup and members of the MCH needs assessment steering committee reviewed and selected the final child health and safety indicators based on state needs, data availability, and resource limitations. The indicators were selected from the U.S. Census, Annie Casey Foundation Kids Count, Healthy People 2010, MCH Title V Block Grant Health Status Indicators and National Outcome Measures, National Survey of Children's Health, National Survey of Children with Special Health Care Needs, Louisiana MCH data profiles, and Louisiana Pregnancy Risk Assessment Monitoring System (PRAMS). The indicators of child health included infant, child, and adolescent mortality; access to medical care, medical home, and school-based health center services; birth weight; breastfeeding initiation and at six months of age; SIDS (Sudden Infant Death Syndrome); child immunization; child asthma (hospitalization); child obesity; child lead poisoning, health insurance status; child poverty; Medicaid-eligible children who received a paid service by Medicaid; EPSDT- eligible children who received a dental service; teen pregnancy; sexually transmitted infections (STI) among children and adolescents; alcohol use, smoking, and substance abuse among adolescent; and high school dropouts. The indicators of child safety included infant, child, and adolescent mortality by cause; infant, child, and adolescent unintentional injury mortality by cause (motor vehicle, accidental suffocation, fire, drowning, firearms, others); intentional injury mortality (homicide and suicide); and substantiated child abuse and neglect. Each indicator had a standardized definition and measurement.

MCH epidemiologists analyzed data for child health and safety indicators at the state level. Since local/regional level data was not available for most of the child health indicators, only the indicators of child safety were analyzed by the nine Office of Public Health regions. When data were available, indicators were analyzed by race (White and Black) and for trends. The national

level data were obtained for each indicator, when available, for data comparison. Data books and presentations of key child health and child safety indicators were prepared by the MCH child health epidemiologist and presented to stakeholders to obtain their perceptions of the health and safety needs of children. (See Appendix D for the detailed lists of the indicators and data sources.)

The qualitative method for assessing child health priority needs in Louisiana involved the use of a needs assessment survey to obtain broad-based feedback from child health stakeholders. State and community level feedback was obtained from leaders and policymakers of the Office of Public Health and of the Childrens Cabinet Advisory Board (CCAB) and *BrightStart*, Louisiana's Early Childhood Comprehensive Systems Initiative. CCAB and *BrightStart* included representatives from child-serving state agencies, children's advocacy groups, children's coalitions, private health practitioners, faith-based community groups, and state legislators. Provider feedback included public health, school-based health, and private sector healthcare providers, which consisted of pediatricians and other physicians, nurses, and social workers. Consumer input, which consisted of parental feedback, was collected with the MCH consumer survey, which assessed the public's view of infant, child, and adolescent health as well as women's health, oral health, and access to medical, dental and mental health services.

A child health needs assessment survey tool was developed and used to obtain input from all stakeholders. The needs assessment survey queried stakeholders to rank their top ten health priority areas for children ages 0-19 years from a given list, with the option to add and rank additional needs not listed. This same list of priority areas was used by the stakeholders to perform rankings by the following age sub-groups: 0-5 years, 6-10 years, 11-14 years, and 15-19 years. The priority areas were derived from the selected child health indicators, which were previously discussed, and from the list of 2005 Title V Block Grant priority areas on the National Survey of Children's Health website. Stakeholders also assessed the capacity of the communities to meet the priority child health needs ages 0-19 years by examining the availability of and accessibility to resources and services from a given list, with the option to add resources and services not listed. This list consisted of resources and services that currently exist in Louisiana. Stakeholders also selected public health strategies, from a list of interventions, they believed were necessary to address each of the top five priority areas/needs for children ages 0-19 years. These strategies included early identification, screening, and referral; preventive/direct services; public education and social marketing; policy development, legislation, and advocacy; education/trainings to professionals; community partnership mobilization; and data, research, and quality assurance. The child health needs assessment survey was disseminated and collected both electronically and in paper form. Paper and electronic versions of the child health needs assessment were given to stakeholders in an attempt to increase response rates. In addition, the child health needs assessment survey was disseminated at the Louisiana American Academy of Pediatrics's Annual Conference in an attempt to achieve input from pediatricians. After compiling the stakeholder input, the Child Health subgroup used a frequency analysis to rank the top ten health needs of children, ages 0-19 years.

The qualitative method for assessing child safety/injury prevention priority areas and needs in Louisiana also involved the use of a needs assessment survey to obtain broad-based feedback from state and local level stakeholders. Louisiana's state and local Child Death Review Panels (CDRP) are managed by the MCH Program. Notably, the state-level and local/regional MCH Child Safety Coordinators also serve as the state and local CDRP Coordinators respectively. Therefore it was decided to use the state and local CDRPs as the target stakeholder groups. The panels include safety/injury prevention policy makers and agency directors/coordinators; physicians from medical professional associations/societies; first responders from emergency

medical service (EMS), fire department, and law enforcement; child protective services, coroners, and other professionals involved in the investigation of infant and child deaths. State-level stakeholder feedback was also obtained from the EMS/Injury Research & Prevention Program (IRPP), which performs the Child Death Review data surveillance, the writing of the CDR annual report to the legislature, and injury morbidity/mortality data surveillance for the state; and from the Emergency Medical Services for Children (EMSC) Advisory Council, which consists of public health and private sector policy makers and pre-hospital and hospital-based health care providers. Consumer input regarding infant, child, and adolescent safety/injury prevention was collected with the MCH consumer survey.

A child safety/injury prevention needs assessment survey tool was developed and used to obtain input from injury prevention and child safety stakeholders to gauge their perceptions of the priority areas, resource and services, and strategies to address the priority areas. An overview presentation of Louisiana infant, child, and adolescent injury-related mortality data preceded the administration of the needs assessment survey. Though the primary age group for the assessment was 0-14 years, which corresponds with the age range for case reviews by Louisiana Child Death Review, other age subgroups were also assessed. The needs assessment survey queried stakeholders to rank their top ten child safety/injury prevention priority areas and needs of Louisiana's children ages 0-14 years from a given list, with the option to add and rank additional needs not listed. This same list of priority areas was used by the stakeholders to perform rankings by the following age sub-groups: 0-5 years, 6-14 years, and 15-19 years. The priority areas were derived from the selected child safety/injury prevention indicators, which were previously discussed, and from the causes of death stated in the National Center for Child Death Review's Program *Manual for Child Death Review*. Stakeholders also assessed the capacity of the communities to meet the priority child safety needs ages 0-14 years and 15-19 years by examining the availability of and accessibility to resources and services from a given list, with the option to add resources and services not listed. This list consisted of resources and services that currently exist in Louisiana as well as those recognized as effective injury prevention services by the National Center for Child Death Review and the Children's Safety Network. Stakeholders also selected public health strategies, from a predetermined list, they believed were necessary to address each of the top five priority areas/needs for children ages 0-14 years and 15-19 years. These strategies included early identification, screening, and referral; preventive/direct services; public education and social marketing; policy development, legislation, and advocacy; education/trainings to professionals; community partnership mobilization; and data, research, and quality assurance. Data which included infant, child, and adolescent injury-related mortality data by leading causes and manner (intentional and unintentional/accidental) was presented after the survey was completed by every individual present. A post prioritization assessment was conducted at the end of the presentation and discussion to gauge if perceptions of priority areas changed. Each stakeholder placed their five stickers on five different priority areas which were identical to those on the survey. After compiling the stakeholder input, the Child Safety subgroup used a frequency analysis to rank the top ten health needs of children, age 0-14 and 15-19 years. (See Appendix D for a copy of the Child Safety Regional Assessment Data book and Survey).

### Adolescent Health

The Adolescent and School Health Program's approach to assessing the health and safety needs of adolescents was also guided by quantitative and qualitative methods of analyses. The quantitative method was based on data analysis by MCH epidemiologists for the 15-19 years age subgroup of the child health and safety needs assessments, as described in the preceding Child Health and Safety section. The indicators of child health which include adolescents and/or was specific to adolescents include adolescent mortality; access to medical care, medical home, and



school-based health center services; immunization and child obesity; health insurance status; child poverty; teen pregnancy; sexually transmitted infections (STI) among adolescents; alcohol use, smoking, and substance abuse among adolescent; and high school dropouts. The indicators of child safety included adolescent mortality by cause and manner; adolescent unintentional injury mortality by cause (motor vehicle, accidental suffocation, fire, drowning, firearms, others); and intentional injury mortality (homicide, suicide, abuse and neglect). Each indicator had a standardized definition and measurement. When data were available, indicators were analyzed by race (White and Black) and for trends. The national level data were obtained for each indicator, when available, for data comparison purpose. These indicators were included in the data books and presentations prepared by MCH epidemiologists to use in the child health and child safety needs assessments process. (See Appendix D for the detailed lists of the indicators and data sources.)

The qualitative method for assessing adolescent health and safety priority needs in Louisiana involved the use of two different needs assessment surveys to obtain broad-based feedback from stakeholders. The Adolescent School Health Program (ASHP) asked physicians, nurse practitioners, registered nurses, licensed behavioral health professionals, and administrative assistant staff (a group of 250) who provide services in the sixty-two (62) school based health centers (SBHCs) in 26 parishes and all nine (9) regions of the state to submit general topics related to health concerns they see in the population they serve. SBHCs provide comprehensive, primary and preventive medical care and behavioral health services to students ranging in age from 2 to 21. From this list of general topics, a survey was compiled that divided the suggested topics into a list of concerns that focused on 2 age groupings (2 -12 and 13-21). The same group was then asked to indicate whether a particular topic was Very Important, Somewhat Important or Not Important to the specific age group based on their experience of providing health care within the SBHCs. The answers to this second request for information provided additional input for use in the child health and safety needs assessments. ASHP also incorporated the results for age subgroup 15-19 years from the child health and child safety needs assessments, which were conducted by the Child Health subgroup, to rank the top ten priority areas and needs for adolescents in Louisiana. ASHP distributed the Child Health survey to the same group of SBHC providers as previously described and their responses were included in the overall Child Health survey results

### Oral Health

The Oral Health subgroup utilized three methods to conduct the MCH Needs Assessment: a facilitated meeting of Oral Health stakeholders to review the consumer data from the MCH survey; an Oral Health Coalition meeting; and a Basic Screening Survey to measure the oral health of Louisiana's third grade population. In December of 2009 the Oral Health Program conducted an organizational meeting for a state-wide Oral Health Coalition attended by approximately 60 stakeholders representing a diverse audience. Attendees included individuals from the public and private sector, medical and dental professionals, Dental School, professional dental associations, and school health workers. A facilitated process was used during the Coalition meeting to determine priority needs and strategies to meet those needs in four identified areas: Policy, Access, Education and Prevention.

In January of 2010, The Louisiana Public Health Institute (LPHI) facilitated a meeting with key oral health stakeholders throughout the state representing higher education, medical and dental providers, and non-profit organizations who met to identify top oral health needs for women and children. Members engaged in a two step process to identify their top oral health needs. First, LPHI and staff from the Office of Public Health's Oral Health Program presented oral health

consumer and indicator data. Presenters shared feedback from the maternal and child health consumer based survey which assessed the importance of oral health among parish health unit clients. Participants also received information on the most recent oral health state and national indicator data available. Next the LPHI facilitator led the participants in a group discussion to review and discuss the summary key findings and developed a list of preliminary oral health needs based on available data and professional expertise. Once preliminary needs were identified, each participant marked their top five needs. Each need was tallied and the top five were recorded.

From 2007 to 2009, the Oral Health Program conducted a Basic Screening Survey to assess the oral health status of Louisiana's children. With the assistance of the Association of State and Territorial Dental Directors (ASTDD), the Oral Health program Epidemiologist utilized a Probability Proportional to Size Design to conduct the first representative sample for the state. The state of Louisiana has 64 parishes; all were included in the sampling methodology. For the purpose of this survey, the 64 parishes were divided into 4 geographical areas: Northern, Central, Southern, and River Parishes. The data was analyzed according to these four areas. The Oral Health Dental Director examined over 3,000 third-grade students for the presence of a dental sealant on a permanent molar; the presence of untreated cavities; the presence of caries experience; and the presence of dental care need. Dental care needs was categorized by "no problem"- absence of untreated decay or requirement to see a dentist so just regular care would be sufficient; "early care"- visible decay or problems and needs to see a dentist in the next 2 weeks; and "urgent care: - very serious decay or problem and needs to see a dentist within 24 hours.

### **Methods for Assessing State Capacity**

#### **Maternal Health**

The maternal health subgroup regional meetings were an essential tool in examining state capacity. As mentioned previously the meetings elicited detailed information from stakeholders regarding the top priority needs of their respective regions and the strategies they identified to address those needs. The MCHB Prioritization methodology used in each of these meetings include a measure assessing "whether resources are available to address the issue." Strategies varied widely across regions and represented a mix of ideas that ranged in regard to the feasibility of their implementation. Each of the strategies identified, mapped to one of the four levels of the MCHB pyramid of health services model; (e.g. direct, enabling, population and infrastructure building services). Using the regional feedback, the maternity subgroup, identified capacity through an assessment of each region's ability to address their identified priority needs. In addition, the maternity subgroups knowledge of available regional services and resources and awareness of MCH program's capacity to address identified strategies were essential to obtaining an accurate assessment of capacity.

#### **Child Health and Safety**

An inventory list of direct, enabling, population, and infrastructure-building services and resources that currently exist in the state from the MCH Program and other state programs was developed for both the Child Health and Child Safety needs assessment survey tool. Child Health and Child Safety stakeholders were asked to assess the capacity of the state/communities to meet the priority needs of children by examining the availability of and accessibility to resources and services on the child health and child safety inventory lists, respectively, with the option to add resources and services not listed. Stakeholders were then asked to select strategies, from the list of essential public health services on the survey, they felt were needed to address each of their top

five priority areas/needs for children ages 0-19 years. These essential public health services, include early identification, screening, and referral; preventive/direct services; public education, /social marketing; mobilize community partnerships; policy development, legislation, advocacy; education/trainings to professionals; and data/research/ quality assurance.

### Adolescent Health

For the purposes of this needs assessment, services and resources which address adolescent needs in Louisiana were included on the inventory lists of services and resources in the child health and safety needs assessment survey tools. Like the child health stakeholders, the ASHP stakeholders of the School-Based Health Center (SBHC) Sponsor's Network also assessed the capacity of the state and communities to meet the priority health needs of children ages 0-19 years by examining the availability of and accessibility to resources and services on the child health inventory list, with the option to add resources and services not listed. Child Safety/Injury Prevention stakeholders also assessed the capacity of the state and communities to meet the priority safety needs of adolescents ages 15-19 years by examining the availability of and accessibility to resources and services on the child safety inventory list. ASHP incorporated the findings for the adolescent age subgroups from the child health and safety needs assessments into their prioritization and strategic planning processes.

Additionally, OPH/ASHP established capacity and needs through a review of the needs assessments submitted to OPH as part of its funding process. OPH reviewed the Department of Education listing of schools to establish the total number of students and schools by region and parish. OPH/ASHP thus identified parishes and regions in the state without access to the resource of SBHC services. The 65 currently established SBHCs in 107 schools with a combined enrollment of over 55,000 students provide only limited access to preventive physical and behavioral health services as compared to over 1,500 public and private schools and 800,000 students in all schools statewide. Reference to the Bureau of Primary Care indicates that most parishes within Louisiana are Health Professional Shortage Areas for primary care, behavioral health, and dental services. These numbers indicate that there is limited capacity and unmet need.

OPH's Adolescent School Health Program (ASHP) assesses capacity and needs on an ongoing basis by requiring a needs assessment for any agency requesting funds to establish a school based health center (SBHC). This needs assessment examines multiple factors such as number of students enrolled in school, ethnicity of school population, poverty level, dropout and graduation rates, pregnancy rates, substance use (including tobacco, alcohol, other drugs), health statistics (rates of STD, cancer, hypertension, cardiovascular disease, asthma, diabetes), designation as a Health Professional Shortage Area, etc. This funding process ensures that SBHCs are established in areas of high need and limited resources. OPH/ASHP requires the sponsoring agency to document its capacity to provide comprehensive primary and preventive medical and behavioral health services through submission of information on its organization's mission, experience, and effectiveness in providing direct medical and behavioral health services, as well as its fiscal viability.

### Oral Health

The Oral Health Program School-Based Dental Sealant program provides dental screening and dental sealant to second and sixth grade children in schools where more than 50% of the children are on free or reduced lunch; nearly 700 schools in Louisiana. The program and its program partners, Federally Qualified Health Centers (FQHC), private dentists, and the state's Dental and Dental Hygiene schools, served only 57 schools in the 2008-2009 school year. The capacity to

serve more schools is affected by several factors: the shortage of dentists, 86% of Louisiana is classified as a Dental Health Professional Shortage Area; the rural nature of the state, the majority of the dentists that serve Medicaid eligible children are in the urban areas; and the small percentage of dentists who accept Medicaid enrolled children. The program uses several criteria to identify school, the first being the percentage of children on free or reduced lunch, second, schools that participated in the Basic Screening Survey and that have children with identified needs, and lastly, schools that are in rural areas.

The Oral Health Program's community water fluoridation program provides money to communities to maintain and initiate community water fluoridation. Currently only 41% of the population receive the benefit of optimally fluoridated water. In 2008 the state passed a mandatory community water fluoridation act requiring communities that have at least 5,000 service connections; nearly 30 communities in the state serving just over 1.2 million citizens. However, the law is essentially unfunded and while the program receives \$100,000 a year from the Preventive Health and Health Services Block Grant, cost estimates are over 8 million. Given the large number of communities with ground source water and multiple wells, the program can fund only one or two communities each year.

### **Data Sources**

The development of information systems that are capable of providing timely and appropriate data for planning and evaluation of programs and policies is a necessity. The MCH Epidemiology team used various data sources throughout the needs assessment process to inform programs of the most recent available data on a variety of MCH relevant topics. National data sources used during the 2010 Title V Needs Assessment include the National Vital Statistics Reports, US Kids Count, US Census, National Immunization Survey, CDC STD Surveillance, CDC Pediatric Nutrition Surveillance, US Communities That Care Youth Survey for Grades 6 to 12, National Survey of Children's Health, and the National Survey of Children with Special Health Care Needs. A summary report "Monitoring the Future: National Results on Adolescent Drug Use" was also used. State-based sources used include data from Louisiana Center for Health Statistics and Vital Records, Louisiana PRAMS, Louisiana Medicaid, Louisiana Hospital Inpatient Discharge, Louisiana STD Prevention Program, Louisiana HIV/AIDS Program, Louisiana Birth Defects Monitoring Network, Louisiana Screening, Referral, Brief Intervention and Treatment (SBIRT), Louisiana Office for Addictive Disorders Caring Communities Youth Survey, and the Louisiana School Based Health Program. Where appropriate, state-based data systems are routinely linked with vital records birth, death, and fetal death data to expand analytic capacity and understanding of successes, problems, gaps, and disparities.

The data sources used for the oral health needs assessment are diverse in nature. The program relied on data from the following national data sources: the CDC's National Oral Health Surveillance System (NOHSS), the Behavioral Risk Factor Surveillance System, CDC's Water Fluoridation Reporting System (WFRS), U.S. Census Bureau, Centers for Medicaid and Medicare Services, National Health and Nutrition Examination Survey, and National Cancer Institute - State Cancer Profiles. In addition to the national data sources, the program also relied on state and local data from the Louisiana Department of Health and Hospitals Medicaid and the Bureau of Primary Care and Rural Health. Dental abuse and neglect data came from the Louisiana Department of Social Services. Other state level data sources are the Louisiana State Board of Dentistry and Louisiana Youth Tobacco Survey. As stated earlier, the program collected primary data on the oral health status of third grade children in Louisiana from the Basic Screening Survey.

Several limitations of data used are noteworthy. The availability of the most current secondary data was a limitation experienced by many of the needs assessment subgroups. The most recent available data from Vital Records was 2007 for births and deaths and 2006 for fetal deaths. Louisiana PRAMS data were not available for 2005-2006 due to the 2005 hurricanes; 2007 response rates were less than 60% rather than at or above the CDC recommended 70%; and Louisiana PRAMS data are not available at regional or parish levels. Women were considered covered by Medicaid if any prenatal visit and/or delivery was Medicaid-paid; Louisiana Hospital Inpatient Discharge Data includes voluntarily reported data from approximately 90% of hospitals state-wide. Louisiana Birth Defects data represent only four of nine public health regions of Louisiana and are therefore not population-based at this time. Louisiana SBIRT data represent a convenience sample of women who were screened across Louisiana; the extent to which the data represent certain subgroups is unknown. The Louisiana Caring Communities Youth Survey (CCYS) achieved a response rate of 60% (2008 CCYS), with considerable geographic, school, and grade variability in response rates. Linked data sources require consideration of the linkage rate; Louisiana requires a minimum of 95% of records to be successfully linked between data sources before the data are used for analyses. All data sources are subject to sufficient sample size in analyses; some subgroups were interested in rare events such as infant mortality at the zip code or parish level stratified by demographic characteristics. In order to accommodate these requests, where possible, data were combined across years and/or only provided when sufficient numbers of events were available.

### **Linkages between Assessment, Capacity, and Priorities**

The Needs Assessment regional and state level stakeholder meetings, epidemiological data and the consumer and provider surveys conducted by each subgroup were the primary sources of information upon which 2010 Needs Assessment analyses were based. Each provided a rich source of data with which to examine the key issues affecting the state's MCH populations.

#### **Perinatal**

The Maternity subgroup's examination of strengths and needs was largely based on the compilation of epidemiological data of common health indicators that comprised the regional presentations. The regional data books that accompanied the presentations were another important source of regional, parish and state level data used to evaluate strengths and needs. The presentations provided stakeholders with an in-depth examination of health indicators utilizing the most currently available data. The facilitated discussion following the data presentations were an essential tool in helping to evaluate capacity, identify where gaps exist, where resources should be focused, and ultimately the selection of priorities.

The MCHB prioritization worksheet was the Maternity subgroup's chief tool used to select priorities in each region. A potential barrier to this process was that stakeholders might base decisions on a priori formed beliefs about what priorities should be that were not rooted in empirical data. However, the efficacy of this particular phase of the process was confirmed by how closely the epidemiological data presented paralleled the priorities selected by regional stakeholders.

#### **Child Health and Safety**

The needs assessment surveys queried stakeholders to rank their top ten child health priority needs from a given list, with the option to add and rank additional needs not listed. Stakeholders also assessed the capacity of the communities to meet the priority child health needs by

examining the availability of and accessibility to resources and services from a given list, with the option to add resources and services not listed. The method of setting priority needs for Child Health incorporated the MCHB prioritization worksheet that considered extent, severity or consequences, acceptability and resource availability. Priority needs were determined by three sources: Child health stakeholders who responded to the Child Health Needs Assessment Survey; the general public who responded to the Needs Assessment Consumer Survey; and data related to child health indicators, collected from the previously discusses data sources. Stakeholder responses were tallied for each health topic for the age group of 0-19 years of age. The Child Health subgroup agreed to combine similar topic areas and assigned a new tally number, based on the average of the combined topic areas. The 10 health topics that received the highest tallies and considered most important were compared with high-ranking infant, child, and adolescent health topics from the Consumer survey and with existing child health data that expressed high, increasing, and/or unchanging rates. Gaps, resource availability, and feasibility of impacting a priority area with existing capacity were discussed for each of these health topics. Based on this process, the five child health needs were selected.

The method of setting priority needs for Child Safety also incorporated a framework that considered various criteria. Extent, severity or consequences, and acceptability of each safety problem were determined by three sources: Child safety stakeholders, or respondents to the Child Safety Needs Assessment Survey; the general public, or respondents to the Needs Assessment Consumer Survey; and data related to child safety indicators, collected from the previously discusses data sources. For the state and local/regional Child Death Review Panel meetings and the state EMS-C meetings, stakeholders completed the survey to gauge perceptions of injury prevention and child safety priority areas, resource and services, and strategies to address the priority areas. When the survey was completed, current state and regional injury data was presented. A post prioritization assessment was conducted at the end of the presentation and discussion to gauge if perceptions of priority areas changed, followed by perceptions of resources/services present and level of availability in their region. Stakeholder responses were tallied for each safety topic for the age group of 0-14yrs of age. The Child Health subgroup agreed to combine similar topic areas and assigned a new tally number, based on the average of the combined topic areas. The 10 safety topics that received the highest tallies and considered most important were compared with high-ranking infant and child safety topics from the Consumer survey and with existing child safety data that expressed high, increasing, and/or unchanging rates. Gaps, resource availability, and feasibility of impacting a priority area with existing capacity were discussed for each of these safety topics. Based on this process, the three child safety needs were selected.

### Adolescent Health

Stakeholders assessed the capacity of the communities to meet the health and safety needs for the adolescents age subgroup 15-19 years by examining the availability of and accessibility to resources and services from a given list in both the child health and the child safety needs assessment tools, with the option to add resources and services not listed. The method of setting priority needs for this adolescent age subgroup also incorporated the MCHB prioritization worksheet. Extent, severity or consequences, and acceptability of each health problem were determined by three sources: Child health stakeholders, or respondents to the Child Health Needs Assessment Survey; Child safety stakeholders, or respondents to the Child Safety Needs Assessment Survey; the general public, or respondents to the Needs Assessment Consumer Survey; and data related to child health and safety/injury prevention indicators, collected from the previously discusses data sources. Stakeholder responses for the 15-19 years subgroup were then tallied separately for health and for safety. The top 10 health topics that received the highest

tallies and considered most important were compared with high-ranking adolescent health and safety topics from the Consumer survey, with existing health and safety data that expressed high, increasing, and/or unchanging rates, and with the results of the ASHP assessment. Gaps, resource availability, and feasibility of impacting a priority area with existing capacity were discussed for each of these topics. Based on this process, the adolescent needs were selected: reproductive health (routine exams, teen pregnancy/pregnancy prevention, STD screening and treatment), substance use/abuse, intentional and unintentional injury (suicide, motor vehicle accidents, use of firearms/weapons), and misuse of cyberspace (sexting, cyber bullying). These adolescent priorities correlated with listing behavioral health and reproductive health services as top needed resources for this age group.

### Oral Health

The Oral Health staff and stakeholders met as a group to participate in a two-step process for assessing the oral health needs of the MCH population. The process to identify and establish priorities began with a presentation on the most recent oral health state and national indicator data followed by a review and discussion of the results of the maternal and child health consumer based survey. The data presented provided key information that helped the meeting participants evaluate the state of oral health of the MCH population, and, in the second step, identify and prioritize needs and strategies.

Key to assessing and prioritizing the oral health needs in children was the information on the oral health status of Louisiana's children collected in the onsite screening of school children, Basic Screening Survey (BSS). The data pointed to a clear need for preventive and restorative oral services in the child population. As mentioned previously there is little parish level oral health data available, however the results of the BSS gave participants a clear picture of the needs in the child population at the regional level as well as areas to target for the dental sealant program.

To assess and prioritize the needs of pregnant women, the group looked at data for the Medicaid Expanded Dental Services for Pregnant Women. Key indicators were data on the number of pregnant women patients treated, the number of providers participating and the amount of dollars spent. All indicators show a small but steady increase from 2004 to 2008, however the MCH Program is aware of assess issues, the availability of participating dentist that are surfacing across the state. With the support of the Maternity program, the Oral Health Program is planning to conduct a telephone survey of participating dental offices. In addition, the program will work with the Louisiana Dental Association to identify barriers experienced by private dentists in serving the Medicaid population.

In the second step of the process, the facilitator let the participants in a group discussion to identify preliminary needs and the strategies to address each need; eight needs were identified. At the conclusion of the discussion, each participant voted on his/her top five needs. Each need was tallied and the top five were recorded.

### Dissemination

The MCH program has developed a plan to share the results of the 2010 needs assessment with its stakeholders, partners and the community. The program will distribute the overall priority MCH needs along with the strategies and methods to assess effectiveness through a coordinated regional approach. Members of the perinatal, child, adolescent, oral and CYSHCN subgroups will continue to distribute and discuss the results of the needs assessments with core partners and community organizations including regional FIMR networks, regional SBIRT networks, regional

child safety networks, oral health coalitions, parent groups and state programs (family planning, HIV/AIDS, Medicaid).

### **Strengths and Weaknesses of Process**

A major strength of the needs assessment process was the valuable insight gained from the myriad stakeholders that have a vested interest in the health of the state's MCH populations. To varying degrees each subgroup held meetings at either the regional or state level that provided a forum for stakeholders to express their views and experiences. These stakeholders ran the gamut of occupational expertise including individuals from public health, education, law enforcement and medicine to name a few. Engaging stakeholders in regional and state level meetings also helped to strengthen partnerships that are vitally important to the mission of the MCH program. An additional strength of the process was the availability and use of epidemiological data by stakeholders to help inform their identification of regional priority needs and strategies to address those priorities. Lastly, the use of survey data to assess provider and consumer knowledge and behavior was another major strength of the needs assessment process. Surveys were conducted by each subgroup. Coupled with the epidemiologic data, the surveys provided a critical piece of data utilized by the MCH program to assess statewide priority needs.

There were several weaknesses in our current methods that affect the interpretability of data and its utility. First, survey data for each subgroup were based on convenience samples, lowering the ability to generalize findings. A second limitation experienced by subgroups was the absence of recent secondary data. For example, similar to the 2005 Needs Assessment, Youth Risk Behavior Survey (YBRS) data were not used to evaluate Adolescent Health. This has been due to the low response rate ( $\leq 60\%$ ) of the YBRS in Louisiana which as result does not permit the weighting of data to the population of 9th through 12th graders in Louisiana. In addition, due to low staffing levels at the state Vital Records Registry there is approximately a two year lag in vital records data which further impedes the availability of recent data.

## **2. Partnership Building and Collaboration Efforts**

### **Maternal Health**

The Maternal Health Program gathered input for the needs assessment from its public and private partners across the state. Among our partners are the state Medicaid Office, the Office of Mental Health, Office for Addictive Disorders, the Office of Public Health, the DHH Chronic Disease Prevention and Control Unit's state Tobacco Control Program, Louisiana Public Health Institute, the American College of Obstetricians and Gynecologists-Louisiana Section, March of Dimes, legislators and local press, faith based organizations, Maternal and Child Health Coalition, and Bureau of Minority Health Access.

Maternity Health partnerships also include the 9 regional Fetal and Infant Mortality Review (FIMR) Teams. MCH funds nine regional Louisiana Infant Mortality Reduction Initiatives (LA-IMRI) across the state. Each regional IMRI consists of the regional OPH epidemiologist and medical director, regional nurse consultant, LA-IMRI coordinator, members of the FIMR Community Action Team and Case Review Team. The Case Review Teams include physicians, coroners, nurses and Office of Public Health representatives, Nurse Family Partnership representatives, and substance abuse coordinators from the Office for Addictive Disorders. The Community Action Teams consisted of multiple groups in each region, but among these are faith based and community leaders, Healthy Start representatives, breast feeding coalitions, tobacco



control program staff, March of Dimes Mom & Baby prenatal care providers and bi-lingual case workers, and mental health specialists.

Through regular team meetings, partnerships and collaborations are formed and common goals and action plans established. Partnerships also included four Healthy Start programs in five regions of the state (Region I-New Orleans, Region II-Baton Rouge, Region IV-Lafayette, Region VII-Shreveport and Region VIII-Monroe), and Children's Coalitions in Monroe, Louisiana and Houma, Louisiana.

### *Child Health and Safety*

Child Health received valuable input and guidance from its collaborating partners throughout the needs assessment process. The Child Health Subgroup consisted of representatives from various OPH state organizations including MCH, Injury Research and Prevention, Oral Health, Genetics, Louisiana Childhood Lead Poisoning Prevention, and the Adolescent School Based Health Programs . The Child Health subgroup reviewed and made recommendations for the overall child health and child safety needs assessment plans as well as for the content and design of the child health and child safety needs assessment survey tools. The Child Health subgroup also participated in the final child health and child safety priority area selection process.

Child Health needs assessment partners for state and community-level participation included program directors, coordinators, and policymakers of the Office of Public Health's Centers for Preventive Health and Community Health, Louisiana's Children's Cabinet Advisory Board to the Governor's Children's Cabinet, BrightStart (Louisiana's Early Childhood Comprehensive System) Steering Committee, and the MCH State and Local Child Safety/Local Child Death Review Panel Coordinators. Child Health also partnered with the Office of Public Health's Center for Community Health and Adolescent School Health Initiative along with the Louisiana American Academy of Pediatrics to obtain feedback from physicians, nurses, social workers, and other health providers in the community.

Child Safety needs assessment partners were primarily the State and Local Child Death Review Panel (CDRP) members and their respective coordinators. The MCH Child Safety/Local Child Death Review Panel Coordinators assisted the Child Health Medical Director and the State Child Death Review Panel/ Child Safety Coordinator in the planning and execution of the child safety needs assessment in their own regions. The coordinators also gave feedback on the safety/injury prevention content in the development of the child safety assessment survey tool. Stakeholder feedback, including strategies, was obtained by the State and Local CDRP members during their respective panel meetings and the Safety Council in Lafourche Parish. Other state-level partners include the Bureau of EMS' Injury Research and Prevention Program and The Emergency Medical Services for Children's Advisory Council meeting.

Child Health had broad-based input from its public-private partners in the both child health and child safety needs assessments processes, which are outlined below:

MCH Child Safety/Local Child Death Review Panel Coordinators: The MCH Child Safety Coordinators, represent the following contracting agencies: Children's Hospital in New Orleans, MCH Coalition in Baton Rouge, Options for Independence in Southeast Louisiana, Area Health Education Centers of Southeast, Southwest, and North Louisiana, and Christus Cabrini Hospital in Alexandria.

BrightStart Steering Committee: BrightStart is Louisiana's Early Childhood Comprehensive System (ECCS) HRSA-MCHB funded grant initiative and is the State's Early Childhood Advisory Council as designated by the Governor. BrightStart has established an early childhood comprehensive system of integrated services and partnerships to enhance children's ability to enter school healthy and ready to learn and to ensure that young children ages 0-5 years and their families have opportunities for optimal emotional, social, physical and cognitive development. BrightStart Steering Committee members represent the following government and non-government agencies and organizations: State's Division of Administration, Governor's Office of Community Programs- Children's Cabinet Executive Director; Office of Family Support, Head Start Collaboration, and Office of Community Services (OCS) within the State's Department of Social Services (DSS); Part C - Early Steps Program-Office of Citizens with Developmental Disabilities, Office of Addictive Disorders, , Office of Mental Health, Children's Special Health Services, Oral Health Program, and the Bureau of Health Services Financing (Medicaid) within the Department of Health and Hospitals; Louisiana Workforce Commission; State Department of Economic Development; State Department of Education (DOE) including the Pre-K and Early Childhood Education Programs section; Board of Elementary and Secondary Education; Office of Youth Development within the Department of Public Safety and Corrections; Louisiana Legislature (a member of the Senate and the House of Representative); Maternal and Child Health Coalition; American Academy of Pediatrics; Children's Defense Fund, Children's Trust Fund, Prevent Child Abuse Louisiana, State Interagency Coordinating Council, Louisiana Association of Nonprofit Organizations and Louisiana Association of United Ways; LSU Early Intervention Institute, and Louisiana Partnership for Children and Families. BrightStart, is administered by the Department of Health and Hospitals, Office of Public Health-Maternal and Child Health Program (MCH), and the grant's efforts are conducted under the auspices and guidance of the Children's Cabinet and the Children's Cabinet Advisory Board.

Children's Cabinet Advisory Board (CCAB): The CCAB provides the Governor's Children's Cabinet with information and recommendations regarding children's issues from the perspective of advocacy groups, service providers, and parents in accordance with Louisiana Legislation RS 46:2605. The CCAB is composed of representatives from the following governmental and non-governmental agencies that providers children's services: State Assistant Secretaries from the Department of Social Services (Office of Community Services and Office of Family Support), the Department of Health and Hospitals (Office of Public Health, Office of Mental Health, Office for Addictive Disorders, and Office for Citizens with Developmental Disabilities), and the Department of Public Safety and Corrections (Office of Youth Development); Directors of the Bureau of Health Services Financing of the Department of Health and Hospitals and the State Head Start Collaboration Project; Presidents of the Louisiana Community and Technical College System and the Louisiana Council of Child and Adolescent Psychiatry; Chief Executive Officer of the Louisiana State University Health Sciences Center, Health care Services Division; Members of the Commission on Perinatal Care and Prevention of Infant Mortality, Louisiana Families In Need Of Services Association, Louisiana Court-Appointed Special Advocate Association, Louisiana Catholic Conference, National Association of Social Workers, Louisiana Assembly on School-Based Health Care, and the Louisiana Chapter of the March of Dimes; and Representatives from the division of administration Department of Labor, Department of Education (academic programs, including early childhood special education, and educational support programs including secondary vocational education), Agenda for Children, Louisiana Children's Trust Fund, Louisiana Council on Child Abuse, Louisiana Maternal and Child Health Coalition, Louisiana Council of Juvenile and Family Court Judges, Juvenile Justice and Delinquency Prevention Advisory Board, Louisiana State University, Louisiana Cooperative Extension Service, Families Helping Families, Louisiana Association of Nonprofit Organizations, Louisiana Association of Childcare Agencies, Louisiana Children's Advocacy Centers Institute

for Infant and Early Childhood Mental Health at Tulane University, Louisiana Primary Care Association, Louisiana Partnership for Children and Families, and parents.

State Child Death Review Panel (CDRP): CDRP performs multi-disciplinary, multi-agency reviews of unexpected, unintentional child deaths of children under 15 years of age, including SIDS, to develop a greater understanding of the causes of child deaths, of the methods for preventing such deaths, and of the gaps in services to reduce the incidence of injury and death to infants and children. Panel members include the state health officer, secretary of the Department of Health and Hospitals, secretary of the Department of Social Services, superintendent of the office of state police, state registrar of vital records in the office of public health, attorney general, a member of the Senate appointed by the president of the Senate, a member of the House of Representatives appointed by the speaker of the House of Representatives, commissioner of the Department of Insurance, executive director of the Highway Safety Commission of the Department of Public Safety and Corrections, state fire marshal, injury research and prevention section of the office of public health, executive director of the Louisiana Maternal and Child Health Coalition, a district attorney appointed by the Louisiana District Attorneys Association, a sheriff appointed by the Louisiana Sheriff's Association, a police chief appointed by the Louisiana Association of Chiefs of Police, a forensic pathologist certified by the American Board of Pathology licensed in Louisiana, a pathologist experienced in pediatrics appointed by the Louisiana Pathology Society, a coroner appointed by the president of the Louisiana Coroner's Association, a SIDS expert of the Louisiana State Medical Society, a pediatrician with experience in diagnosing and treating child abuse and neglect of the state chapter of the American Academy of Pediatrics, and Four citizens-at-large.

Local Child Death Review Panels include representatives of law enforcement, child protective services, public health, and emergency medical services; a prosecutor, pediatrician or family medicine provider, a coroner, and other agencies, providers, and professions involved in protecting children's safety and health.

Emergency Medical Services for Children (EMSC) Advisory Council: The EMSC Advisory Council advises the department and the coordinator of the EMSC program on all matters concerning emergency medical services for children, including the formulation of policy and regulations. This Governor-appointed advisory council consists of a board certified pediatric surgeon, practicing pediatrician, pediatric critical care physician, board certified pediatric emergency physician, pediatric psychiatrist, emergency physician, emergency medical technician, paramedic, and a family practice physician; 2 registered emergency nurses; representatives of nursing schools, vo-tech emergency medical services education; an administrator of an ambulance service company; and parents with children under 18 years of age.

### Adolescent Health

In an effort to assess the health services for youth, OPH/ASHP engaged multiple state and private agencies. Besides the 27 sponsor members of the SBHC Sponsor Network, OPH/ASHP partners with Medicaid, the Department of Education, the Louisiana Obesity Council, Sexually Transmitted Disease Program, HIV/AIDS Program, Immunization Program, Bureau of Primary Care and Rural Health, Juvenile Justice Program and Juvenile Judges Council, Oral Health Program, Office of Mental Health and Addictive Disorders, Metropolitan Human Services District, the Louisiana Assembly on School Based Health Care, the Louisiana Public Health Institute, Blue Cross Blue Shield, School Health Connection, the Orleans Parish School Board, the Recovery School District, and others. The 27 sponsor members are the Louisiana State University Health Sciences Center (LSUHSC) Department of Pediatrics, St. Gabriel Health

Clinic, Ouachita Parish School Board, CHRISTUS Schumpert Health Systems, Richland Parish Hospital, Madison Parish Hospital, Washington/St. Tammany Regional Medical Center, LSUHSC/Bogalusa Medical Center, Allen Parish School Board, CHRISTUS Saint Patrick Hospital, Our Lady of Lourdes Hospital, St. Helena Community Health Center, CHRISTUS Saint Frances Cabrini Hospital, St. Martin Parish School System, Health Care Centers in Schools, Primary Care Providers for a Healthy Feliciana, West Feliciana School Board, Jackson Parish Hospital, Jefferson Parish School System, Medical Center of Louisiana at New Orleans, Innis Community Health Center, Teche Action Board, Inc., Methodist Health System Foundation, Richardson Medical Center, St. Francis Medical Center, Lafayette Parish School System, St. Charles Community Health Center and Morehouse Community Medical Center.

### Data/Health Statistics

Over last 10 years, the MCH program has had a very strong relationship with the OPH State Center for Records and Statistics (vital records). By providing identified vital records and hospital inpatient discharge data, the State Center for Records and Statistics supports the MCH program to conduct the data linkage of birth (and fetal death records when appropriate) with infant death, child death, maternal death records, and hospital inpatient discharge data as well as with other MCH-partner data, including Medicaid, newborn screening, birth defects, STDs, HIV/AIDS, and WIC. In addition, the State Center for Records and Statistics assists the MCH program in conducting LaPRAMS, analyzing data for MCH data books and MCH data profiles, and investigating infant mortality underreporting. Vital records data have been used as key data for MCH Block Grant Health Status Indicators and National Outcome Measures and Needs Assessment.

A memorandum of understanding (MOU) for inter-agency data-sharing between the OPH and the state Department of Health and Hospital's Medicaid agency was established in 2005. Under this agreement, the MCH program can readily access identified Medicaid eligibility and claim files to link with vital records as well as data of newborn screening, birth defects, STDs, HIV/AIDS, WIC, hospital discharge inpatient surveillance, and PRAMS. The MCH program has Medicaid and birth linked data to define live birth deliveries paid for by Medicaid for many years. Recently the data linkage of Medicaid with fetal death records has been conducted. This linked data is used for analysis of the perinatal period of risk project among live births and fetal deaths whose deliveries were paid for by Medicaid. Many studies using Medicaid linked data have been conducted. Results of data analyses using Medicaid linked data are also used for MCH Block Grant Health Status Indicators and Needs Assessment, and published at the Louisiana Morbidity Reports. Additionally, by using Medicaid data, the MCH program is successfully able to conduct the Louisiana family planning waiver grant evaluation. A copy of the data sharing agreement can be found in Appendix D.

Due to unavailability of Louisiana Youth Risk Behavior Survey (YBRS) data, the MCH program has used the Caring Communities Youth Survey (CCYS) data during the last several years. The survey is conducted by the Picard Center for Child Development and Lifelong Learning at the University of Louisiana at Lafayette under the joint direction of the DHH Office of Addictive Disorders (OAD) and the Louisiana Department of Education (DE). As a representative for the University of Louisiana at Lafayette, OAD, and DE, the Picard Center has become a key partner of the MCH program to provide CCYS data from 2004. The data has been used for education and public health research aimed at improving the understanding of the consumption and consequences of substance use, substance abuse, gambling, and related risk and protective factors among adolescents in Louisiana. In addition, the data has been used for annual MCH Block Grant report and Needs Assessment. The survey is offered in the fall of every other year for all

Louisiana public and non-public schools among 6th, 8th, 10th, and 12th graders. An agreement of data sharing for 2010 CCYS data between the MCH program and the Picard Center has been established and waiting for approval.

In 2004 the MCH and Louisiana Sexually Transmitted Disease Prevention (STD) programs co-submitted a data linkage application to the Louisiana State Center for Records and Statistics. The purpose of this application was to link vital records with STD data. The STD program has become a key partner of the MCH program to assist in providing data of STDs during pregnancy since 2004. The data linkage procedures using STD and vital records data from 1997 to 2007 were successfully conducted with support from both programs and Louisiana State Center for Records and Statistics. The linked data were used to define the trends and risk factors of STDs during pregnancy as well as affects of STDs on birth outcomes. Results of data analyses using the linked data were used for MCH Block Grant Needs Assessment, annual MCH profiles, MCH data book, and also were presented at the national STD prevention and the CDC's MCH-Epidemiology conferences.

### Oral Health

The Oral Health Program had broad-based input from its public and private partners in conducting the oral health portion of the MCH Needs Assessment. Key to identifying the oral health needs of children was the Basic Screening Survey conducted by the program to determine the oral health status of Louisiana's 3<sup>rd</sup> grade population. The survey was conducted with the support of the Louisiana Department of Education, the Louisiana School Nurse Association, local schools and school nurses, and private practice dental practitioners, dentists and hygienists. The screenings took place in 75 schools in 34 parishes. Over 120 school nurses were trained on conducting the screening.

Also providing collaborating in the assessment process were the staff of the Louisiana Public Health Institute for facilitating a meeting of the Oral Health Coalition where attendees identified oral health issues for access, education, prevention and policy. Representatives from The Health Enrichment Network, Health Care Centers in Schools, Creative Communications, Inc., Greater Baton Rouge Community Clinic, Healthworks, LLC, DHH Asthma Program and the Capital Area Agency on Aging providing logistical support for the meeting. The program also collaborated with the Children's Dental Health Project and Dr. Lynn Mouden, Dental Director for the Arkansas Oral Health Program to conduct a Policy Tool Workshop; another opportunity to identify oral health issues among all populations.

Finally, in a culminating meeting led by Louisiana Public Health Institute, participants utilized the results of the consumer survey and the prioritized list of issues developed at the Oral Health Coalition and the Policy Tool Workshop to complete the identify and prioritize the oral health needs assessment.

### **3. Strengths and Needs of the Maternal and Child Health Population Groups and Desired Outcomes**

#### Overall Health Status

A 2009 report by the United Health Foundation ranks Louisiana 47<sup>th</sup> out of 50<sup>th</sup> in overall health, representing the third least healthy state in the nation. This ranking reflects a marked improvement over recent years, with the change from 2008 to 2009 identified as the state with the second greatest improvement in overall health during that time. The report is based on 22 core

measures, including infant mortality, adequacy of prenatal care, immunization coverage, infectious diseases, obesity, cigarette smoking, binge drinking, children in poverty, health insurance, and several other measures. Louisiana's poor ranking stems from its high infant mortality rate, high rate of cancer and cardiovascular deaths, high rate of premature death, high rate of infectious diseases, high rate of uninsured population, high rate of preventable hospitalizations, and low high school graduation rate. Over the past year, 2008 to 2009, the average health dollars targeted toward public health programs and initiatives in Louisiana has decreased from \$94 to \$90 per person.

According to the 2009 National Kids Count Data Book, Louisiana ranked 49<sup>th</sup> out of the 50 states in "Indicators of Child Well-being." Factors contributing to Louisiana's poor ranking relate to high percent of low birth weight infants, high infant mortality rate, high percent of children living in families where no parent has full-time, year-round employment, high percent of children living in poverty, high percent of children in single-parent families, high percent of teens who are high school dropouts, and high percent of teens not in school and not working. Specifically, Louisiana ranked 49<sup>th</sup> for both infant mortality and percent of low birth weight infants; 42<sup>nd</sup> in child deaths; 43<sup>rd</sup> in teen deaths; 39<sup>th</sup> for the teen birth rate; 47<sup>th</sup> for the percent of teens who are high school dropouts; and 45<sup>th</sup> for percent of teens not attending school and not working. Socioeconomic factors such as the percent of children in poverty; the percent of children in families where no parent has a full-time, year around employment, and the percent of families with children headed by a single parent also influenced Louisiana's low ranking. The state ranked 48<sup>th</sup>, 49<sup>th</sup> and 49<sup>th</sup> in each of these measures, respectively. Although these latter indicators are not directly related to health status, they do reflect socioeconomic and environmental factors that affect the health of children.

Louisiana has among the lowest life expectancy rates in the United States. The average life span for African-Americans in Louisiana today (72.2 years) is shorter than that of Colombians, Vietnamese and Venezuelans. The average life span of an African-American in New Orleans in 2007 was 69.3 years, nearly as low as life expectancy in North Korea. These rates result partly from the high burden of chronic disease in Louisiana as well as racial disparities in these diseases. The rates of death from heart disease, cancer, stroke are high in Louisiana. In 2006 age adjusted rates, Louisiana ranks ninth highest for heart disease and stroke mortality and fifth highest for cancer mortality in the United States. According to 2005 data from the BRFSS survey based on self-reported height and weight, the highest prevalence rates of obesity in the United States were seen in Louisiana, Mississippi and West Virginia. According to the 2009 Trust for America's Health Report, Louisiana has the 8<sup>th</sup> highest rate of adult obesity and the 7<sup>th</sup> highest rate of overweight youths (ages 10-17) in the nation. The most recent BRFSS data on hypertension show that in 2007, reproductive aged White women were 15% likely to have hypertension while almost a quarter of Black women had hypertension (23.2%). On self ranking in 2008 13.7% of reproductive aged women (15-44) in Louisiana ranked their health as Fair/Poor (9.5% White women, 18.8% Black women).

According to a December 2009 Louisiana Health Insurance Survey (sponsored by the Louisiana Department of Health and Hospitals), the 2009 estimate for uninsured children (under age 19 years) who were eligible for Medicaid in Louisiana was 5.3% (39,765) statewide – a decline from 5.5% in 2007. Medicaid is a source of coverage for 43.4% (510,266) of children (under age 19) in Louisiana. The 2009 statewide uninsured estimate for nonelderly adults (19-64) under 200% of the federal poverty level was 20.1% (540,490) – only a 0.1% decline from 2007. The 2007-08 Louisiana Medicaid Annual Report indicated that approximately 27% of Louisiana's population received Medicaid services. The percent of Medicaid recipients has remained level since 2007 and is up slightly from 2006 (25%).

### Overall Economic Well-Being

According to the US Census from 2000 to 2008, the total population of Louisiana fell by 1.3% from 4,468,976 to an estimated 4,410,796 people. In terms of racial makeup, Louisiana has two main racial groups, White 64.8% and Black 32.0%, with 3.2% as other. This is vastly different from the racial makeup of the US, where in 2008, an estimated 79.8% of the population is White, 12.8% of the population is Black, and 7.4% is other. Louisiana has a relatively small Hispanic population compared to the US as a whole, although the proportion of Hispanic individuals has increased since the 2005 hurricanes. A comparison of Louisiana and the Nation's racial and Hispanic origin distributions is available in Figure 1 and Figure 2 of Appendix A respectively. The total number of Louisiana women of childbearing age has decreased from 1,005,468 (22.5% of total population) in 2000 to 920,873 (20.9% of total population) in 2008. Teenagers 15-19 years and children 0-14 years comprised approximately 7.5% and 20.7% of Louisiana's population respectively in 2008. The state population estimates from 2000 and 2008 can be found in Appendix B, Table 1.

Although 74.3%, of the of the state's population lives in a Parish designated as part of a Metropolitan Statistical Area (MSA), geographically, Louisiana is a predominantly rural state. Only 29 of the 64 Parishes are designated as being part of a MSA, defined by the US Office of Management and Budget as having a core urban area of 50,000 or more population.

In 2008, the US Bureau of Economic Analysis reported Louisiana a having a per capita personal income of \$36,371 compared to the national average \$40,208. This shows an increase of 2.8% from 2005. In 2008 Louisiana median household income was \$43,635 a 2% increase since 2003. The unemployment rate, reported by the Louisiana Department of Labor, in December of 2009 was 7.5%, as compared to a national unemployment rate of 10%. Both rates have risen since 2008 when Louisiana had an unemployment rate of 5.5% and the national unemployment rate was 7.4%.

According to the US Census Bureau American Community Survey, Louisiana had an overall poverty rate of 17.3% in 2008, accounting for approximately 730,000 people. This rate was equivalent to that of Kentucky, Arkansas, and the District of Columbia; Mississippi was the only state to exceed this rate, with a rate of 21.2%. The US Census Bureau reported a 2008 national rate of 13.2%, up from 12.5% in 2007. There were 39.8 million people in poverty in 2008, up from 37.3 million in 2007.

The National Center for Children in Poverty reported that 252,603 (23%) Louisiana children under the age of 18 years were considered poor in 2006-2008, 4% more than the National average of 19%. The Louisiana rate was equivalent to that of Kentucky, while only Mississippi and the District of Columbia exceeded this rate. When considering only children under the age of 6 years, 25% of Louisiana's young children were considered poor, 3% more than the National average of 22%. Arizona and Kentucky had rates equivalent to Louisiana, while Georgia, Texas, Arkansas, New Mexico, Mississippi, and the District of Columbia exceeded Louisiana.

### Maternal Morbidity

#### *Unintended Pregnancies and Prenatal Care*

Women less than 20 years old have the highest percentage (77.7% in 2007) of *unintended pregnancies* in Louisiana. According to the Louisiana Pregnancy Risk Assessment Monitoring System (LaPRAMS), the percent of unintended pregnancies among Louisiana women of all age

groups has increased from 51.6% in 2000 to 54.8% in 2007. Data from 2007 also showed that 58.8% of Louisiana women reported that they or their husbands were not using birth control when they got pregnant. An unintended pregnancy can significantly influence the interval of time that a woman has between pregnancies. It is recommended that women have an inter-pregnancy interval of at least 24 months in order to reduce the risk of adverse perinatal and maternal outcomes. In 2007, an estimated 17% of women waited less than 24 months between pregnancies. This number may be higher if women had prior pregnancies ending in a miscarriage or fetal death that may not have been recorded properly.

*Early access to prenatal care services* plays an important role in reducing poor birth outcomes. The percent of women entering prenatal care in the first trimester has risen from 84.1% in 2004 to 87.1% in 2006. In 2007, a slight decrease was seen in that 86.9% of women entered prenatal care during the first trimester state-wide, falling short of the Healthy People 2010 goal of 90% early entry into prenatal care. The Black to White disparity ratio for first trimester entry into prenatal care has remained around 1.5 each year from 2004 to 2007. For Whites, in 2007, early entry into prenatal care was above to the Healthy People 2010 target at 92.2%. Among Blacks, 79.6% entered prenatal care early. Geographically, many Louisiana parishes do not reach the Healthy People 2010 goal. Specifically, Orleans parish, the parish in which New Orleans is located, has an 80.1% rate of entry into first trimester prenatal care, well below the Louisiana average of 86.9% and the Vernon parish percent is 94.7%.

Louisiana ranks among the best in adequacy of prenatal care. A 2009 United Health Foundation report ranked Louisiana as 3<sup>rd</sup> in the nation for adequacy of prenatal care as measured by the Kessner index. Despite its high ranking, Louisiana failed to meet the Healthy People 2010 objective of at least 90%. Louisiana uses the Kotelchuck index to monitor early and adequate prenatal care. Based on this measure, 84.8% of women received early and adequate prenatal care during pregnancy in 2007. The Black to White ratio of early and adequate prenatal care remained constant at 1.1 from 2004 to 2007, with 88.8% of White women and 79.2% of Black women receiving early and adequate care in 2007. As many areas in Louisiana continue to face challenges with access to prenatal care services, ongoing monitoring is required.

Medicaid is currently the primary mechanism for women to access prenatal services in Louisiana. In 2007 Medicaid covered 68.4% of all deliveries. For Black women in Louisiana, Medicaid pays for 90.1% of all births and 53.8% of White births. In the past in Louisiana, many of the Medicaid births were in a state operated hospital system. Currently, only 7% of births are now in the state operated hospital system and prenatal care services previously available in the state hospital and public health system are now served by private providers and hospitals.

#### *Perinatal HIV Transmission*

As of December 2009, there were 5,167 women living with HIV in Louisiana and women accounted for 32% of the new HIV/AIDS diagnoses in the state. Thirty-five percent of these women were in the highest fertility period, childbearing ages of 15-34. There is a large racial disparity in the number of women living with HIV in Louisiana. Of the 5,167 women living with HIV infection in Louisiana, 762 (15%) are White, 4,250 (82%) are Black and 112 (2%) are Hispanic. Also, as of December 2008 approximately 2,678 babies have been born to HIV-infected women in Louisiana, and 7% were infected with HIV perinatally.

In FY 2007, Louisiana passed legislation (Louisiana RS 40:1300:13) that requires any physician providing medical care to a pregnant woman to conduct an HIV test as a component of her routine prenatal laboratory panel unless the patient specifically declines (“opts out”). In addition,



the law allows physicians to test children born to women whose HIV status is unknown at the time of delivery.

### *Sexually Transmitted Diseases*

Rates of Sexually Transmitted Diseases (STD) in Louisiana are among the highest in the country. For 2008, Louisiana ranked 1<sup>st</sup> (highest) for primary and secondary syphilis rates with 704 cases, 1<sup>st</sup> for congenital syphilis rates, 2<sup>nd</sup> for gonorrhea rates with 9,317 cases, and 5<sup>th</sup> for Chlamydia rates with 22,250 cases.

### *Preconception and Interconception Care*

Preconception and inter-conception care is a major need in Louisiana's maternal population and was listed as a top priority by six of the nine regions during the needs assessment process. The health of a woman entering a pregnancy is important to health outcomes. Lifelong events of the individual woman will have impact upon pregnancy outcomes, and planning for a healthy pregnancy should not wait until after conception. Risk-appropriate *prenatal care services* play an important role in identifying medical and behavioral factors that can cause poor birth outcomes. However, the eight months or less of prenatal care cannot be expected to reverse a lifetime of poor health resulting from untreated chronic conditions compounded by limited access to health care.

As previously mentioned, Louisiana has one of the highest burdens of chronic disease in the United States. Diabetes, obesity, and hypertension are all chronic health problems that are more likely to occur among low-income individuals. The women too often enter pregnancy with poor management of pre-existing health problems that cannot be reversed or adequately modified during prenatal care. Also, low income women also face a disproportionate burden of illness stemming from poverty and are at greater risk for experiencing poor maternal and birth outcomes. Almost 70% of all women in Louisiana who deliver a live birth are covered by Medicaid. Medicaid coverage during pregnancy enables the women to receive care for chronic health conditions. However, Louisiana Medicaid's coverage for health services related to pregnancy ends 60 days postpartum. Louisiana data shows that, except for contraceptive services, over seventy percent of the postpartum women with Medicaid lose their health benefits after the sixty days postpartum limit.

Women with pre-existing chronic health conditions benefit from optimization of their condition and medication management prior to conception, as often the first prenatal visit is not until well after embryonic organ formation has occurred. To significantly improve outcomes in these women, we must address these issues prior to conception. National experts call for a "life course" approach to reducing infant mortality. In 2006, the Centers for Disease Control and Prevention (CDC) issued a report containing a broad range of recommendations to improve the preconception health of women in the United States. These recommendations emerged from many discussions with a wide range of national experts and a growing body of research that documented the importance of interventions, such as screenings, treatment, and educational tools for women before conception.

### *Maternal Mortality*

Maternal deaths are defined by the World Health Organization as "the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management,

but not from accidental or incidental causes.” Included in these deaths are ICD–10 codes A34, O00–O95, and O98–O99. Health People 2010 goals seek to achieve a maternal mortality rate of less than 3.3 deaths per 100,000 live births. In 2006, the US rate of maternal deaths reported by the National Center for Health Statistics was 13.3 per 100,000 live births. In Louisiana, the corresponding rates of maternal deaths were 17.5 in 2002-2004 and 12.1 in 2005- 2007. The most common causes of maternal death were eclampsia and preeclampsia, obstetrical embolism and hemorrhage of pregnancy, childbirth or placenta previa. In addition to maternal deaths due to these selected causes, The Louisiana MCH program monitors mortality rates of women who die while pregnant or within one year of termination of pregnancy (including birth live births and fetal deaths), irrespective of cause of death. The rates of the pregnancy-associated deaths for Louisiana have fallen in recent years, from 89.2 in 2005 to 83.9 in 2006 to 80.2 per 100,000 in 2007. The most common causes of pregnancy-associated death were motor vehicle accidents, homicide and obstetric causes of death occurring while pregnant or within 42 days after delivery. Of the obstetric causes of death, eclampsia and pre-eclampsia were the most common.

### *Infant and Child Morbidity*

#### *Preterm Birth*

Louisiana has a very high rate of preterm birth (PTB), defined as a birth before 37 completed weeks gestation. Of the 63,186 Louisiana resident births in 2006, the rate of PTB was 13.8%. Of the 66,063 Louisiana resident births in 2007, the PTB rate fell to 13.0%. Of the 42,824 births covered by Louisiana Medicaid in fiscal year 2007, 14.6% were preterm. Total first year costs of all births covered by Medicaid in fiscal year 2007 was \$313,160,500, with 62.3% of total cost related to preterm births at \$195,141,262. Late preterm birth (34-36 week gestation) comprises a large and slightly growing proportion of all births in Louisiana. Rates of late PTB have risen from 8.4% in 2002 to 9.3% in 2004 to 9.8% in 2006. The first decrease in several years was seen in 2007, with a rate of 9.1%.

A high infant mortality rate driven by a high prematurity rate continues to be one of the major concerns of the Louisiana MCH Program statewide. Approximately 45-50% of preterm births are idiopathic, 30% are related to preterm rupture of membranes and another 15-20% are attributed to medically indicated or elective preterm deliveries. Reducing the numbers of preterm births would reduce the number of LBW babies and meaningfully reduce infant mortality in Louisiana. There are areas of the state with particularly low rates of early entry into prenatal care, high infant mortality, and high LBW rates.

Analysis of perinatal deaths has been done utilizing the Perinatal Periods of Risk approach (PPOR). This approach uses time of death and birth weight to assess the areas of excess mortality and to help pinpoint contributing causes of death. The PPOR assessment concluded that maternal health and prematurity were the leading causes of mortality in each region.

#### *Very low (VLBW) and low birth weight (LBW)*

VLBW and LBW are major risk factors associated with infant mortality and are associated with preterm birth. There has been little change in the VLBW or LBW rates in Louisiana in recent years (See Appendix A, Figure 6). A very slight decrease in VLBW was noted from 2.3% in 2001 to 2.2% in 2006 and 2007. The 2007 rate of VLBW births among Whites (1.3%), Blacks (3.7%), and all races (2.2%) remains higher than the HP 2010 target of 0.9%. The racial disparity of VLBW births, indicated by the Black to White ratio, fell from 2.9 in 2004 to 2.5 in 2005, but rose to 2.7 in 2006 and returned to 2.9 in 2007.

Very low birth weight (VLBW, <1,500 grams) infants are at increased risk of death as well as future health problems among survivors. Hospitals with neonatal intensive care units/ nurseries (NICU) designated as “Level III” or higher have the technology and capability to offer the most advanced neonatal care available, including subspecialty care and advanced life-saving techniques. In 2007, 31 Louisiana hospitals had a Level III or higher neonatal nursery, 9 of which were Level III R. The Healthy People 2010 goal is to have at least 90% of all VLBW births born in Level III or higher facilities. In 2004, 89.1% of Louisiana VLBW infants were born in Level III or higher facilities, nearly reaching the Healthy People goal. The rate fell to 86.8% in 2005 but has risen to 87.8% in 2007, suggesting it is possible for Louisiana to achieve the Healthy People goal by 2010. In order to better understand factors influencing deliveries occurring in lower level facilities, a special study was done using 1998-2004 data. Results showed that during this time, 9,205 (2.0%) births to Louisiana residents were VLBW. Factors significantly associated with delivering a VLBW birth in a level II or lower facility included living in a rural area (over twice as likely), presence of abnormal newborn conditions (over five times as likely), and being greater than 1000g at birth. Black race, younger maternal age, less than high school education, and inadequate prenatal care, were also significantly associated with delivery in a level II or lower facility. In 2007, a review of VLBW deliveries in level I or II facilities was conducted by the MCH Epidemiology Program. Results indicated that only a few lower-level hospitals accounted for the majority of VLBW deliveries in lower level facilities. Further, a high percentage of these deliveries were Medicaid-paid. These results were shared with the Louisiana Medicaid program for follow-up on hospital practices and policies in these select facilities. The Maternal Child Health Program continues to monitor the percent of VLBW births delivered in Level III or higher facilities as part of the Title V MCHB performance measures. <sup>1</sup> National Performance Measure 17 identifies the percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates. Louisiana Vital Records and Statistics identified the annual indicators at 86.0, 86.8, 88.4, 87.7, 87.7 for years 2004, 2005, 2006, 2007, 2008. (2007 and 2008 data are provisional). The percent of very low birth weight (VLBW) births delivered at high-risk facilities has been steadily increasing.

The percentage of LBW infants has not improved, trending from 10.5% in 2001 to 11.0 in 2004, 11.5 in 2005, 11.4 in 2006, and 11.3 in 2007. Louisiana ranks 49th in the nation in LBW births, with rates remaining more than double the HP 2010 goal of 5%. Increases through 2005 followed by slight decreases in LBW deliveries were seen for both Black and White women. A wide racial disparity remains, with 15.8% of Black infants delivered LBW in 2007, compared to 8.4% of White infants. From 2004 to 2006, the rate of LBW births was approximately 2 times higher among Black women as compared to White women. According to Louisiana Medicaid data, 12.7% of Medicaid-eligible pregnant women delivered low birth weight babies as compared to 7.4% among the non-Medicaid population.

#### *Access to Healthcare*

Although there has been progress in decreasing financial barriers that affect access to health care services for low-income infants, children, and adolescents through the Medicaid Louisiana Child Health Insurance Program (LaCHIP), access to health care services remain a problem in some areas of the state. Much progress has been made in coverage for children, with the rate of uninsured children decreasing from an estimated 24% in 1998 to 11.1% in 2003 to 7.6% in 2005 to 5.4% in 2007. A Louisiana Department of Health and Hospitals report states that the number of uninsured children fell from 97,403 to 64,355 between 2005 and 2007. The report also indicates that while the most recent decline in uninsured children is partly attributable to population shifts caused by Hurricanes Katrina and Rita in 2005, officials also believe increased awareness of the LaCHIP has been a driving force behind this reduction.

### *Preventive Health Services*

With the statewide implementation of the Department of Health and Hospitals' (DHH) CommunityCARE Program, progress had been made in the delivery of preventive health services to children enrolled in Louisiana Medicaid and LaCHIP. Participating healthcare providers must provide enrolled children with immunizations; KIDMED or Early Periodic Screening, Diagnosis and Treatment (EPSDT) periodic screens; medical, vision, hearing, and dental screens; outpatient and hospital inpatient care; health education; referrals to specialists; and primary care case management. According to Medicaid data, there were over 500 providers that provided services to 354,887 KIDMED recipients from the state fiscal year of July 2007- June 2008. The percentages of Medicaid-eligible children who received a paid service by Medicaid increased from 70.7% in 2001, 83.2% in 2006 to 89.9% in 2008 (HSCI #07A). The percent of Medicaid enrollees under age 1 year who received at least one periodic screen increased from 88.7% in 2004 to 89.9% in 2008 (HSCI #02). The percentage of LaCHIP enrollees under age one year who received at least one periodic screen increased from 86.4% in 2004 to 91.3% in 2008 (HSCI #03).

Immunizations can provide both individual and community-level (herd immunity) protection against certain infections and illnesses. However, various reasons prevent all individuals from receiving the recommended course of immunizations. Louisiana monitors the percent of 19 to 35 month olds that receive the full schedule of age appropriate immunizations through data reported in the National Immunization Survey. In 2002, Louisiana reported its lowest immunization rate in four years with only 61.9% of 19 to 35 month olds receiving the full schedule of age appropriate immunizations. Efforts to increase coverage have resulted in an estimated coverage rate of 81.9% in 2008. This exceeds the Healthy People 2010 vaccination coverage target of 80% for the currently recommended series.

The Louisiana Childhood Lead Poisoning Prevention Program is a CDC-funded program offering universal screening and monitoring of blood lead levels for children 6 months to 6 years of age. A major risk factor for childhood lead poisoning is living in a house built before 1950 when lead paint was commonly used. In Louisiana, 20% of all homes and 40% of homes in Orleans parish were built before 1950. Beginning in 2008, the program extended designation of high-risk areas from four parishes to all 64 parishes in Louisiana. The most recent data indicate that in 2009, 62,013 (17.8%) of children in the eligible age group were screened for lead poisoning. Blood lead levels equal to or greater than 10 ug/dl were reported for 2.2% of those screened; the corresponding national rate from 2006 was 1.2% (CDC Lead Poisoning Data).

### *Infant Mortality*

Between 2000 and 2007, Louisiana experienced a 2.6% decline in the number of live births. In 2007, Louisiana had 66,063 live births (See Appendix A, Figure 3 for additional years). The infant mortality rate in Louisiana decreased from 10.4 in 2004 to 9.0 per 1,000 live births in 2007; this is the lowest infant mortality rate for Louisiana residents since the year 2000 when the infant mortality rate was 8.9 per 1,000 live births.

Infant mortality continues to be a major concern of the Louisiana MCH Program. The United Health Foundation ranked Louisiana 49<sup>th</sup> in its 2009 report and the National Vital Statistics Reports indicated that Louisiana ranked in the top five states with the highest infant mortality rate (IMR) each year from 2000 to 2006. Louisiana consistently fails to meet the Healthy People 2010 objective of less than 4.5 infant deaths per 1,000 births. In addition, the IMR for Louisiana consistently exceeds the US rate (US 2006 IMR=6.7 per 1,000), usually by more than 3 infant deaths per 1,000 live births (LA 2006 IMR=10.0 per 1,000). The 2007 IMR (rate=9.0 per 1,000)

was the lowest reported since the year 2000, when the low rate was in part due to underreporting of infant deaths weighing less than 500-grams at birth. Preliminary Louisiana data from 2008 show an IMR of 9.3 per 1,000, indicating a possible continuance in lower infant mortality for Louisiana when compared to historical data.

Final 2007 infant mortality data suggest considerable variability by geographic area. Historically, Orleans parish, part of one of the largest metropolitan areas in Louisiana, has been one of the Louisiana parishes to experience high infant mortality. However, all-race IMRs were 11.3, 9.8, 11.0, 9.1, and 7.6 in 2003, 2004, 2005, 2006, and 2007, respectively. This apparent decreasing trend for Orleans parish may in part be due to population shifts and changing health since the 2005 hurricanes. In contrast, East Baton Rouge parish, a metropolitan area containing the state's capital, has remained relatively stable during this time, reporting IMRs between 9.2 and 11.3 per 1,000 during this time period, culminating in a 2007 rate of 10.7. Another parish with historically high IMR, Caddo (Shreveport), reported consistently high IMR over the 5-year period, with all-race IMRs of 12.0, 14.4, 12.5, 12.0, and 13.2 per 1,000 in 2003, 2004, 2005, 2006, and 2007, respectively. For the combined period of 2005-2007, three parishes, West Baton Rouge, Claiborne, and East Carroll, were the only parishes to report IMRs exceeding 20 deaths per 1,000 births. As very few births occurred in Claiborne and East Carroll parishes, these high rates may be statistically unstable. However, there were 22 deaths and 1,019 live births in West Baton Rouge parish in this 3-year period, suggesting this parish may be a priority for targeting additional resources.

Louisiana has a large racial disparity that exists between Whites and Blacks in infant mortality (See Appendix A, Figure 4). For the 2005-2007 combined period, the Black IMR was 14.9 and the White IMR was 6.5 per 1,000. While three parishes reported all-race IMRs in excess of 20 deaths per 1,000 births, 13 parishes reported Black IMRs exceeding 20 per 1,000. However, all but three of these rates were based on fewer than 10 infant deaths, making interpretation of stability difficult. The ratios of Black to White IMR for the state were 2.1, 2.5, and 2.2 in 2005, 2006, and 2007, respectively. The disparity worsened in 2006 due to an increasing IMR for the Black population but a decreasing IMR for the White population compared to the prior year. However, in 2007, IMRs dropped for both races, thereby reducing the racial disparity as well. Statewide, White IMRs rose from 6.4 in 2003 to 7.7 in 2004 then fell annually to 6.2 in 2007. The average annual percent change for White IMRs from 2003 to 2007 was a net 2.5% decrease. In contrast, Black IMRs rose annually from 13.8 in 2003 to a high of 16.0 in 2006, then falling in 2007 to 13.8. The average annual percent change for Black IMRs from 2003 to 2007 was a net 1% increase. It is hoped that the new IMRs will continue to show a decreasing trend for both races with a further reduction in disparity.

Causes of infant deaths were analyzed using statewide death certificates from 2006. Leading causes of death followed the same rank order for Whites and Blacks, with conditions originating in the perinatal period followed by congenital malformations, deformations, and chromosomal abnormalities and SIDS being the three leading causes. Despite remarkable differences in rates, race-specific rank order remained similar during both the neonatal and post neonatal periods. For neonatal deaths, almost 73% were due to conditions originating in the perinatal period (rate=8.2 per 1,000, 80% of Black and rate=2.1 per 1,000, 59% of White infant deaths), with an additional 21% due to congenital malformations, deformations, and chromosomal abnormalities (rate= 1.6 per 1,000, 15% of Black infant deaths and rate= 1.1 per 1,000, 31% of White infant deaths). For post-neonatal death, the leading cause of death was SIDS, accounting for 22.1% of total infant deaths (rate=0.9 per 1,000), followed by 18.0% due to injury (rate= 0.7 per 1,000), followed by 16.8% due to congenital malformations, deformations, and chromosomal abnormalities (rate=0.6 per 1,000). By race, the leading cause of postneonatal death for Whites was congenital

malformations (rate=0.8 per 1,000) while SIDS was the leading cause for Blacks (rate=1.3 per 1,000).

### *Child Mortality*

Prior to 2000, Louisiana experienced an overall decreasing trend in the child death rate; recent years indicate that the rate rose from 30.8 deaths per 100,000 children in 2000 to a high of 35.5 in 2004 to a low of 21.7 in 2006, rebounding slightly to 25.3 in 2007. Louisiana's child death rate remains higher than the Kids Count 2006 national rate of 19 deaths per 100,000 children. For the period 2005 to 2007, the death rate was higher in early childhood, 39.2 deaths per 100,000 children aged 1-4 years, compared with that in late childhood, 23.2 deaths per 100,000 children aged 5-14 years. Compared to equivalent data from 2000 to 2002, the current rate is much lower for the 1-4 year age group (2000-02 rate= 52.1) but not very different for the 5-14 year age group (2000-02 rate=25.3). The Black to White racial disparity in the death rates was 1.8:1 among the early childhood population and 1.4:1 in late childhood. The early child death rate ranged from 33.9 to 64.2 in the state's nine Public Health Regions, whereas the late child death rate ranged from 17.6 to 27.5 per 100,000. Public Health Region II (greater Baton Rouge area) had the lowest reported mortality rates for both childhood age groups.

The 2005-2007 leading causes of deaths to children aged 1 to 14 years were unintentional injury followed by homicide and diseases of the nervous system. The annual rate for unintentional injury deaths in children aged 1-14 years (Health Status Indicator #3A) decreased from 14.2 in 2005 to 10.1 in 2006, and remained at 10.4 per 100,000 in 2007. For 2005-2007 combined, Motor vehicle crash (MVC) deaths (National Performance Measure #10 and Health Status Indicator #3B) accounted for the largest number of unintentional injury deaths (rate=5.2 per 100,000). Drowning and fire were the second and third leading causes of death due to unintentional injury (rates=2.1 and 1.8 per 100,000, respectively). The rate of deaths due to MVCs fell from 5.1 in 2005 to 4.7 in 2006, but rose to 5.8 per 100,000 in 2007. MVCs were the leading cause of death in all nine public health regions.

### *Adolescent Morbidity*

The main threats to the health of adolescents (10-24 years) are the choices they make and risky behaviors in which they partake. The six main categories that encompass the major causes of morbidity and mortality in the adolescent population are unintentional and intentional injury, tobacco use and substance abuse, reproductive health, mental health, chronic disease and health promotion, and access to care.

### *Access to Healthcare*

Access to health care services for adolescents in Louisiana is limited in many areas of the state. Progress has also been made in providing health insurance coverage for adolescents. The percentage of uninsured adolescents decreased from an estimated 13.8% in 2006 to 12.6% in 2008 according to the AAP State Reports 2007 and 2009 on Children's Health Insurance Status & Medicaid/CHIP Eligibility & Enrollment, respectively. The National Survey of Children's Health also showed a decrease in the percentage of uninsured adolescents ages 12-17 years from 9.5% in 2003 to 6.2% in 2007. Increased awareness of LaCHIP/Medicaid through outreach efforts has contributed to this reduction.

### *Preventive Health Services*

Progress has also been made in the delivery of preventive health services to Louisiana adolescents. The percentages of Louisiana Medicaid-eligible children ages 15-18 years who received at least one initial or periodic screen increased from 52% in FY 05 to 67% in FY09 and from 52% to 72% for ages 10-14 years. According to the NSCH, more Louisiana children ages 12-17 years received one or more preventive medical care visits in 2007 (85%) than in 2003 (65.5%). However, only 49.1% of children ages 12-17 years received health care that meets the AAP definition of medical home in 2007 compared to 65.8% in 2003.

Not all adolescents receive the recommended course of immunizations. However, in 2008, estimated immunization coverage for Louisiana adolescents ages 13-17 years was at or the national average for the following: one or more doses Tdap/TD at 75% (72% national avg.); one or more doses MCV4 at 54% (42% national avg.); and two or more doses MMR at 89% (89% national avg.). Louisiana adolescents were just below the national average for coverage with two or more doses VAR (with no varicella history) at 33% (34% national avg.); three or more doses HepB at 85% (88% national avg.); and one or more doses of HPV at 36.6% (37.2% national avg.)/three or more doses HPV at 17% (18% national avg.).

### *Teen Births and Sexually Transmitted Diseases*

Nationally, the *rate of births among teens* 15-17 years of age decreased from 1991 to 2005, with a slight upward turn reported in 2006. The state of Louisiana has also seen a decrease in the rate of teen births age 15-17 years, from 34.8 per 1,000 female teens in 2000, to 26.8 per 1,000 in 2005, with an increase to 29.5 per 1,000 in 2006. The decrease through 2005 was seen for both White and Black teens, although the rate of teen births to Black females remained disproportionately higher than to White females, with a 2.5 to 3.0 fold disparity in rates. A greater decrease in teen births from 2000 to 2007 occurred to Black teens as compared to White teens. Specifically, the rate of teen births to Black females aged 15-17 decreased from 58.8 in 2000 to 46.2 per 1,000 in 2007, a 21.4% decrease; the rate of teen births to White females decreased from 19.5 in 2000 to 18.8 in 2007, representing only a 3.6% decrease. Rates to teens age 15-19 years followed a similar pattern as the rates to 15-17 year-olds, showing a decreasing trend through 2005 followed by an increase in 2006 and 2007. The 2007 Louisiana crude teen birth rate was 55.9 per 1,000, while the corresponding rate for White and Black teens were 41.1 and 78.5 per 1,000, respectively. In 2007, the highest rates of pregnancy among teens 15-19 years of age were in the central part of Louisiana (Alexandria region rate=69.0), followed by the Shreveport area (rate=67.8). In contrast, the Baton Rouge and New Orleans metropolitan regions had the lowest rate of teen births with rates of 44.1 and 47.2 per 1,000, respectively. Among White females, the central and southwest regions had the highest teen birth rate in 2000, with rates of 62.0 and 56.0 per 1,000. By 2005, these same regions remained the highest for teen pregnancy among Whites; however rates had fallen to 57.0 and 48.8 per 1,000, respectively. In 2007, the same regions lead the state for White teen births; however, the central region rate fell to 55.6 per 1,000 while the southwest region rate rose to 53.5 per 1,000. In sum, these two regions have led the state in high teen birth rates among White teens for several years. Among Black teens, the central region had the highest teen birth rate in 2000, followed closely by the southwest and northshore regions. All three regions experienced teen birth rates among Black teens above 100 per 1,000. In 2005, the south central region of the state had the highest teen birth rate among Black teens, but the central region took the lead again by 2007, with a reported rate of 100.1 per 1,000, nearly double the rate of White teens.

Risky behaviors that adolescents engage in can lead to pregnancy or sexually transmitted diseases (STDs). In 2007, 13.8 % of all Louisiana resident births were to teens. In 2007, Louisiana ranked

1<sup>st</sup> highest, (rate=12.4 per 100,000 population) in the US for primary and secondary Syphilis, as well as for congenital syphilis (rate=55.1 per 100,000 live births). Gonorrhea and Chlamydia also continue to be a problem in the state, showing increasing trends over the past several years. In 2007, there were 11,137 cases of gonorrhea reported in Louisiana (rate=259.7 per 100,000 population; 252.5 per 100,000 female population). There were 19,362 cases of Chlamydia in Louisiana (2007 rate =451.6 per 100,000 population); the corresponding rate for females was 665.0 per 100,000 female population. Gonorrhea and Chlamydia are more prevalent among the adolescent and youth populations than other age groups. Of all reported Gonorrhea cases, 29.6% occurred among teens aged 15 to 19 years old, and 35.4% occurred among 20 to 24 year olds. Of all reported Chlamydia cases, 37.7% occurred in the 15 to 19 year age group, and 39.5% among 20 to 24 year-olds. Louisiana ranked 2<sup>nd</sup> highest for Gonorrhea and 7<sup>th</sup> highest for Chlamydia. All 2007 prevalence rates all indicate an increase over 2006. Rates of sexually transmitted diseases (STDs) during pregnancy are also monitored by linking STD Control program data with live birth records. In 2007, the prevalence of syphilis, gonorrhea, and Chlamydia during pregnancy was 0.2%, 1.6%, and 4.9%, respectively. In 2007, Louisiana ranked 5<sup>th</sup> highest in state AIDS case rates and 11<sup>th</sup> in the number of AIDS cases diagnosed in 2007. The metropolitan New Orleans area ranked 2<sup>nd</sup> and the metropolitan Baton Rouge area ranked 3<sup>rd</sup> in AIDS case rates in 2007 among the large Metropolitan areas in the nation. The majority of new infections are in males, African Americans, and persons aged 25-44. 19% of new HIV cases diagnosed in 2009 were between the ages of 13-24 years old.

#### Adolescent Mortality

The top three leading causes of death for adolescents in Louisiana from 2005 to 2007 were unintentional injury (44% of deaths, rate=41.8 per 100,000), intentional injury/homicide (30%, rate=28.4), and diseases of the circulatory system (4%, rate=4.2). The top three causes of death for White youth in Louisiana were unintentional injury (58% of White deaths, rate=51.8 per 100,000 Whites), accidental poisoning and exposure to noxious substances (15%, rate=13.8), and suicide (13%, rate=11.4). For Black youth the top cause of death was homicide by firearm (39% of Black deaths, rate=42.0 per 100,000 Blacks), followed by unintentional injury (26%, rate=28.1), and diseases of the circulatory system (4.4%, rate=4.7).

In 2007, the leading cause of death for all adolescents was injury. Importance differences by race emerged in that the leading cause of death among White adolescents was unintentional injury compared to intentional injury among Black adolescents. Unintentional and intentional injury combined accounted for 75.7% of all White adolescent deaths and 72.4% of all Black adolescent deaths. Unintentional injury alone accounted for about 77% of White injury deaths but only 36% of Black injury deaths. MVCs claimed the lives of 543 White adolescents (36% of all White adolescent deaths, 47% of White injury deaths) and 194 Black adolescents (16% of all Black adolescent deaths, 22% of Black injury deaths). In 2006, the rate of MVC related deaths for Louisiana adolescents aged 15-24 years was 34.4 per 100,000, 24% higher than the national rate of 26.0 deaths per 100,000 adolescents aged 15-24 years. MVCs also account for the majority of non-fatal unintentional injuries; according to the 2007 Louisiana hospital discharge data, the rate of nonfatal injuries due to MVCs was 113.1 per 100,000 for 10 to 24 year olds and 138.9 per 100,000 for 15 to 24 year olds.

#### Cross-cutting issues across all population groups

##### *Behavioral Health*



Substance use during pregnancy was identified as a major need and is routinely monitored in Louisiana in an effort to target resources to improve pregnancy outcomes. Although tobacco and alcohol use are reported on the birth certificate, underreporting of these measures suggest that the population-based LaPRAMS surveillance data provide a better estimate of substance use. Smoking during pregnancy has been associated with poor perinatal outcomes and low birth weight. The percent of women reporting smoking during the last trimester of pregnancy increased from 11.8% in 2002 to 12.6% in 2007, however, a state-wide response rate of <65% of women surveyed requires that this estimate be interpreted with caution. A 2000-2004 LaPRAMS study indicated that White women were 6.6 times as likely to report cigarette use in the last trimester compared to Black women. After controlling for race, maternal age, and gravid, additional factors associated with cigarette use included low educational attainment, being unmarried, and life stressors such as having a lot of unpaid bills, being in a physical fight, and having someone close with a drinking or other substance use problem. A similar pattern to tobacco was seen for alcohol use, with approximately 4.9%, 6.8%, and 5.5% of women reporting drinking during the third trimester in 2002, 2004, and 2007, respectively. The same 2000-2004 LaPRAMS study indicated that White women were 70% more likely to report alcohol use compared to Black women. After controlling for gravida, being in a physical fight was significantly associated with alcohol use. Interestingly, educational attainment showed no statistical association in this analysis.

Additional data obtained through a convenient sample of those who are participating in the Screening, Brief Intervention, Referral and Treatment (SBIRT-Healthy Babies Initiative), using the validated *4PsPlus* screening tool, identified that among women screened in private obstetrical provider non-WIC sites cumulative between 5/05/05-12/30/09, 18.3% used tobacco cigarettes, 6.7% used alcohol, 3.2% used marijuana, 0.5% used drugs since they knew they were pregnant. Screening in WIC sites cumulative between 7/16/05-12/30/09 indicated that 14.4% of women used tobacco cigarettes, 3.7% used alcohol, 1.8% used marijuana, 0.1% used drugs since they knew they were pregnant. In 2009, SBIRT screens in Non-WIC sites indicated that 20.9% used tobacco cigarettes, 7.8% used alcohol, 3.0% used marijuana, 0.8% used drugs since they knew they were pregnant; screens in WIC sites also identified that 17.8% of women used tobacco cigarettes, 4.7% used alcohol, 1.8% used marijuana, 0.1% used drugs since they knew they were pregnant. Results also showed that 7.1% of all screened pregnant women identified at risk for domestic violence and 16.4% identified at risk for depression in 2009. Approximately 17,000 women participate in OPH-WIC during pregnancy which indicates that 25% of the Office of Public Health-WIC populations are being offered the SBIRT screen at this time. WIC SBIRT data indicates that 87.2% of women screened in 2009 identified Medicaid as their insurance, with 6.7% with private insurance and 6.1% as not having insurance.

According to the 2008 Communities that Care Survey, alcohol is the most commonly used substance among adolescents in Louisiana. The average age for initiation of alcohol use was 12.5 years. Approximately 26.8% of 6<sup>th</sup>, 8<sup>th</sup>, 10<sup>th</sup> and 12<sup>th</sup> graders surveyed stated that they had used alcohol in the past month and 50.8% reported using alcohol at least once in their lifetime. Cigarettes were the second most commonly used substance among adolescents in Louisiana. The 2008 Louisiana CCYS showed that 28.6% of students in grades 6<sup>th</sup>, 8<sup>th</sup>, 10<sup>th</sup>, and 12<sup>th</sup> used cigarettes at least once in their lifetime and 10.7% of students in the same grades used cigarettes at least once in the past 30 days; the average age for initiation of cigarette use was 12.1 years.

The rate of child abuse and neglect is used as an indicator of the breakdown in the parent/child and family system. The MCH program tracks the incidence of child abuse and neglect in its State Performance Measure #3, the rate of children under 18 who have been abused or neglected as reported as validated cases of child abuse and neglect. Cases of abuse and neglect are reported

through the Office of Community Services and are reported in the Title V Block Grant as State Performance Measure #3. Rates of child abuse and neglect increased from 9.3 per 1,000 population under 18 years of age in 2008 to 11.7 per 1,000 in 2006 and decreased to 9.2 per 1,000 in 2008. Historically, cases of child neglect comprises approximately one third of the validated cases.

Parenting education/family support is a cross cutting issue that can impact most of the priority needs of children. According to the 2007 National Survey of Children's Health, 10.2% of children live with parents who experience high levels of stress from parenting. High stress is reported more often by the parents of children living in single-mother households. In addition, CYSHCN have parents who are twice as likely to report high levels of stress.

Absenteeism and children's participation in activities outside of the school setting are also indicators of a breakdown in the parent/child and family system. In 2007, the percent of children age 6-17 who missed 11 or more days of school in the previous year was 6.8% compared to 5.3% in 2003. In 2007, 75.0% of children age 6-17 participated in activities outside of school compared to 80.6% in 2003.

### *Nutritional Health*

Weight gain during pregnancy is an important factor in maternal and fetal outcomes. While inadequate weight gain has been strongly and consistently associated with poor neonatal outcomes, especially low birth weight and very low birth weight, excessive weight gain is associated with gestational diabetes, large-for-gestational-age infant, cesarean delivery, and long-term maternal weight retention. In 2009 the Institute of Medicine released new pregnancy weight gain guidelines based on pre-pregnancy BMI. An analysis of the Louisiana Pregnancy Risk Assessment Monitoring System (LaPRAMS), using data collected from 2002-2004 and 2007, identified that only 34.8 % of Louisiana women achieved appropriate weight gain as recommended by the Institute of Medicine(IOM), with 23.1% under-gaining and 42.1% over-gaining.

LaPRAMS offers self-reported maternal pre-pregnancy weight and height, from which body mass index can be calculated. LaPRAMS data indicate that the percent of women who are overweight and obese have changed very little over time. The percent of women in the overweight category (pre-pregnancy BMI=25 to <30) was 22.9%, 22.8% and 21.2% in 2002, 2004, and 2007, respectively. The percent of women in the obese category (pre-pregnancy BMI= 30+) was 19.5%, 21.5% and 21.3% in 2002, 2004, and 2007, respectively. Reducing the percent of overweight and obese women entering pregnancy could help not only improve pregnancy outcomes but also potentially reduce maternal morbidity including hypertension, diabetes, and other conditions exacerbated by excess body weight.

The Pediatric Nutrition Surveillance System (PedNSS) collects information on nutritional parameters among children under 5 years who are enrolled in the Women, Infants, and Children Supplemental Food Program (WIC). National Performance Measure #14 tracks the percentage of children (2 to 5 years) on WIC greater than or equal to the 95<sup>th</sup> percentile for BMI-for-age. From 2002-2007 this measure indicates a static trend in children on WIC at or above the 95<sup>th</sup> percentile. In 2007 the percent of children who were obese (at or above the 95<sup>th</sup> percentile) in Louisiana was 13.8% compared with a national percentage of 14.9%, while previous percentages in Louisiana were 14.0 in 2004, 13.3 in 2003 and 13.5 in 2002. During the 2007-2008 school year, height and weight taken on approximately 12,000 children (2-19 yrs old) seen in School Based Health Centers in Louisiana revealed 46.5% are considered overweight or obese.

Nutrition Risk Codes are used in WIC to assess a participant's nutritional risk status, tailor the food package to address nutritional needs, design appropriate nutrition education, and make referrals to health and social services for follow-up as necessary. In Louisiana the most common nutrition risk codes include inappropriate feeding practices for children (20.75 %), environmental tobacco smoke exposure (9.0%), low hemoglobin or hematocrit values (7.88%), infant born of a woman at nutrition risk (6.94%), and pre-pregnancy or postpartum overweight (6.48%).

### *Oral Health*

Children in Louisiana have many oral health problems; children from families with low incomes and who are Medicaid-eligible, have more untreated dental caries than children from higher income families. These children suffer from dental disease at a rate almost five times greater than their more affluent counterparts, according to the US General Accounting Office, Oral Health Dental Disease is a Chronic Problem among Low-Income populations and Vulnerable Populations (2000).

In 2007-2009, the Oral Health program conducted a Basic Screening Survey with a representative sample for Louisiana, collecting information on the oral health status of 3rd grade children as reported in National Performance Measure # 9. According to the survey, 41.9% had untreated dental caries, 65.7% had dental caries experience, only 33.2% had dental sealants, and lastly 42.7% had to be referred to dentists for treatment. A parent questionnaire indicated the following: 16% of children reported to have a toothache during the last 6 months, 49% of children have not seen a dentist for more than 6 months, and 5% of children have never been to a dentist. The survey also indicated that of the children reported seeing a dentist, 72.3% went to get a routine examination and cleaning and 11% could not receive care when needed. When comparing oral health status by school type, children in public schools have more untreated cavities and caries experience and, as a group, a larger percentage requires dental treatment when compared to children in private schools. However, the proportion of children with dental sealants does not differ by school status. Disparities exist in oral health status among different races in Louisiana. African American children are also most likely to have caries experience as compared to other races, and almost half are in need of the dental care followed by "others", and Whites. The prevalence of untreated cavities is higher among "others" (Hispanic, Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, Multiracial and Unknown) followed by African Americans, and the prevalence of dental sealants is high in Whites as compared to Blacks and others. The survey was designed to capture geographical estimates of oral health by dividing the state into four areas, Northern, Central, River Parishes, and Southern. The highest percentage of caries experience is present in the Northern Area, while the Central Area had the highest percentage of untreated cavities. The Southern and River Parishes Areas have a higher percentage of 3rd graders with at least one or more dental sealants on their permanent molars as compared to the Northern Area which had the lowest percentage.

LaPRAMS is an ongoing, population-based risk factor surveillance system designed to describe selected maternal behaviors and experiences that occur before and during pregnancy as well as during a child's early infancy. Based on LaPRAMS data, in 2007, 33.6% of women reported that they needed to see a dentist for a problem, compared with 27.3% in 2004. Almost 37% of women reported that they went to a dentist or dental clinic during pregnancy in 2007 compared to 32.4% in 2004. Almost 38% of women in Louisiana reported that they talked to a dental or other health care worker about how to care for their teeth and gums during pregnancy in 2007, compared with 33.5% in 2004. Racial disparities with regard to dental care were evident in

2007; 39.3% of Black women reported needing to see a dentist, while 30% of White women reported having dental problems; 32.4% of Black women reported seeing a dentist, while 39.8% of White women reported seeing a dentist during their pregnancy in 2007. Forty percent of Black women reported talking with dental or other health care worker about how to care for their teeth and gums, while only 36% of White women reported talking to a dental or other health care worker about dental care in 2007.

Dental services are provided to Medicaid-eligible pregnant women through the Expanded Dental Services for Pregnant Women program. The program has shown growth in the amount of dollars spend from \$268,918 in State Fiscal Year (SFY) 2005 to \$2,436,539 in SFY 2009. The increase can be accounted for by the increase in reimbursement rates and the increase in the number of services provided to the patient; cost per patient in SFY 2005 was approximately \$130 as compared to \$425 in SFY 2009. The number of patients treated through EDSPW increased by 173% from 2,085 patients served in SFY 2005 to 5,708 served in SFY 2009. However, for the same time period, the number of providers only showed a modest 21% increase from 268 to 343. Even though usage of the dental services has increased, anecdotal evidence suggests that access to care is still a barrier.

During SFY 2009, there were 39,924 total claims requested from Medicaid under EDSPW program. An analysis of the data for SFY 2009 by level of services shows that out of the total claims, 61% were for Level 1 services or primary prevention (Examination, Radiographs, and Prophylaxis), 5% were for Level 2 or Secondary Prevention (Full mouth Debridement and Periodontal Scaling), and 34% were for Level 3 or Restorative services (Amalgams, Resins, Pin Retention, Stainless steel/Resin Crowns and Extractions). However, the money reimbursed for these services is in inverse proportion to the level of services. In the same time period, 23.2% of the total expenditure was reimbursed for Level 1 services, 9.5% for Level 2 services and 67.3% for Level 3 services. From the SFY 2005 to SFY 2009, this trend has remained steady. Since dental services end when the pregnancy ends, anecdotal evidence suggests that many women begin treatment but are not able to complete needed care prior to the conclusion of the pregnancy.

Access to dental services is also challenging in Louisiana. Even though there has been an increase in the number of providers participating in the EDSPW program, still there many parishes where there were no claims filed. The number of parishes where there were no claims filed has varied little from 18 in the SFY 2005 to 16 in SFY 2009.

There are many factors that contribute to poor oral health including access to fluoridated water, access to dental care, and poverty. Only 41% of Louisiana residents receive the benefits of fluoridated water which is one of the most effective, safe, and economical ways to provide caries prevention to the population. Of the seven urban population centers, only three have fluoridated water. Areas with the least amount of community water fluoridation are the west, central and northern parts of the state. Access to care is challenging due to a large rural population with few Medicaid dental providers. In Louisiana 56 parishes (87.5% of the state) are designated as Dental Health Professional Shortage Areas with the state, having on average, 40% less dentists and 42% less dental hygienists than other states. There are many factors that contribute to poor oral health including the access to fluoridated water, access to dental care, and poverty. Access to care is challenging due to a large rural population with few Medicaid dental providers. According to the 2008 Behavioral Risk Factor Surveillance System, 54.5% of Louisiana residents with an annual income of less than \$15,000 per year did not visit a dentist or dental clinic.

Improving oral health among children and pregnant women in Louisiana is a priority need. Oral health related morbidity can be reduced by increasing community water fluoridation, increasing access to restorative and preventive dental services for children and pregnant women. Increasing the number of dental providers that treat Medicaid-eligible children and pregnant women is a priority of the MCH Program. Sealants use, an excellent preventive measure, needs to be more widely utilized; sealant programs could reach the populations most susceptible to dental caries and areas without dental providers. Although fluoridation is the safest, most cost effective way to reduce caries prevalence, fluoridation is underutilized in Louisiana.

### *Consumer Perspective*

#### Maternal Health

Results of the statewide consumer survey expressed the public's perceptions and assessment of the importance of women's health issues. Prenatal care was the highest ranking women's health issue with 96.4% of respondents indicating it as an issue of importance. Healthy eating was the second highest ranked issue (93.6%) followed by STDs (93%), chronic disease (92%), physical activity (90%), grief support (89.6%), alcohol use during pregnancy (89.5%), prescription drug use during pregnancy (89.0%), family planning/pregnancy spacing (88.7%) and obesity (88.6%).

#### Infant & Child Health

Consumers were asked to assess the importance of several infant and child health issues. Childhood asthma was ranked as the overall leading infant and child health issue of importance by respondents. Healthy eating (97.1%), childhood vaccinations (97%), fire (94.4%), poisoning (94.1%), physical activity (93.8%), drowning (93.7%), homicides (93.3%), abuse and neglect (92.9%) and motor vehicle crashes (92.5%) were also among the top infant and child health issues of importance. It is important to note that breastfeeding was viewed as an issue of low importance with only 63.3% of respondents indicating it as an issue of importance. Breastfeeding was also the lowest overall ranking issue of all categories included in the consumer survey which suggests that targeted efforts are needed to improve perceptions of the importance of breastfeeding.

#### Adolescent Health

Vaccinations/immunizations (96.2%) were the leading issue of importance in regard to adolescent health. Healthy eating (95.9%), physical activity (95.5%), abuse and neglect (95%), health education (94.1%), teen pregnancy (93.8%), suicides (93.7%), motor vehicle crashes (93.6%), and grief support (93.5%) were also leading issues of importance among respondents.

#### Oral Health

Dental care for children over 5 years old (95.9%) was the leading oral health issue of importance among respondents. However, dental sealants and water fluoridation were the lowest ranking oral health issues at 77.3% and 75.5% importance, respectively. This suggests that targeted efforts are needed to improve perceptions of the importance of dental sealants and water fluoridation.

#### Access

Consumers' responses indicated concern with regard to the lack of access to services prior to pregnancy and after pregnancy. Prior to pregnancy, 19.8% of respondents noted that their lack of

access to services was directly related to a lack of insurance coverage while 18.3% cited limited access due to the lack of insurance after pregnancy. This is of particular interest when considering that only 6.6% of respondents noted limited access due to a lack of insurance during pregnancy.

Feedback from the consumer survey also revealed that provider accessibility was yet another barrier to accessing services. Respondents (18%) noted that there was a lack of providers close to home for services needed during pregnancy. However, only 10.2% of respondents noted this was an issue prior to pregnancy.

### *Priority Health Areas for Enhancement or Strengthening*

#### *Maternal Health*

Enhancement of services which promote and establish preconception and interconception care for a targeted group of high risk women, including those with diabetes, hypertension, and prior preterm birth are needed. Louisiana will implement a pilot program that begins with women who are already eligible for health care services (TANF, Medicaid prior to pregnancy, SSI) and provide primary health care and social support for these women.

Louisiana MCH will continue to focus on behavioral health needs of the maternal population, with an emphasis on maternal depression and substance use. Louisiana MCH is planning to address maternal nutrition, including collaborating with Nutrition Services to conduct training for WIC staff on the new IOM weight gain guidelines.

#### *Infant and Child Health*

Decreasing intentional and unintentional injury is essential if Louisiana is to improve the rates of child and adolescent mortality and morbidity. Especially concerning are the areas of family violence and firearms.

To address the increasing concern of childhood obesity in our state, MCH is planning a childhood obesity prevention program in childcare settings across the state. The childcare program will include a Registered Dietitian working with childcare settings to implement the NAP SACC (Nutrition and Physical Activity Self- Assessment for Child Care) program, an evidence-based program designed to enhance policies, practices, and environments in child care by improving the nutritional quality of food served, the amount and quality of physical activity, staff-child interactions, and the facility nutrition and physical activity policies and practices and related environmental characteristics. Louisiana MCH will also collaborate with Louisiana Department of Social Services to ensure Louisiana childcare licensure regulations include strong nutrition and physical activity policies.

Efforts designed to reduce substance abuse and risky sexual behavior are needed to address Louisiana's rates of teen pregnancy, sexually transmitted diseases and adolescent injury. OPH/ASHP is committed to placing great focus on these issues through innovative partnerships and initiatives.

### *Quantitative and Qualitative Analyses' Congruence*

MCH obtained valuable feedback from consumers around the state in an effort to assess the importance of women's and children's health. Survey results provided regional stakeholders with rich information in order to engage in further qualitative analyses and discussion. The congruence

of the consumer qualitative feedback, along with regional qualitative analyses and quantitative analyses is examined below.

### *Maternal Health Subgroup*

The results of the qualitative strengths and needs analysis for the maternal health subgroup revealed findings that largely confirm the states quantitative analysis of strengths and needs. The high level of congruence of these data not only suggests that the region's identification of priority needs were rooted in empirical data but is also an indicator of the utility of the qualitative assessment process. It also reflects consumers' perspectives regarding the importance of key health issues. The results of the qualitative strengths and needs analysis show that preconception /interconception health, behavioral health, preterm birth and health disparities were identified as the priority needs. These were among the most frequently identified preliminary priority needs across the nine administrative regions. While the frequency in which these priority needs were identified was important in determining these top priority needs, the process of determining the state's top priorities needs in the qualitative methodology was also based on other factors including, the MCH programs capacity to address the need, and whether the needs were in line with the objectives of the MCH program.

Behavioral health was highlighted across several regions as an important need to address. Primary among the issues relayed by stakeholders were the lack of services for women in need of mental health treatment. Quantitative data did show that a high percentage of women report behavioral health problems. Data from SBIRT reveal that among women screened, a high percentage of women report feeling depressed. In addition, 86.6% of consumer survey respondents viewed depression and stress as an issue of importance. SBIRT data also show that of women screened a high percentage report alcohol use and smoking during pregnancy. Data from Louisiana PRAMS similarly show an increasing trend in the use of alcohol and smoking during the third trimester of pregnancy. It is important to note that consumers viewed alcohol and tobacco use during pregnancy as an important issue with 89.5% and 88.1% responding, respectively. Moreover, that regions identified a shortage of behavioral health service providers was consistent with the maternity programs assessment of available regional resources.

Reducing infant mortality through decreasing preterm birth was also identified as a priority need. Decreasing preterm birth as a strategy to reducing infant mortality is consistent with the results of the maternity subgroups quantitative analysis. Preterm/low birth weight births were the leading cause of infant mortality in Louisiana from 2004 to 2006. As such, these data suggest that lowering preterm birth would be an effective strategy to reducing the infant mortality rate. High rates of infant mortality were observed across regions. In 2007, the infant mortality rate was 9.0 per 1,000 births which was well above the national average in 2007 and that of the HP2010 objective. Moreover, a multivariate analysis assessing indicators of repeat preterm birth revealed that preterm birth was a risk factor for repeat preterm birth providing further evidence of the need to reducing preterm birth.

The reduction of racial health disparities was another priority need of the maternity subgroup, while racial disparities was only identified in two regions as a priority need. However, that large Black-White differences exist across most of the health indicators examined in the quantitative needs assessment resulted in the decision to include reduction of racial health disparities among the state's top priority needs. The epidemiologic data confirm the importance of including health disparities as a priority need. Data from the BRFSS show that Blacks have worst health outcomes in a range of chronic conditions including diabetes, hypertension and self reported health status.

Results of qualitative analyses identified breastfeeding as a priority need in order to improve breastfeeding rates around the state. The results of qualitative analysis revealed that a lack of family support in encouraging and supporting breastfeeding among women was common in many regions. In addition, results of qualitative analyses showed that doctors and hospitals in some regions provide inadequate support for breastfeeding initiation. Results of the consumer survey illustrated a very low importance for breastfeeding among the general public. Only 63% of total respondents viewed breastfeeding as an important issue. This was the lowest ranked issue of all issues included in the consumer survey. Quantitative data confirm the results of qualitative analyses. Louisiana has one of the lowest rates of breastfeeding initiation in the U.S. The rate of breastfeeding initiation in Louisiana in 2006 was well below the national average and the HP2010 objective. Data from Louisiana PRAMS 2006 also show that nearly 50% of women did not receive guidance from hospital staff on breastfeeding.

Preconception/interconception health was identified in the majority of regions as a priority need. Consistent with this finding, results of the quantitative analysis also placed preconception/interconception health among the state's top priority needs. Data from the quantitative analysis of strengths and needs provide strong evidence to support the inclusion of preconception/interconception health as a priority need. For example, findings from 2006 Louisiana PRAMS, show that a high percentage of women in Louisiana report being obese prior to pregnancy. Specifically, 20% of women reported being obese in Louisiana prior to pregnancy in 2007. Furthermore, consumer feedback suggested that obesity was of importance with 88.6% of respondents. In addition to high rates of obesity prior to pregnancy Louisiana PRAMS asks women, during the month before you got pregnant with your new baby, how many times a week did you take a multivitamin or prenatal vitamin? In 2006, only a quarter of women reported taking a multivitamin every day.

The reduction of racial health disparities was another priority need of the maternity subgroup, while racial disparities was only identified in two regions as a priority need. However, that large Black-White differences exist across most of the health indicators examined in the quantitative needs assessment resulted in the decision to include reduction of racial health disparities among the state's top priority needs. The epidemiologic data confirm the importance of including health disparities as a priority need. Data from the BRFSS show that Blacks have worst health outcomes in a range of chronic conditions including diabetes, hypertension and self reported health status.

### *Child Health Subgroup*

Consistent with trends in data revealed from the Maternal Health subgroup analysis, the results of the qualitative strengths and needs analysis of the Child Health subgroup are largely congruent with the quantitative analysis of strengths and needs. The results of the Child Health qualitative strengths and needs analysis methods show that unintentional/intentional injuries, obesity/healthy eating, behavioral health, parenting education, and teen pregnancy were identified as priority areas.

Injury data show that among children ages 1 to 14, external causes of mortality were the leading causes of death from 2002 to 2007. In this category, the primary causes of mortality were motor vehicle accidents, accidental drowning and accidents caused by exposure to smoke, fire, and flames. While death rates for each of these causes of death declined from 2005 to 2007 when compared to the 2002 to 2004 time period, rates remain well above 2006 U.S. rates. Consumer feedback suggests that the public is concerned about child injury with 94.4% of respondents



citing fire as an issue of importance in child health. In addition, drowning and motor vehicle crashes were also issues of importance with 93.7% and 92.5% of respondents, respectively.

Limited data on obesity and childhood nutrition remains an issue. However, in 2007 Louisiana had the 7<sup>th</sup> highest rate of overweight youths (ages 10-17) in the nation. The percent of children younger than 5 years old who were obese (defined as at or above the 95<sup>th</sup> percentile) in Louisiana was 13.8% in 2007, slightly lower than national average of 14.9% in that same year. The percentage of children defined as obese has remained relatively stable since 2002 indicating the continuing need for interventions to address childhood obesity. Consumer feedback echoes the importance of addressing childhood obesity with 89.4% of respondents citing childhood obesity as an issue of importance.

Teen pregnancy was also identified as a need from the regional stakeholder qualitative analyses. Additionally, consumers indicated that teen pregnancy was an important issue with 93.8% of respondents. The results of quantitative analyses are consistent with the qualitative findings. Quantitative data show the teen birth rate in Louisiana remains high. These data show that the Black teen birth rate is nearly 2 times higher than the White rate. Moreover, that the teen birth rate in Louisiana (55.9) remains higher than the U.S. rate (41.9) in 2007 is largely due to this Black-White disparity.

Similar to the Maternity subgroup, behavioral health was an identified need among the child health group. Only 55.3% of children age 2 to 17 years who reported behavioral health problems requiring counseling, actually received counseling. Nearly 90% of children ages 6 to 17 exhibited two or more positive social skills. There were 35% of children ages 4 months to 5 years determined to be at moderate or high risk of developmental or behavioral problems based on parents' specific concerns.

#### **4. MCH Program Capacity by Pyramid Levels**

##### **Direct Health Care Services**

According to the Louisiana Department of Health and Hospital's Primary Care and Rural Health Department (2010), every parish has at least one health provider shortage area (HPSA) designation. Health Professional Shortage Area designations, or HPSAs, are defined by the Louisiana Department of Health and Hospitals as areas which lack access to primary care providers (i.e., family practice, OB/GYN, pediatrics, internal medicine, and/or general practice), dental providers, and/or mental health providers. Of the 64 Louisiana parishes, there are 42 primary care/dental/ mental health HPSAs; 60 primary care HPSAs; 52 mental health HPSAs, and 56 dental HPSAs. Approximately 25% of Louisiana residents live in rural areas, but only 14% of primary care physicians practice in rural areas. Also, approximately 40% of Louisiana medical school graduates and physicians completing graduate medical education are leaving Louisiana for residency programs and practice opportunities in other states.

##### *Perinatal Health*

The current number of Medicaid OB/GYN providers varies from parish to parish in Louisiana. According to the Louisiana Department of Health and Hospitals, there are 34 parishes in Louisiana that do not have access to a Medicaid OB/GYN provider and 6 parishes which only have access to 1 Medicaid OB/GYN provider (See Appendix C, Map 4). However, Louisiana

ranked third best in the nation for adequate prenatal care, assuring first trimester entry and the optimal number of prenatal visits.

Women need health care coverage across the lifespan, particularly women with previous infant death, preterm birth, chronic diseases and infections. Research has shown that we cannot undo in seven to eight months of prenatal care, the results of a lifetime of poor health, poor health access, and stressors of pervasive poverty and racial disparities. Pregnant women identified with HIV, substance use, or mental health problems, are often refused by the Medicaid private obstetricians and are referred to the public hospital clinics for prenatal care.

Although private providers are the most common sources for prenatal care, the state parish health units and the system of State-supported hospitals continue to serve as a safety net for maternity patients without Medicaid or other health insurance or in areas where there is a shortage of private health care providers. Prenatal care continues in the Office of Public Health parish health units in the two northern, mostly rural and poor, regions of the state. There were 4,269 prenatal visits and 14,741 pregnancy tests given in parish health units statewide in 2009. In northwest Louisiana, LSU-Shreveport medical center provides prenatal teams composed of a nurse practitioner, nurse, social worker, and a director to oversee the program. The teams provide both prenatal care and family planning services within inner city clinics, funded by MCH. The March of Dimes Mom & Baby Mobile Health van has provided onsite services in the New Orleans and Lake Charles areas. However, funding remains an unresolved issue after June 30, 2010 and the services may be discontinued, which will leave these areas with few options.

Louisiana's Medicaid Family Planning waiver program addresses pregnancy spacing for women under 200% FPL, and covers all FDA approved-contraceptive related services for all women age 19-44 years. Women are eligible for an initial physical exam, STD/HIV screening, pap smear and up to four visits per year. Contraceptive services include counseling, medications/supplies and sterilization. In 2009, 72,637 women were enrolled in the Family Planning Waiver. However, this program does not cover other health-related services such as treatment for STIs, atypical pap smears, diabetes, depression, hypertension and other chronic diseases. This has been a barrier to private provider participation in Take Charge Family Planning Waiver.

MCH provides funding for the Office of Public Health Family Planning Program, serving 58,158 women in Fiscal Year 2009. MCH provided additional funding for women receiving Family Planning services to receive a year's supply of Folic Acid at the time of their visit; 34% of women received the Folic Acid supplements in the first year and educational materials and information on the importance of Folic Acid both through dietary intake and supplements. Plans are in place to expand to all women in Family Planning

### *Infant and Child Health*

Access to and availability of primary health care providers is a priority health concern for infants and children in Louisiana. Positive strides were made to increase the adequacy of primary care for Medicaid enrollees, primarily by extending eligibility criteria for health insurance to children and increasing enrollment of eligible children into the Medicaid Program. The number of uninsured infants and children in Louisiana decreased from 24% in 1998 to 5.4% in 2007. However, health insurance alone cannot reduce the inequities in healthcare access. Therefore, beyond expanding health insurance coverage for children, further efforts are also needed to increase patient utilization of services and healthcare provider participation in the Medicaid Program.

Provision of preventive health care services including screening, immunization, and health and parenting education, is essential in maintaining and improving the health of infants, children, and adolescents. Privatization of health services for Medicaid-eligible children in Louisiana has led to a decrease in the role of the state Office of Public Health in providing direct services for low-income, uninsured children. Due to this privatization of preventive and primary care health services for children enrolled in Medicaid, the parish health units no longer provide well-child screening services for low-income, uninsured children. However, parish health units in all of the 64 parishes provide Women, Infants, and Children (WIC) Supplemental Food Program and immunization services.

Access to pediatric sub-specialty care services is also a challenge in Louisiana. Providers are located primarily in the urban areas of the state. Although Medicaid will pay for specialty services for conditions found through EPSDT screenings, there are limited numbers of specialty providers who accept Medicaid clients, and Medicaid reimbursement levels to providers are sub-optimal

The state-supported hospitals located in each of the 9 Office of Public Health regions of the state continue to serve as a “safety net” for no- or low-cost primary and specialty care services in areas of the state where there is a shortage of pediatric health care providers. Federally Qualified Health Centers (FQHC) are also “safety net” providers of primary health care in underserved urban and rural communities. Basic health and preventive services (including dental and vision care) for children, and patient case management (including counseling, referral, and follow-up services) are included in the scope of services offered by FQHCs.

The Medicaid Program has addressed some of the problems of access to primary and preventive care for children enrolled in the Medicaid program through the implementation of the Community Care Program. Medicaid and LaCHIP recipients in Louisiana are enrolled in the Department of Health and Hospitals’ (DHH) CommunityCARE Program, which is a comprehensive health delivery system that links recipients to a primary care physician, creating a “medical home”. The participating physicians provide enrolled children with preventive care, including periodic screens, outpatient and hospital inpatient care, health education, referrals to specialists, and primary care case management. KIDMED is the screening component of Louisiana’s Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program, which is available to Medicaid eligible children under the age of 21 years. KIDMED provides medical, vision, hearing, and dental screens, as well as immunizations, according to a periodicity schedule recommended by the American Academy of Pediatrics. There were over 500 providers that provided services to 354,887 KIDMED recipients from the state fiscal year of July 2007- June 2008.

A promising practice to improve healthcare provider service delivery to Medicaid/LaCHIP eligible children is incentive bonus payments for specific services rendered. Since its implementation in 2006, Louisiana’s statewide opt-in CommunityCare Immunization Pay-for-Performance Initiative continues to provide incentive bonus payments to participating Louisiana Medicaid Primary Care Case Management (PCCM) enrolled providers to increase the number of 24-month-old Medicaid/CHIP-eligible children who are up-to-date with childhood vaccines. Data for the first year of this initiative (July 2006 - June 2007) indicated that immunization rates improved in 62 percent of provider practices receiving incentive payments, with an average increase of 9.76 percent in the percentage of 24-month-old children in these practices considered up-to-date with childhood immunizations.

### *Adolescent Health*

School Based Health Centers (SBHC) are administered by OPH provide convenient access to primary and preventive care for students who might otherwise have limited or no access to health care and to meet the physical and emotional health needs of adolescents at their school site. However, these services are generally not available during the summer or after school hours. Every SBHC is required to have referral information available for summer and after hour care, but this usually consists of referral to a community health center or hospital emergency room. Only 8 percent of public school students receive services from School Based Health Centers. Expansion of the number of SBHC sites is contingent on increased state financing and the engagement of private, non-profit agencies to partner in the establishment of new sites.

Despite the expansion of the number of SBHCs in recent years and efforts at coordination with multiple agencies/resources, health care services for adolescents in Louisiana are nonexistent or underrepresented in many areas of the state and remain extremely fragmented. Scarcity of providers, lack of transportation, underfunding, and sustainability of funding are some of the reasons for the status of adolescent health services.

#### *State's Capacity:*

Currently, there are only 65 SBHCs in the state. In the 2007-2008 school year 62 SBHCs in 26 parishes served 95 public schools and provided access to nearly 60,000 students. In 2008-2009, OPH had 62 SBHCs and provided access to approximately 55,000 students. There were over 142,000 student visits to the SBHCs. Of these 142,000 visits, primary and preventive health services (approximately 50,000 visits) were the most common reason for visits and behavioral health (approximately 31,000 visits) ranked as the second most common reason. A full-time, licensed behavioral health professional is a contract requirement for all OPH-funded SBHCs (see Appendix D for a list of sponsors and schools served).

SBHC sponsors are contracted to providing a detailed list of direct care services based on national best practices recommendations. SBHCs provide comprehensive primary medical, social, and behavioral health services, as well as health education, promotion, and prevention services designed to meet the psychosocial and physical health needs of students in the context of their family, culture, and environment. SBHC services are provided by a multi-disciplinary team, with medical, behavioral, and administrative personnel.

#### *Oral Health*

Access to oral health care is a problem. In Louisiana, 87.5% of the state is a Dental Health Professional Shortage Area. On average in Louisiana, among Medicaid- eligible children, one dentist is available for 1,161 children. In FY 2008 only 32% of the Medicaid eligible children received any dental services. Among the total number of licensed dentists, only 26% are participating in the Medicaid program. From 2005 to 2009, the percentage of children enrolled in Medicaid who received any dental services increased from 30.8% in FFY 2005 to 38.3% in FFY 2009. Only 16% of the dentists participating in Medicaid billed Medicaid for \$10,000 or more. Medicaid reimbursement rates and covered services have increased over the last few years; however the state has seen only small gains in the number of dentist billing Medicaid for reimbursement.

Medicaid eligible pregnant women with periodontal disease can receive dental services. Due to the shortage of providers, women often are not able to find a provider until they are further along in their pregnancy. In some cases, treatment is required beyond pregnancy, however there is no

provision for dental services postnatally. Extending dental treatment or providing treatment between pregnancies is a concern to MCH program.

Ensuring access to preventive, evidence based dental interventions for the MCH population is a priority concern of the MCH program. Dental sealants use, an excellent preventive measure, needs to be more widely utilized. Sealant programs could reach the populations most susceptible to dental caries and with the least access to dental services. The Oral Health Program's initiative has resulted in services to only 9% of targeted schools in the state, and only 33.2% of children have a dental sealant on one or more of their permanent molars (Basic Screening Survey-2007). This compares to the Healthy People 2010 goal of 50%.

Community water fluoridation is considered by the CDC to be one of the ten greatest public health accomplishments of the 20th Century. Every \$1 invested in water fluoridation saves \$38 in dental treatment costs (CDC). However, fluoridation is underutilized in Louisiana with only 41% of our citizens benefiting from optimally fluoridated water as compared to 69% of Americans. An emerging promising practice is the application of fluoride varnish in medical homes, currently allowed in 35 states. The Louisiana Chapters of the American Association of Pediatric Dentists and the American Academy of Pediatrics are working together to implement a fluoride varnish program in Louisiana.

#### State's Capacity:

Dental services are provided to Medicaid-eligible pregnant women with periodontal disease. The program has shown growth in the amount of dollars spend from \$268,918 in State Fiscal Year (SFY) 2005 to \$2,436,539 in SFY 2009. The number of patients treated increased from 2,085 patients served in SFY 2005 to 5,708 served in SFY 2009. However, for the same time period, the number of providers only showed a modest 21% increase from 268 to 343. Even though usage of the dental services has increased, anecdotal evidence suggests that access to care is still a significant problem.

The Oral Health Program coordinates a school-based dental sealant program, for 2nd and 6th grade students in schools where over 50% of students are eligible for a free or reduced lunch. The school-based sealant program conducts preliminary dental screenings by a dentist and then applies sealants on appropriate teeth. This initiative has received HRSA funding from 2006-2009 and then renewed from 2009-2012 to provide professional services, supplies and equipment. While this initiative has resulted in services to only 9% of targeted schools in the state, the capacity is there for continued expansion. The school-based sealant program is continuing to work on sustainability of this initiative through securing Medicaid reimbursement for the placement of a dental sealant. Funds realized from Medicaid reimbursement would then be utilized to contract for services, maintain portable dental equipment and initiate active referral services for children with need.

#### *Behavioral Health*

There has been increased identification of maternal and infant/early childhood mental health problems in MCH programs. Perinatal depression (including cases of postpartum psychosis), suicidal thoughts and behaviors, a variety of diagnosed and undiagnosed Axis 1 and Axis 2 mental health conditions, domestic violence and exposure to other traumatic events, significant losses, exposure to substance use, and high levels of psychosocial stress all contribute to poor pregnancy, maternal, and child health outcomes, including prematurity, maternal mortality, infant growth and developmental problems, and risk for abuse and neglect. Such issues are identified

readily through the Nurse Family Partnership program as well as through SBIRT screening, brief intervention, referral and treatment program.

A significant need is perinatal psychiatric services. Typically women who need medication may get prescriptions from their primary care provider (Ob-gyn), or the local community mental health center. Unfortunately, many of these providers have little expertise in this area, resulting in inconsistent or lack of access to needed services. The MCH program is working with the state Office of Mental Health to devise methods to address this large unmet need.

There are very few public-supported mental health services for children under the age of 5 years. In most instances mental health services are only available for children with the most severe mental health needs. Also, there is a shortage of mental health providers trained in infant and early childhood mental health.

Behavioral health visits consistently rank second, with approximately 31,000 encounters, in reason for use of the SBHCs, outranked only by general preventive medical visits. While these behavioral health services provided a needed resource to the over 55,000 children and adolescents in the 107 schools that are linked to the 65 SBHCs statewide, behavioral health services for the remainder of Louisiana youth in schools without SBHCs continue to be fragmented and difficult to access. Gaps include inadequate prevention programs and out of school programs designed to bolster family support and to curtail risky behaviors; lack of outpatient mental health, substance abuse and social services for youth; and lack of residential treatment centers for emotionally disturbed, behaviorally disordered adolescents. SBHCs provide accessible behavioral health services to school-age youth, but these services are generally not available during the summer or after school hours.

OPH petitioned Medicaid at both the state and national level to permit Medicaid reimbursement for behavioral health services provided in SBHCs. This reimbursement is a key component in sustainability for current SBHC sponsors, as well as an incentive to attract other potential sponsors. Though the petition was approved at both levels, Medicaid reimbursement for SBHC behavioral health services has not been implemented.

Social work and mental health services are limited for the MCH population. Within the Office of Public Health, social work services include assessment, counseling, and referral services to those identified with psychosocial needs. However, the number of social workers within MCH has decreased. Improvements in mental health services for the MCH population have occurred since the last needs assessment, but still fall far short of being available for prevention and in providing appropriate interventions.

#### State's Capacity:

The state-supported hospitals located in each of the 9 Louisiana regions continue to serve as a "safety net" for inpatient, emergency, and acute mental/behavioral health services to the uninsured and under-insured, especially in areas of the state where there is a shortage of mental health providers. Also, Federally Qualified Health Centers must provide or facilitate access to such health-related services as substance abuse and mental health services.

All Louisiana School-Based Health Centers (SBHCs) must employ a minimum of one full-time, qualified behavioral health professional to provide direct behavioral health care. Behavioral health services include psychosocial assessments, treatment plans, individual and group

counseling, progress/follow-up notes, and any activity related to the psychosocial/emotional well-being of the child.

Specially trained licensed mental health clinicians provide direct and consultative services to 7 of the 16 Nurse Family Partnership (NFP) teams. These clinicians support NFP nurses in the identification of women in need of mental health services, guide nurses in providing support as appropriate, provide direct in-home services as needed, and assist with referral to more intensive services when indicated. In addition, there are clinical services for perinatal depression to participants of Nurse Family Partnership and Healthy Start in Orleans Parish and in Region 5 (Lake Charles area).

The Children's Bureau Project LAST is contracted by the MCH program to provide grief and trauma intervention services to families who have lost an infant to sudden infant death syndrome, or SIDS, and to children from infancy through 17 years of age who have experienced trauma/loss, violence, or disaster. Children's Bureau of New Orleans is a private, non-profit United Way partner which offers a variety of counseling services to children and families in New Orleans.

The Office of Mental Health has developed the Early Childhood Supports and Services (ECSS) program which provides both social and mental health services to families with children age 5 years and younger. This program is currently located in 12 communities around the state; MCH programs can serve as community partners for the ECSS program and both give and receive referrals through the community resource process which is part of every case review in ECSS programs. Parents with mental health problems may be referred for additional mental health services; in some cases, parents may be treated through ECSS.

CART (Child-Adolescent Response Team) is a crisis response service offered through DHH Office of Mental Health. The mission of the program is to provide crisis counseling and intervention services to children, youth, and their immediate family. CART assists the family in the stabilization of their crisis and provides the family with advocacy, referral, and support.

LA-Y.E.S. is child-focused, family-driven system of care established for children and youth ages 3-21 years with serious emotional and behavioral disorders and their families in Orleans, Jefferson, Plaquemines, St. Bernard, and St. Tammany parishes. Under the system of care, all the resources in a community from child-serving organizations to local children's mental health councils work together, as directed by the parents and caregivers, to develop an individualized service plan that's right for the child and can be followed in the community. It is funded through a cooperative agreement between the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Louisiana Office of Mental Health. The LA-Y.E.S. Consortium is a community group comprised of family members, agency representative, mental health professionals, teachers, and individuals working with children that provides many educational and informative resources, supports, and services to individuals working with youth with special mental health needs.

### *Nutritional Health*

The Louisiana Board of Examiners on Dietetics and Nutrition reports on the total number of licensed persons practicing dietetics/nutrition in Louisiana. As of March 2010, there are 1133 licensed dietitians/nutritionists in Louisiana and 10 dietitians/nutritionists with their provisional licensure.

State's Capacity:

There are approximately 33 public health nutritionists that serve the 64 Louisiana public health units. The public health nutritionists play a vital role in seeing clients who come through the health units, particularly for high risk nutrition visits, children with special health care needs, and family planning visits. Due to the limited number of nutritionists, there is often a waiting list for high risk nutrition visits and family planning and children special health services nutrition visits are often by referral only.

### **Enabling Services**

#### *Primary State Concern(s)*

Poverty levels can be a broad measure of the health status and welfare of the MCH population. Eligibility rules help the state and MCH Program assess needs of the MCH population, based on the estimated number of eligible women and children to participate in such government programs as Medicaid, LaCHIP, and WIC programs but who remain uninsured. Enrollment in the Medicaid Program is the first step in providing access to available health and support social services.

The health status and welfare of the MCH population also rely on the recruitment and retention of health and social service providers. There is a need for parenting education, family support services, home visitation, case management, care coordination, and bereavement support. Equally important is the need to exchange health information across these systems of care.

The development of culturally appropriate services is an ongoing challenge for Louisiana. Approximately 55% of Louisiana's children are White and 39% are Black; less than 4% are of Hispanic origin, and the remaining are composed of non-Hispanic Asian (1.6%), and non-Hispanic American Indian (.6%). Because of the small numbers of Hispanics, American Indians, and Asians, most of the data available on health outcomes is limited to White and Black residents. Nevertheless, the disparities between these two races are staggering. First of all, 72% of African American children in Louisiana live in low income families (<200% FPL) compared to 26% of White children. Rates of maternal deaths, infant, and child deaths (through age 9) in African Americans are consistently at least twice as high as Whites. Based on 2007 PRAMS data, health-related behaviors are also different: 48% of African American women reported always or almost-always bed-sharing with their infant compared to 21% of White women; 45% of African American women reported placing their children on their backs for sleeping compared to 60% of White women; 38% of African American women reported ever breastfeeding compared to 64% of White women; 28% of African American women reported partner violence during pregnancy compared to 16% of White women; and in contrast, African American women reported half the frequency of cigarette smoking and alcohol use both before pregnancy and currently.

Because of the significant maternal and child health disparities in Louisiana, it is incumbent upon the Maternal Child Health program to continue to improve methods of identifying disparities/health care needs in minority populations. As more direct services are provided by the private sector, MCH must continue to monitor access and outcomes and provide guidance and leadership in development of preventive and primary health care services as well as system (e.g., access, linguistic, transportation, attitudinal, and behavioral) strategies to assure that services are acceptable to minority children and families, and that specific health disparities are being addressed and improved. Ongoing development of a culturally sensitive and competent workforce is an essential part of this process; appropriate communication with direct service



providers regarding disparities will also be needed. A particular challenge is in gaining the “voice” of under-represented populations in planning, education, and service development.

### *Barriers*

Language and cultural beliefs affect access to health services, especially for the Vietnamese and growing Hispanic populations.

Barriers to health information systems include system compatibility, few common data sets across programs, HIPAA, and affordability of health information systems.

Due to a lack of community-based health services such as FQHCs and Rural Health Centers, which serve the uninsured and under-insured populations, families have to rely on transportation services to access health care services. Transportation is also a major barrier for the MCH population. Transportation issues were clearly identified in the Consumer Survey conducted as part of the Needs Assessment. More than 13% of those surveyed who were women of reproductive age had transportation problems during pregnancy. Although the Medicaid Program provide transportation, issues of provider reliability and limits on travel distance present a problem for many clients.

Barriers to healthy eating include limited or no access to fresh fruits and vegetables. Grocery stores in low income neighborhoods often do not provide fresh produce. Also, fresh produce is often too expensive for families on limited or low income budgets.

### *Financial Access*

Louisiana is a leader nationally in reducing the number and rate of uninsured children in the state. Louisiana’s Medicaid Program and the Medicaid expansion program, Louisiana Children’s Health Insurance Program (LaCHIP), are designed to bring quality health care to uninsured children under 19 years of age, in moderate income families up to 200% FPL at no cost. During SFY 2007/08, about 27% of Louisiana’s population were enrolled in the Medicaid Program, with a majority of children aged 20 and under making up 64.2% of the total enrollment.

LaCHIP Affordable Plan (LAP) is a new LaCHIP health insurance program for uninsured children in moderate income families whose gross income is between 200% and 250% FPL. It is not a Medicaid expansion program, but instead was implemented as a “stand-alone” program administered by Louisiana Office of Group Benefits (OGB), which serves as a third party administrator for the management of claims payments through their preferred provider organization network.

Most obstetricians in the state participate in the Medicaid LaMOMS program, an expansion of Medicaid coverage for pregnant women. From 2004 to 2006 the percentage of Medicaid paid deliveries increased steadily. In 2006, 68% of births were financed by Medicaid. Louisiana now ranks among the best states in providing early and adequate access to prenatal care. Prenatal care services play an important role in identifying medical and behavioral factors that can cause poor birth outcomes. In 2006, the Maternal and Child Health Program successfully advocated for all women with incomes up to 200 percent of the Federal Poverty level (FPL), regardless of immigration status, to be covered during pregnancy by Medicaid.

### *Cultural Acceptability*

Providing culturally appropriate resources and services in a sensitive and respectable setting is an issue of growing importance. This point is illustrated in consumers' perception of provider respect when accessing health services. Among total respondents, 6.9% noted a lack of respect by the provider when accessing dental services for children and adolescents. This is compared to only 0.8% of total respondents citing provider respect as an issue when accessing medical services for pregnant women.

The MCH program is committed to providing cultural acceptable services and utilizes several approaches to address this issue. Staff development trainings address sensitivity to the variety of cultural needs and issues encountered in MCH settings and populations, including identification of institutional or service-delivery practices that may increase or decrease utilization of health services by the minority population. Methods to increase sensitivity to interpersonal attitudes and behaviors that may reflect negative cultural biases take place periodically with the MCH administrative staff and will continue to be a focus. Educational programs on cultural competence, focusing on racial, economic and linguistic issues, are provided to staff of MCH programs including Nurse Family Partnership, child care health consultants, and other program staff who work within MCH.

MCH health and safety campaigns, targeted public service announcements, flyers and other print materials, the Partners for Healthy Babies website, and the *Happy and Healthy Kids* newsletter are developed with the primary goal of reaching the diverse MCH population. Therefore, health education strategies include formative and evaluative research which is conducted with consumers to receive feedback on specific messages and to test relevance, appropriateness, and effectiveness of campaigns and materials. Also, many of the health education materials are simultaneously developed, produced and printed for Spanish-speaking audiences. For example, MCH educational materials on SIDS risk reduction and perinatal depression are available in Spanish.

Language translation services are available in the Louisiana Department of Health and Hospitals. The Office of Public Health (OPH) contracts with the ATT Language Line Service to provide translation in the appropriate language for non-English speaking clients in the public health units. Also, the Louisiana Medicaid online and paper enrollment process and educational information are available in Spanish and Vietnamese.

### *Linkages*

The MCH program has developed strong linkages with existing programs and services in an effort to provide quality healthcare services. These partnerships facilitate greater access to primary, secondary and tertiary healthcare resources while also providing information on critical support services.

### *Health Provider Recruitment and Retention Services*

Med Job Louisiana offers statewide recruitment services to all Health Professional Shortage Areas in the state through a partnership between the Department of Health and Hospitals, the Louisiana Area Health Education Centers, and the Louisiana Rural Health Access Program.

### *Community-Based, Coordinated Primary Care*

FQHC's and Rural Health Centers provide services which help ensure access to basic health services as well as facilitate access to comprehensive health and social services. Specifically, health centers must provide: case management services; services to assist the health center's patients gain financial support for health and social services; referrals to other providers of medical and health-related services including substance abuse and mental health services; services that enable patients to access health center services such as outreach, transportation and interpretive services; and education of patients and the community regarding the availability and appropriate use of health services.

OPH's Adolescent School Health Program (ASHP) provides enabling services by requiring all school based health centers (SBHCs) to become Medicaid/LaCHIP enrollment sites, to provide health education, to coordinate care with the primary care providers, to participate in Louisiana's Immunization Program and utilize the Louisiana Immunization Network for Kids System (LINKS). SBHC sponsors are contracted to providing a detailed list of direct care services based on national best practices recommendations. Additionally, sponsors are required to provide enabling services (Medicaid enrollment site, health education, care coordination with the primary care provider, enrollment in Louisiana's immunization network system, etc.).

#### *Community-Based Outreach and Services*

Most of Louisiana's uninsured children are eligible for health insurance at little or no cost to families. In an effort to reduce the number of uninsured children, Department of Health and Hospitals (DHH) manages two enrollment initiatives. The Louisiana Covering Kids & Families (CKF) Coalition Project, a state-funded, community-based outreach and education project, was implemented by the Louisiana Department of Health and Hospitals to continue the enrollment efforts of the federally funded (by Robert Wood Johnson Foundation) Louisiana's Covering Kids Covering Kids & Families initiative, which ended in 2007. The CKF Coalition Project consists of 11 regional coalitions that help to reduce the number of uninsured children by increasing awareness of and providing families of eligible children enrollment assistance into LaCHIP in all parish communities in the state. In February 2009, DHH implemented the Louisiana MaxEnroll Initiative, which is a four year project funded by the new Robert Wood Johnson Foundation's Maximizing Enrollment grant. The goal is to enroll 98% of eligible children in Medicaid or LaCHIP by year 2013. One of the strategies used to achieve this goal is Express Lane Eligibility (ELE), a process that allows DHH to use an eligibility determination by another approved agency to determine eligibility for LaCHIP and Medicaid.

Sabine Parish Neighborhood Place, located in Many and Zwolle, Louisiana, is an integrated service delivery system that provides a one-stop shop for state services. Together with the Sabine Parish School System and the community, the State Departments of Education, Health and Hospitals, Social Services, the Louisiana Workforce Commission, and the Office of Juvenile Justice partnered to provide Sabine residents with community-oriented services that will enable them to apply for the services they need for themselves and their families all under one roof. Neighborhood Place services focus on the critical areas of student achievement, health care, social services, workforce and youth development.

Shots for Tots, Louisiana's Infant Immunization Initiative, is a network of public and private entities working cooperatively to update and educate parents and providers to ensure the highest level of immunizations possible. The vision of the program is to have 90% of all children immunized with their primary series by age 2 years.

### *Home Visitation and Support Services*

Home visiting and case management services enable high risk families to access a wide range of services needed for a healthy pregnancy. The Nurse Family Partnership (NFP) program is an evidence-based intervention with the goals of improving pregnancy health, child health and development, and economic self-sufficiency of the participants served. A highly trained registered nurse meets regularly with the client in her home, beginning early in pregnancy and continuing until the child's second birthday. This program, developed by David Olds, PhD, has been shown to improve significantly short and long term health, social, developmental, and economic outcomes of the mothers and infants served. Currently, there are 16 NFP teams in Louisiana; the program is available in 52 of 64 parishes, and serves approximately 16% of potentially eligible clients. The NFP program is funded through a mix of federal (Maternal Child Health Block grant, Medicaid and TANF), state, and local/private sources. The long term goal is to expand NFP coverage to 50% of all eligible first-time, low income pregnant women. In order to develop teams, the OPH-MCH program contracts and partners with a variety of state and local entities. Four teams are funded primarily through Office of Public Health; in addition, contracts have been developed with LSU School of Public Health, New Orleans; Jefferson Parish Human Services Authority; Capital Area Human Services Authority; Nicholls State University School of Nursing; Medical Resources and Guidance, Inc.; Southwest Louisiana Area Health Education Center; LSU Health Sciences Center, Shreveport, Monroe, and Alexandria; and St. Tammany Parish Hospital. Funding for support of NFP has come from community resources including the Institute of Mental Hygiene in New Orleans, Baptist Community Ministries (BCM), and the New Orleans United Way. There has been a concerted effort from entities outside of government to increase advocacy and visibility of the NFP program within communities, including specific efforts on behalf of NFP by the foundation Baptist Community Ministries, the NFP National Service Office, and a recent grant funded by the Pew Foundation to the Tulane Institute of Infant and Early Childhood Mental Health. These efforts have increased visibility of NFP both within communities for potential clients and with potential partners, and with state legislators.

Healthy Start is a program whose goal is to reduce infant mortality and improve maternal and child health disparities. Healthy Start provides, to those women who qualify, case management, coordination of care, transportation to health care visits, prenatal and parenting education and support, referral to community services, mental health screenings and referrals, and job preparation and support. Healthy Starts are funded primarily through direct grants from HRSA, with additional support from the MCH program. Currently there are four Healthy Start programs in Louisiana serving New Orleans, Baton Rouge, Lafayette, and northeast Louisiana. The four Healthy Start programs cover five of the nine regions of the state, The City of New Orleans Healthy Start program collaborates with the MCH Fetal and Infant Mortality Review (FIMR) program through the hiring of a registered nurse, who is 0.5 FTE Healthy Start and 0.5 FTE FIMR. Healthy Start of Greater Baton Rouge continues to be a collaborative effort with the FIMR Program. In 2009, this group produced an extensive Resource Directory for physicians and the community. The Healthy Start at Family Tree of Lafayette also provided a contract position for a 0.5 FTE Healthy Start registered nurse, who is also 0.5 FTE FIMR funded by MCH. Healthy Start at Family Tree provides extensive education throughout the community with a focus on mental health services. Healthy Start program also collaborates with the FIMR groups both in the northwest in Shreveport and in the northeast in Monroe. MCH funds case management and outreach services in conjunction with Healthy Start in North Louisiana,

EarlySteps, in the Louisiana DHH, Office for Citizens with Developmental Disabilities, is Louisiana's Early Intervention System under the Individuals with Disabilities Education Act, Part C. EarlySteps provides services to families with infants and toddlers from birth to three years (36

months) who have a medical condition likely to result in a developmental delay, or who have developmental delays. EarlySteps has a SPOE, or single point of entry, for eligibility determination of referred children. Family Service Coordinators develop IFSP (Individualized Family Service Plan) for children accepted into the program. EarlySteps' scope of services includes transportation to and from an EarlySteps service only and translation Interpreter services for foreign language and sign language.

Early Childhood Supports and Services (ECSS), in the Louisiana DHH-Office of Mental Health, provides a coordinated system of screening, evaluation and referral services and treatment for children ages 0 through 5-years and their families. ECSS is present in 12 parishes. ECSS family support services assure that families have the necessary personal support, information and skill to cope, to maintain family integrity, and to enhance the likelihood that children with serious emotional disturbance can successfully remain at home. Service elements include respite care, care and education, telephone trees, parent support groups, parent case manager training, home aide services, transportation, and advocacy services

The MCH Program offers bereavement support to families whose infants have died. Louisiana Child Death Review, which is managed in the MCH Program, offers bereavement support services at no cost to families who have lost an infant to SIDS or to an undetermined cause. These home visitation services are rendered by OPH social workers and nurses statewide and by Children's Bureau, Project Last, in New Orleans and Jefferson Parishes through a contract with the MCH Program. The purpose of the home visit is to provide information to families regarding grief reactions, local support services, and referral, if needed, for further grief counseling. Also, families who have experienced a loss are mailed a sympathy card which also contains information for families about grief and bereavement resources nationally and in their communities. MCH's Fetal Infant Mortality Reduction Initiative (FIMR) performs nurse home visits to mothers who have experienced a pregnancy loss or the loss of an infant as part of their case review process. The purpose of this visit is to gather perinatal information from a mother using a questionnaire and to provide them with bereavement resources.

Louisiana Medicaid's Medical Transportation Services provides non-emergency transportation to a medical appointment for Medicaid recipients who does not have or cannot get transportation. Medicaid enrollees have the option to choose any transportation provider enrolled in their service area who accepts Medicaid. Medicaid's Friends and Family Transportation Program pays friends or family members of Medicaid recipients to take them to the doctor when certain conditions are met.

### *Nutrition Services*

The USDA's Special Supplemental Nutrition Program for *Women, Infants, and Children (WIC)* provides nutritious foods, nutrition information, nutrition screening/assessment, and referrals to other health and social services for low-income pregnant, breastfeeding, and postpartum women, infants, and children under 5 years old. Louisiana. Public Health Units are the primary providers of WIC Services in the State, and WIC currently provides services to 125,000 participants a month through 130 clinic sites. In 2009, Louisiana's WIC program provided services to approximately 111,276 infants and children, and served an average of 37,371 women each month, of which 17,521 were pregnant, 15,449 postpartum, and 4401 breast-feeding. Also, in October 2009, fruits, vegetables, and whole grains were added to the national WIC food package. WIC's provision of fresh produce is a positive step toward removing barriers to healthy eating. This major change also provides a unique opportunity for the public health unit professionals to work with low income families to change long standing dietary habits.

Louisiana's Commodity Supplemental Food Program (LA CSFP) is also a USDA nutrition program. It is one of 26 CSFP state programs nationwide and is currently the second largest CSFP in the country, with 76,000 participants. LaCSFP is designed to supplement the diets of low-income pregnant and post-partum women, children to the age of 6 years, and seniors over the age of 60.

### *Behavioral Health Services*

The Screening, Brief Intervention, Referral and Treatment Program (SBIRT)-Healthy Babies Initiative enables pregnant women to be screened, at the site of their private provider or WIC site, for alcohol use, substance use, tobacco use, depression, and domestic violence which are known to increase risks of adverse pregnancy outcomes. In affected pregnancies there are higher rates of preterm births, low birth weight infants, and infant mortality. Any woman who has a positive screen receives a brief intervention immediately after the screening and referral(s) to community services.

Women and infants, who are served by the NFP program, are regularly assessed for depression, interpersonal violence, substance abuse, family stress/support, problems with parenting, and child health/development. Nurses provide information and support regarding these issues and can make referrals when issues are beyond the scope of their role. However, it is not unusual for clients with significant mental health issues that impact functioning to be reluctant to enlist mental health services, or mental health services may not be available.

### *Emerging Issues in Louisiana*

Department of Health and Hospitals is preparing to phase in a system of managed care for Medicaid recipients entitled Coordinated Care Networks (CCNs). The goal of this effort is to control costs and improve health outcomes.

In Louisiana, the Governor's office, and the Secretaries of the Departments of Social Services, Health and Hospitals, Education, and the Office of Juvenile Justice, have undertaken a cross-departmental effort to develop a coordinated system of care (CSoC) for children and youth with behavioral health disorders that are at risk for or currently involved with the child welfare and/or juvenile justice systems. The CSoC is an evidence-based model that is part of a national movement to develop family driven and youth guided care, keep children at home, in school, and out of the child welfare and juvenile justice system. The CSoC model facilitates the development of a system that delivers services that are well-coordinated, culturally competent, child and youth guided, family-driven and community-based. An important CSoC goal is the reduction of highly restrictive out of home placements through the creation and maintenance of coordinated and effective community based service. Implementation is targeted for FY 2012.

### **Population-Based Services**

Population-based services are an important part of the MCH Program in order to improve the health of the MCH population in Louisiana. Population-based services are those that are available for an entire population, rather than for an individual, and are essential for a comprehensive approach to addressing the needs of the MCH population.

### *Pregnant Women*

### *Prenatal Care/Low Birth Weight:*

The MCH Program funds the statewide Partners for Healthy Babies social marketing campaign which promotes healthy behaviors during pregnancy and initiation of early entry into prenatal care. The campaign uses traditional multimedia approaches including, television, radio, website, print material, baby-fair mall events, and most recently social media advertising to promote messages about risk behavior. A fundamental component of the Partners for Healthy Babies project is the Title V funded toll-free helpline, and corresponding website. This helpline 1800-251-BABY (2229) and web [www.1800251BABY.org](http://www.1800251BABY.org) play a vital role in linking women and their families to services throughout the state. The Partners for Health Babies helpline is operated by the American Pregnancy Association, Inc. During 2008 and 2009 respectively, it received approximately 2,950 and 4,274 calls and provided health information and made referrals to medical and social services statewide. The helpline has 24-hour coverage. The website had 14,105 and 10,735 unique visitors in 2008, 2009 respectively. In the summer 2008, data driven strategic planning with MCH stakeholders and community partners was conducted to determine a 3 year plan for Partners for Healthy Babies and subsequent campaign focus. It was decided to include preconception health messaging and strategies as a major part of campaign's efforts. Subsequently, a new sub-campaign has been developed under Partners for Healthy Babies, called *The Stork Reality*, to address preconception health. *The Stork Reality* reaches out to women (and men) who are not actively seeking to get pregnant, using a range of tactics including traditional multi-media to new innovative approaches such as social media (Facebook/Twitter) and interactive web advertising. Formative and evaluative research is ongoing to assess relevance and effectiveness of the Partners for Healthy Babies' strategies and tactics to its consumer and target audiences. Additional audience segmentation for project focus is planned to address disparities in low birth weight and infant mortality. Faculty from the Tulane University School of Public Health, Community Health Sciences provides oversight for the design, implementation and evaluation of this project as well as other population –based health promotion efforts the MCH program.

### *Infants and Children*

Population-based activities for infants and children are funded in part by MCH.

### *Newborn Screening*

The Office of Public Health is responsible for oversight of the legislatively mandated newborn screening efforts in the state. The OPH Genetic Diseases Program, in collaboration with the State Public Health Laboratory, operates a statewide Newborn Heal Stick Screening and Follow-up Program, which screens for all 28 of the disorders recommended by the American College of Medical Genetics (ACMG), except for hearing loss. The 10 most common diseases listed on this panel are PKU, congenital hypothyroidism, biotinidase deficiency, sickle cell disease, galactosemia, argininosuccinic aciduria, citrullinemia, homocystinuria, maple syrup urine disease and medium chain acyl coA dehydrogenase deficiency. All newborns in the state are screened before discharged from the hospital. The Louisiana Newborn Screening Rule (Louisiana Administrative Code 48:v.6303.08) was amended to provide more clarity to providers on the timing of collection of newborn screening and to provide guidance on collection of screenings post transfusion. The new rule became effective January 2008. Estimates indicate that 98% of newborns who are screened and identified with a condition received the appropriate follow-up services. The Louisiana Newborn Screening Advisory Committee continues to make important

recommendations on the development of the program. The membership includes representation from specialists, private physicians, and patient advocacy groups.

### *Newborn Hearing Screening*

In accordance with Act 653 passed by the Louisiana Legislature in 1999 and the Administrative Rules adopted in 2002 the Office of Public Health administers the newborn hearing screening program, which is called Louisiana's Early Hearing Detection and Intervention Program (EHDI). EHDI is responsible for the identification of hearing impairment in infants and that a statewide system of services is available for families. Louisiana law requires that every baby born in a birthing center in Louisiana be screened for hearing loss before discharge. All 60 of the birthing hospitals in Louisiana provide universal new born hearing screening. In 2008, 97.0% of the 64,786 infants born in Louisiana hospitals were screened prior to discharge. Of the infants screened, 5.5% were found to be in need of additional testing. EHDI has the Sound Start Program which works towards helping each hospital in the state reach 100% compliance with the legislation. State and local coordinators are available to help each hospital create and manage the highest quality hearing-screening program. Families of infants who are deaf or hard of hearing receive information from the program on deafness and hearing loss, communication modalities, educational opportunities, and family support groups. The Hearing, Speech, and Vision Program has an Advisory Council that makes recommendations to the program on the rules and regulations, quality assurance, and program planning and evaluation. The goal of EHDI is the "1-3-6-plan": screening before one month of age, diagnosis before three months of age, and intervention before six months of age.

### *Lead Screening*

The Louisiana Childhood Lead Poisoning Prevention Program (LACLPP) within the the Office of Public Health is 100% federally funded through a cooperative agreement with the Centers for Disease Control (CDC). The purpose of LACLPPP is to eliminate childhood lead poisoning in Louisiana through a comprehensive approach to prevention and the management of children six months to six years of age found to have elevated blood levels. LACLPPP provides population-based surveillance system for lead levels of children six months to six years of age. Information from the surveillance system is used to determine high risk populations in the state and focus efforts to assure screening for all those at risk with the most efficient use of available resources. Other LACLPPP services include identification of children with elevated blood lead levels through universal screening of all children six months to six years of age as mandated by Louisiana Administrative Code 48.V.§7005, §7007, §7009 (effective October 20, 2008); monitoring of blood lead levels in children; care coordination for children with elevated blood lead levels; and environmental inspection for children with elevated blood lead levels. Community and professional education on childhood lead poisoning is also provided. In 2009, approximately 2.2% of 6 month to 6 year old children who are screened have elevated blood lead levels. CDC has initiated the Healthy Home Initiative, which is a comprehensive approach to healthy environments. Along with lead poisoning control, issues such as asthma triggers, injury prevention and pesticide poisoning prevention will be addressed. LACLPPP is incorporating healthy homes activities into its operations. LACLPPP's Community Advisory Board makes important recommendations to the program on the rules and regulations, quality assurance, and program planning and evaluation



## *Immunization*

The Immunization Program in the Office of Public Health is responsible for oversight of immunization efforts in the state. The MCH Program provides funding to assist the program in their efforts. The 2008 National Immunization Survey report shows that Louisiana has achieved the number 2 rank in the nation at 81.9% for 4:3:1:3:3:1 vaccination series among children aged 19--35 months immunizations, which exceeds the *Healthy People 2010*'s established vaccination coverage target of 80% for the 4:3:1:3:3:1 vaccine series.

Louisiana participates in the Vaccines for Children Program (VFC) whereby public purchased vaccine is available at no charge to enrolled public and private health care providers for eligible children. Children through 18 years of age that meet at least one of the following criteria are eligible for VFC: Medicaid Eligible, Uninsured, American Indian or Alaskan Native - as defined by the Indian Health Services Act. Underinsured children are eligible to receive vaccine only if they are served by a Federally Qualified Health Center, Rural Health Clinic or Office of Public Health, Parish Health Unit and 317 or state funding is available. (Undersinsured – a child whose health insurance benefit plan does not include vaccinations.) Children whose health insurance covers the cost of vaccinations are not eligible for VFC program benefits, even when a claim for the cost of the vaccine and its administration would be denied, if submitted to the insurance carrier for payment, because the plan's deductible had not been met.

The Immunization Program has also implemented Louisiana Immunization Network for Kids Statewide (LINKS), a statewide web-based immunization and tracking system. LINKS currently has 2,993 enrolled sites and 3.0 million individuals enrolled in LINKS (with approximately 33.5 million recorded shots). The LINKS registry now also sends out reminder/recall notices to citizens who are due or overdue for vaccinations, which has been proven to have an impact on raising immunization rates.

## *Intentional and Unintentional Injury*

Injuries are the leading cause of death in children nationally and in Louisiana. More children in Louisiana die of injuries than from all medical conditions combined. The MCH Program provides funding for a State- level Child Safety Coordinator and 9 Regional Child Safety Coordinators, who work to decrease unintentional injury-related morbidity and mortality of children ages 0-14 years, and Sudden Infant Death Syndrome (SIDS)-related deaths. The MCH Regional Child Safety Coordinators, who are certified in injury prevention through the University of Delaware, coordinate community-based systems of unintentional injury prevention initiatives in the 9 OPH regions of the state that address the leading causes of unintentional injury-related mortality and morbidity of children under 15 years of age. They also distribute approved products to reduce unintentional injuries of children due to motor vehicle crashes (car seats and booster seats), accidental suffocation/strangulation (portable cribs, infant sleep sacks), fire (smoke detectors), and falls (bike helmets) to high risk families in their communities. As Nationally Certified Child Passenger Safety Technicians, the Child Safety Coordinators perform motor vehicle child restraint inspections to ensure that children ages 0-16 years are properly restrained in the correct restraint system for their age and size every time they travel in a motor vehicle. As certified Louisiana Child Care Health Consultants, the Child Safety Coordinators provide to child care center staff the child safety/injury prevention training needed to obtain or maintain their child care center licensure with the Department of Social Services. The coordinators work collaboratively with the Office of Public Health's Injury Research Prevention

Program and with Emergency Medical Services for Children (EMSC) to deliver injury preventive services in their communities.

Increasing child deaths due to intentional injury, including child abuse and neglect, supports the need to sustain statewide child abuse prevention efforts, including parenting education. The MCH Program supports the efforts of the Department of Social Services (DSS) to implement the state's legislation for infant relinquishment entitled Safe Haven, with trainings and public awareness of Safe Haven. The Office of Public Health nurses perform health assessments of DSS-Office of Community Services (OCS) child clients suspected of medical neglect. This safety net service is rendered upon request by OCS when a child has no established medical home. A statewide child abuse prevention intervention in Louisiana, which is funded by the MCH Program, is the Happy and Healthy Kids Parenting Newsletter. There are 28 issues of the newsletter that address the psycho-social and emotional development of infant from birth to five years of age. The newsletter is available to all parents and caregivers of children by subscription at no cost. By January 2010, over 10,000 subscribers were enrolled via the website or by subscription card. Newsletters with subscription cards have been distributed through the parish health units, birthing hospitals, pediatric offices, and via the OPH Vital Records and Statistics with the mailing of birth certificates. Monitoring, tracking and evaluation is ongoing and results are used to assist with best methods of distribution and promotion of the newsletter.

#### *Sudden Infant Death Syndrome (SIDS) Services*

In Louisiana, SIDS is the leading cause of death of infants 1 month to 12 months of age. Also, Louisiana SIDS rate remains approximately twice the national rate and the rate for Black infants remains twice that for White infants. The MCH Program funds and coordinates the efforts of the SIDS Risk Reduction and Safe Sleep Program, which is designed to reduce infant deaths due to SIDS and unsafe infant sleep environments by increasing public awareness about the risk factors and risk reduction practices. Distribution of printed materials, health professional and child care staff trainings and multi-media approaches, including innovative channels of communication, are utilized to educate parents and the general public. The "This Side Up" social marketing campaign, which began in 2002, continues to encourage parents of infants to place healthy babies on their backs for sleeping and promotes a safe sleep environment for babies. "Floor Talkers" was a new, innovative, in-store media messaging project for the program which communicated SIDS risk reduction and safe sleep messages via large adhesive decals applied to tiles on the floors of aisles in grocery and retail stores statewide. It has been identified as a promising practice by the Association of SIDS and Infant Mortality Program. A public awareness campaign to address infant suffocation risks is currently being developed for 2010. Bereavement support is also provided to families who have experienced a loss of an infant suddenly and unexpectedly from SIDS through a home visit by local public health nurses and/or social workers.

#### Oral Health

##### *Fluoridation*

In the 2008 Regular Session of the Louisiana legislature, the Louisiana Dental Association, a partner of the Oral Health Program, sponsored a bill to mandate water fluoridation. The resulting law, Act 761, mandates that public water systems with over 5,000 service connections initiate fluoridation as funds are identified by the State. Twenty-five water systems fall under Act 761. MCH facilitated the initiation of fluoridation in the city of Oakdale in 2005 and Crowley in 2008. The City of Walker, began preparing their water system for fluoridation in 2007, and will begin fluoridation in early 2010. The fluoridation program also works closely with the DHH-Center for

Environmental Health to ensure that all water operators are trained in the safety and reporting requirements for water fluoridation.

The Oral Health Program was the recipient of a five- year grant from the Centers for Disease Control to enhance the infrastructure of the Oral Health Program, including the fluoridation management program. The Oral Health Program was able to hire an engineer in 2009 to oversee the technical aspects of the fluoridation program, including approving design plans for water systems, and ensuring the safe delivery of optimally fluoridated water. In 2009, the program hired a fluoridation coordinator who is responsible for conducting community organizing and outreach, and health education with community leaders, policy makers, and civic groups.

### **Infrastructure-Building Services**

The State MCH Program conducts needs assessment, planning, program development, monitoring, evaluation, and workforce development through its central office staff. MCH Management Team includes the MCH Program- Title V Director, a Maternity Program Medical Director, Child Health Medical Director, Perinatal Nursing Consultant, MCH Assistant Administrator, MCH Nutritionist, Nurse Family Partnership Clinical Director, Oral Health Program Manager, MCH Epidemiologist, and Health Education/Communication Coordinator. Other state MCH staff include Health Educator for Child Health, Child Death Review/Child Safety Coordinator, Mental Health Coordinator, Nurse Family Partnership Program Manager and Nurse Consultant, SSDI Epidemiologist, PRAMS Epidemiologist and Data Manager, MCH Epidemiologist for Needs Assessment, Maternity Program Monitor, Breastfeeding Coordinator, MCH Policy and Program Coordinator, Contract Monitor and Administrative Assistant.

### **Promoting Systems of Services**

#### ***Feto-Infant Mortality Review (FIMR)***

The Maternal and Child Health Program sponsors a state-wide FIMR program as a key part of the Louisiana Infant Mortality Reduction Initiative. Region VI in Alexandria, Louisiana, was the first to begin reviews in 2003, followed closely by Region VII in Shreveport, and as of December 2009, all nine public health regions in Louisiana have active FIMR programs serving 29 different parishes. Public-private partnerships address the reduction of infant mortality in each of the 9 public health regions. This includes a scientific review panel & community coalition examining the causes of fetal and infant deaths in their respective region and making recommendations to reduce the infant death rate. In 2009, Registered Nurses hired by MCH abstracted and presented 225 cases of fetal and infant deaths from 35 participating hospitals to 8 regional medical case review teams. Results included recommendations to regional community coalitions and action on issues such as Fetal Alcohol Syndrome, Sudden Infant Death, prematurity, folic acid, interconception and preconception.

Each region's program is led by a FIMR coordinator, who is responsible for coordinating the regional infant mortality reduction initiative to increase access to care and eliminate disparities in the health care outcomes of women and infants in the region. The coordinator provides links between hospitals, private physicians, community members and public health workers to address infant mortality in the region. The network of nine regional FIMR programs is directed by a leadership team at the state level that provides state-wide communication, guidance, and continuing education.

The Louisiana Fetal and Infant Mortality Review Network is based on the National FIMR initiative supported by the American College of Obstetricians and Gynecologists. This national

best practice program is an anonymous review process of stillbirths and infant deaths. A summary of these reviews is presented to the community in order to understand the modifiable circumstances associated with infant deaths, improve services and resources for women, infants and families and potentially reduce the occurrence of future deaths and ultimately reduce infant mortality in the state of Louisiana. FIMR examines social, economic, cultural, safety, and health systems factors associated with fetal/infant deaths, plans and participates in interventions and policies to address these factors and assesses the progress of the interventions to provide a conduit between state and local regions.

FIMR is a community owned, action-oriented cycle of improving maternal and infant health. The process begins when a fetal or infant death occurs in a community. Confidentiality of all case information is maintained. Information about the infant death is abstracted by FIMR Registered Nurse (RN) staff. Sources include vital records, public health, medical, and social service records. An interview with the mother who has suffered the loss is conducted by the FIMR RN, if the mother agrees. The RN assesses the needs of the family and refers to bereavement support and community resources if indicated. The FIMR Case Review Team (CRT) composed of physicians, coroners, health, social service and other experts from the medical community, review the case and interview summary. The CRT then identifies issues and makes recommendations to the Community Action Team. The Community Action Team (CAT), a diverse group of community leaders, faith based groups, administrators, legislators and others in the community involved with women, infant and family issues, reviews the Case Review Team's recommendations, prioritizes identified issues, then designs and implements interventions to improve service systems and resources. In Louisiana, the MCH CDC-assigned epidemiologist provides data to the FIMR groups. Annual Fetal and Infant Mortality Meetings address the issues identified through regional FIMR reviews, input from regional FIMR Community Action Teams, and incorporates Best Practice programs identified at the national and state level.

Dr. Michael Lu, a leading authority on Preconception and Interconception, presented at a two-day FIMR conference in 2007. Dr. Ira Chasnoff, leading authority on Fetal Alcohol Syndrome and Alcohol Related Neuro-Developmental Disorders, gave presentations in four regions of the state in 2007, a statewide videoconference for all Office of Public Health nurses, nutritionists, social workers, nutrition educators in 2008. Also, in Spring 2009, six of the nine regional FIMRs and the Maternity Medical Director and Nurse Director attended the Bereavement Services training program conducted by Gundersen Lutheran Medical Foundation and funded through collaboration with the Healthy Start of New Orleans.

#### *The Louisiana Perinatal Commission*

The Louisiana Perinatal Commission formulates a State Perinatal Plan, adopting guidelines for maternal and neonatal care and requiring a concordance in level between obstetrical and neonatal services, i.e., for a neonatal Level III facility, obstetrical services should be of Level III as well. The Louisiana Office of Public Health (OPH) continued to provide epidemiological data analysis updates through presentations at Louisiana Perinatal Commission and regional Fetal-Infant Mortality Review (FIMR) meetings. The MCH Program Director and the MCH Maternity Medical Director, as members of the Perinatal Commission, and the MCH Epidemiology group, served as a resource for data and information to the Perinatal Commission regarding relevant MCH issues. The MCH Epidemiology group updated information on very low birth weight deliveries by level of delivery hospital. The State Perinatal Commission guides appropriate levels of maternal and neonatal care and MCH continues to work with the Commission.

*BrightStart (Louisiana's Early Childhood Advisory Council)*

BrightStart is Louisiana's Early Childhood Comprehensive Systems Grant Initiative, which is a framework for service systems integration and partnerships. To maintain this framework, BrightStart functions under the auspices of the Louisiana Governor's Children's Cabinet and the Advisory Board, with the MCH Program providing administrative support and direction for the management of the grant initiative. Two coordinators oversee all activities of the grant that are carried out by the 5 workgroups. The Children's Cabinet, a policy office of the Governor, supports development of and provides administrative structure, oversight, and monitoring of the systems that impact all children and is composed of the Secretaries of State Departments that provide services to children. The Children's Cabinet Advisory Board consists of Assistant Secretaries from State Departments, non-profit agency representatives, health and educational institutions, juvenile court, and professional organizations to accept input from advocacy groups, service providers, and parents. The Board makes recommendations to the Cabinet. The BrightStart Steering Committee provides technical assistance and guidance and consists of representatives from state agencies; local education, health care, and social service organizations; parents; and child advocacy groups. Five Focus Area Work Groups of partners and stakeholders carry out the activities of the implementation plan, which center around building quality programs and a system's infrastructure through professional development; public engagement; program licensing and accountability; and sound financing, as they relate to the grant's priority areas.

Through the work of BrightStart, much has been done to integrate systems and build infrastructure to support early childhood, and the following integrative accomplishments illustrate the collaboration with state and non-governmental partners:

Senate Concurrent Resolution (SCR) 83 links state agencies involved with young children and their families to BrightStart for implementation of BrightStart's Strategic Plan (henceforth called the State Early Childhood Plan, SECP) and requires legislative reporting every six months

Early Childhood System Integration Budget (ECSIB) was written into statute, requiring the creation of a budget by the Division of Administration to support and inform the work of the BrightStart Initiative that is outlined in the priority areas of BrightStart (access to healthcare and a medical home, early care and education, parenting education/family support, and socio-emotional/mental health).

BrightStart supported and coordinated infant mental health trainings for professionals across systems including: professionals in the Office of Public Health, the Office of Community Services, Part C-Early Steps and the Division of Child Care and Early Childhood Education.

Development and implementation of the statewide Louisiana Mental Health Consultation Program for Child Care, improving the quality of care within over 200 child care centers that have participated in the program, a collaborative with Tulane University School of Medicine, Department of Psychiatry and Neurology and Office of Family Support's Division of Child Care and Early Childhood Education within the Department of Social Services

Development and implementation of a quality rating system (QRS) for child care centers, called Quality Start, with over 40% of Class A child care centers participating, and implementation of the School Readiness Tax Credits to support Quality Start

Development of Core Competencies and provision of statewide and regional trainings with national speakers for parent educators in Louisiana. Summits were held in partnership with the

annual Prevent Child Abuse Louisiana Conferences, which included a parenting education tract over the last three years.

BrightStart has produced the “Investing in Early Childhood: A Road Map to Economic Success for Louisiana”, which outlines a plan for strategic and comprehensive investments in early childhood. To date, 22 organizations have officially endorsed this plan, and it has been incorporated into the Child Poverty Prevention Council’s Report to the Legislature. The Road map includes a plan for reducing child abuse and neglect, reducing pre-term births, creating a mixed delivery system for LA-4 pre-k and child care/Health Start, expanding preventive early childhood mental health services and strengthening parenting education programs.

### *Louisiana Child Death Review*

The Louisiana State Child Death Review Panel (CDRP) was established in 1992 by the Louisiana Legislature. This multi-disciplinary team of professionals was tasked with collecting and reviewing reports relating to the investigation of unexpected deaths of children under the age of seven. Since 1999, the State CDRP reviews unexpected, unintentional deaths of children under 15 years of age, including SIDS (sudden infant death syndrome), and makes mortality prevention recommendations to the Legislature.

The mission of Louisiana Child Death Review is to perform multi-disciplinary, multi-agency reviews of unexpected, unintentional child deaths of children under 15 years of age to develop a greater understanding of the causes of child deaths, of the methods for preventing such deaths, and of the gaps in services and, thereby, reduce the incidence of injury and death to infants and children.

The State CDRP has four main goals: 1. Review the investigation and classification of each child death in Louisiana; 2. Describe unexpected child deaths in Louisiana; 3. Identify the risk factors of child deaths; and 4. Disseminate the findings of the Panel to agencies and groups that can use this information to prevent future deaths.

Louisiana follows the National Center for Child Death Review guidelines and operating principles. The objectives are to: ensure the accurate identification and uniform, consistent reporting of the cause and manner of every child death; improve communications and linkages among local and state agencies and enhance coordination of efforts; improve agency responses in the investigations of child deaths; improve agency response to protect siblings and other children in the homes of deceased children; improve criminal investigations and the prosecution of child homicides; improve delivery of services to children, families, providers, and community members; identify specific barriers and system issues involved in the deaths of children; identify significant risk factors and trends in child deaths; identify and advocate for needed changes in legislation, policy, and practices and expanded efforts in child health and safety to prevent child deaths; and increase public awareness and advocacy for the issues that affect the health and safety of children.

In 2001, Local Child Death Review teams were started in each of Louisiana’s nine regional public health offices. The local panels are tasked with the following: Identify risk factors for injury or death of children; share information among agencies which investigate child death and/or provides services to children and families; improve local investigations of unexpected/unexplained child deaths by participating agencies; improve existing services and systems for children and/or identify gaps in services at the local level; identify trends relevant to

unexpected and/or unexplained child injury and death; and educate the local public about the causes of child injury and death and how to prevent such tragedies.

The MCH Program provides the staff support for the 25-member State Child Death Review Panel, which is legislatively mandated. The MCH Program provides the staff for the State and Local Child Death Review Panels. State CDRP staff includes the Child Health Medical Director (who also serves as the SIDS Program Medical Director), State CDRP Coordinator, the child mental health consultant, and the SIDS Risk Reduction and Safe Sleep Program Coordinator. State panel staffing also included an epidemiologist from the Bureau of EMS' Injury Research Prevention Program. MCH funds the Local CDRP Coordinators, who also serve as the Regional Child Safety Coordinators. They coordinate community-based systems of unintentional injury prevention initiatives in the 9 OPH regions of the state to address the leading causes of unintentional injury-related mortality and morbidity of children under 15 years of age, including SIDS.

Louisiana Child Death Review has incorporated into its process the National Center for Child Death Review's recommendations for effective reviews. Louisiana Child Death Review has worked to establish linkages with local coroners, law enforcement, fire departments, child protective services, emergency medical services, and other professionals involved in the investigation of sudden unexpected infant deaths and child deaths to use the CDC Sudden Unexpected Infant Death Investigation Reporting Form to standardize and improve data collection at infant death scenes. The Panels also use the National Center for Child Death Review's data reporting for case reviews to promote consistent diagnosis and reporting of the findings of infant and child deaths. MCH provides outreach and training of the coroners, death scene investigators, and first responders on recommended death scene investigation procedures to better determine causes of death of infants who die suddenly and unexpectedly.

#### *Adolescent School Health Initiative*

The 27 members of the School-Based Health Center (SBHC) Sponsor Network engage in infrastructure building through participation on medical, behavioral health, and administrative subcommittees of the Network. These subcommittees assist the central OPH office in formulating policy related to best practices and standards of care for medical and behavioral health services in SBHCs. The SBHC Sponsor Network has been involved in changing laws related to including protection for nurse practitioners and physician assistants within minor consent law language and advocacy efforts at the state and national level for increased funding for SBHCs. As part of its efforts to build infrastructure, OPH certifies non-OPH funded entities to enroll as Medicaid providers based on an evaluation of that entity's adherence to OPH/ASHP standards of care for SBHCs. OPH petitioned Medicaid at both the state and national level to permit Medicaid reimbursement for behavioral health services provided in SBHCs. This reimbursement is a key component in sustainability for current SBHC sponsors, as well as an incentive to attract other potential sponsors. Though the petition was approved at both levels, Medicaid reimbursement for SBHC behavioral health services has not been implemented.

#### *Oral Health Coalition*

Infrastructure Building services include surveillance, epidemiology and evaluation to identify oral health needs and set priorities for the MCH/CHSCH population. The state-wide Oral Health Coalition, a diverse stakeholder group, addresses the issues of prevention, access, education and policy and identifies strategies to improve the state's oral health indicators. Through the 3rd grade Basic Screening Survey, analysis of Medicaid data, and the Surveillance and Evaluation

Plans, the program defines gaps in service, collaborates to implement initiatives, and measures improvement.

As a recipient of a 2008-2013 CDC Infrastructure and Capacity Building Cooperative Agreement, the program has hired a full time School Based Dental Sealant Coordinator, a Fluoridation Engineer and a Program Epidemiologist/Evaluator. In addition, the cooperative agreement requires that the program work toward sustainability through the creation of a state-wide Oral Health Coalition and the development of an Oral Health State Plan. The program has developed a surveillance system and is in the process of completing a Burden of Oral Disease Document to identify disparities and to target population based interventions. Evaluation activities are guided by the five-year evaluation plan.

### *Standards of Care and Training*

#### *Screening, Brief Intervention, Referral and Treatment Program (SBIRT)*

Effective screening, brief intervention and treatment of pregnant women for alcohol use, substance use, tobacco use, depression, and domestic violence offers opportunity for improved outcomes. In response, the MCH program began collaboration with the Louisiana Office of Addictive Disorders (OAD) and Office of Mental Health (OMH) to design, implement, and evaluate a screening and treatment program for pregnant women of Louisiana. Other partners and members of the state leadership team include Louisiana Medicaid, Louisiana Office of Community Support, and American College of Obstetricians and Gynecologists (ACOG)-Louisiana Section, and the March of Dimes. SBIRT was initially piloted in the Baton Rouge region in 2005, and three additional regions were added in May 2007. All Office of Public Health WIC site staff were trained in January 2008 and implementation is current in eight of the nine regions, with many parish health units in all nine regions participating in 2010. A small proportion of private clinics and providers participate in the SBIRT program which is an ongoing challenge. Efforts are underway through Medicaid to initiate a Pay for Performance to encourage private Medicaid providers to participate.

Ira J. Chasnoff, MD, Childrens Research Triangle, Chicago, conducted trainings throughout the state in 2005, 2007, 2008, and 2009, on Best Practices in usage of the 4PsPlus, a tool validated through his national and international research. Through ongoing consultation and trainings by Dr. Chasnoff, the Baton Rouge region initiated a screening and treatment center for Fetal Alcohol Syndrome (FAS) and Alcohol Related Neurodevelopmental Disorders (ARND). The Maternal and Child Health – Fetal and Infant Mortality Review Program (FIMR) co-sponsored Dr. Chasnoff's regional presentation on SBIRT, FAS and ARND, resulting in additional interest in expanding the child evaluation program to other regions of the state.

#### *Breastfeeding Initiative*

MCH initiated a program, titled *The GIFT* (Guided Infant Feeding Techniques) in 2006 in order to increase breastfeeding rates in Louisiana. The National Immunization Survey (2005) showed Louisiana's breastfeeding initiation rate at 47% and 22% at 6 months of age. PRAMS data (2007) reported 53.3% of women ever breastfed. *The Gift* targets all birthing hospitals in Louisiana and is endorsed by the Louisiana Chapter of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. The GIFT Program supports birthing facilities in improving breastfeeding policies and practices by providing technical support and training to increase Louisiana's breastfeeding initiation and duration rates. The GIFT Program held 18 trainings at birthing hospitals throughout the state with 540 health staff trained. There are



14 hospitals statewide that are *Gift* certified facilities. The GIFT Program also initiated and directs a statewide breastfeeding coalition, entitled the Louisiana Breastfeeding Coalition (LBC). The LBC is guided by a 12-member steering committee and protects, promotes and supports breastfeeding through improved public policy, professional education, workplace breastfeeding initiatives, information sharing among lactation consultants, development of regional/local coalitions and has a website being developed with links to the state helpline and website (1800-251-BABY). The Central Louisiana Breastfeeding Coalition, one of several regional breastfeeding coalitions, developed a program of mothers in the community visiting and supporting new breastfeeding moms.

The Louisiana Breastfeeding Coalition supports regional and statewide training and technical support to support breastfeeding mothers through birthing facilities. The trainings resulted in additional hospitals beginning the certification process. The Office of Public Health WIC program also developed a program of community support persons for breastfeeding moms and breastfeeding pumps are available through the parish health unit WIC program. In addition, the Nurse Family Partnership program has focused on increasing the initiation of breastfeeding among the first-time, low-income women served by this program. At present approximately 44% of NFP clients initiate breastfeeding, and approximately 16% continue to breastfeed when their infants are 6 months of age.

#### *Louisiana's Quality Start*

The Office of Family Support in the Department of Social Services, through a collaborative effort with BrightStart (Louisiana Early Childhood Comprehensive System initiative), established a voluntary, 5-star Quality Rating System (*Quality Start*) for childcare. Louisiana was the 15th state to establish a quality rating system for child care. Currently over 40% of Class A child care centers are participating in Quality Start. Also, in 2007, the Louisiana Legislature passed a very unique package of tax credits known as the School Readiness Tax Credits which are a comprehensive effort to support *Quality Start* through tax breaks to families, child care providers, child care teachers and directors and businesses that support child care centers participating in Quality Start.

#### *Child Care Health Consultant Program*

The Child Care Health Consultant Program, which is coordinated by MCH, promotes the high quality level of practice for child care facilities by providing certification-based training for public and private health and safety professionals to become Louisiana Child Care Health Consultants (CCHCs). The training is based on child care standards from the Second edition of Caring for Our Children's National Health and Safety Performance Standards: Guidelines for Out-of-Home, which has 707 of the highest attainable health and safety standards and recommendations for U.S. child care facilities. The Adult Learning and cultural/linguistic competencies for CCHCs are included in the training. The Child Care Health Consultants provide the mandated health and safety trainings to out-of-home child care centers and early education facilities as well as support, assist, and problem-solve with childcare providers in order to achieve safer, healthier childcare facilities in Louisiana.

#### *Louisiana Parenting Education Network (LAPEN)*

LAPEN is an association for professional parent educators in Louisiana which formed in 2007 through the BrightStart Initiative's parenting education/family support workgroup. A 2007 a survey of state funded parenting education programs conducted by BrightStart showed that there

were a number of nationally recognized model programs being used in Louisiana, including Nurse Family Partnership, Nurturing Parenting Programs®, HIPPY, and Parents as Teachers. Besides issues related to fidelity to the models, a large number of programs (41%) reported no specific training requirements for their parent educators prior to teaching, and a large number (45%) reported no specific annual training for their educators. Few programs reported that they were accredited, credentialed or certified in any way, and there was no statewide organization to support parenting educators in Louisiana nor was there a state coordinating entity for all of the parenting education programs in the state. LAPEN provides leadership and infrastructure to support Louisiana's parent educators from every field, promotes best practices in parenting education, provides and promotes continuing education and professional development opportunities for parent educators. With the guidance of BrightStart, LAPEN operates under the auspices of the Louisiana Partnership for Children and Families, an advocacy organization with a mission to promote one vision and voice for Louisiana's children and improve the well-being of children and their families through public policy advocacy, education and awareness, and data-driven efforts. LaPEN has developed core competencies which define knowledge, skills, and attitudes for Louisiana's parent educators and professionals who work with families of children ages 0-18 years.

LAPEN has held 3 annual LAPEN Summits, which were pre-conferences to Prevent Child Abuse Louisiana's annual conferences 2007-2009 and 3 regional training sessions for Parent educators in the state. Topics of the regional trainings included Evaluating Parenting Education Programs, Continuous Quality Improvement, and The High Road to Quality Parenting Education. LAPEN also developed a Professional Development Portfolio, which is designed to help parent educators to keep track of their training and professional development experiences that relate to the core competencies.

#### *Adolescent School Health Initiative*

SBHC sponsors are contracted to providing a detailed list of. OPH's Adolescent School Health Program monitors all contracted School Based Health Centers to ensure that the services being provided follow the standards listed below, which are based on national best practices recommendations: screening for Type 2 diabetes mellitus, diabetes management support; screening for Hypertension, referral of students with suspected/diagnosed hypertension, ongoing monitoring of pre-hypertensive students; screening and treatment for gonorrhea, chlamydia, and other STDs; HIV prevention, screening and counseling, referral for treatment; screening and referral for cervical cancer; screening for tobacco use, access to tobacco cessation counseling; monitoring for up-to-date immunizations, administering required vaccines; ensuring that physical exams are comprehensive and include risky behavior assessments; taking yearly height, weight, BMI measures; identifying students who are overweight/obese; providing lifestyle counseling; identifying students with asthma, formulating written asthma plans; identifying students with poor school performance; referral for physical evaluation and behavioral health support, coordinated improvement with the school staff; decreasing time away from school/out of class because of illness; serving as Medicaid/LaCHIP enrollment centers; providing individual and group behavioral health counseling; requiring a minimum of 20 hours of primary care provided by a physician, nurse practitioner or physician assistant; and requiring a full time, licensed behavioral health professional.

#### *Nurse Family Partnership*

The MCH Nurse-Family Partnership (NFP) uses experienced registered nurses to provide intensive home visiting services to first time mothers and their children. Standards of care for

NFP are developed and implemented by several sources. All nurses are required to adhere to professional nursing practice standards and code of ethics. The NFP National Service Office (NSO) and the Louisiana MCH NFP program set forth requirements for training and knowledge that are needed in order for NFP nurses to implement the program. NFP training initially involves 4 core units of NSO NFP education/training and 5 units of Louisiana developed Infant Mental Health training. Ongoing training involves at least 40 hours of program related continuing education annually. On the local level, NFP nursing supervisors assure that staff meets nursing licensure requirement and initial and ongoing training needs.

The NFP program is guided by 18 NSO Model elements, which are supported by evidence of effectiveness based on research, expert opinion, field lessons, and/or theoretical rationales. When the program is implemented in accordance with these model elements, implementing agencies can have a high level of confidence that results will be comparable to those measured in research. Supervisors conduct monthly client record reviews, quarterly supervisory visits with each nurse, weekly reflective supervision with each nurse, weekly case conferences with the staff and annual client satisfaction surveys to assure that nursing and program standards are being met. Nursing and NFP competencies are developed and monitored at least annually by the local NFP supervisor. In addition, MCH NFP management staff conduct annual or more frequent quality assurance/improvement site visits to assure that local staff meet all education and ongoing education needs and that the local site is implementing the NFP program in fidelity to the model and maintaining all standards of care.

NFP Program effectiveness is monitored by intensive and extensive data collection by the direct service staff during each home visit. Data regarding program participants is entered and collated within the NFP NFO clinical information system database. NFP NSO generates quarterly and annual evaluation reports from the clinical information system data. The reports are disseminated to each NFP site and the NFP state management team to inform operational and clinical quality improvement plans, as well as to demonstrate attainment of programmatic goals and outcomes. In addition, MCH NFP management staff collect monthly reports from each local site regarding productivity and efficiency.

#### *Louisiana Council on Obesity Prevention and Management*

The Office of Public Health is responsible for the oversight of the Louisiana Council on Obesity Prevention and Management; a council mandated by state legislation. The Louisiana Council on Obesity Prevention and Management (Louisiana Obesity Council) was created by state legislation in 1999 and is housed in the Nutrition Section of the Office of Public Health. Obesity rates continue to climb and the resulting medical complications are having a devastating effect on the state budget. The MCH Program actively participates with this council. In 2008 the Obesity Council was instrumental in receiving \$110,000 in funding through the National Governor's Association to help improve obesity rates among the states youth. Funding was used to assist Louisiana elementary and middle schools in advancing the level of implementation of their local school wellness policy (a federal mandate). The School Wellness Policy Implementation Project included a survey of school principals, state-wide focus groups, and the development and distribution of the 2009 Louisiana School Wellness Policy Action Plan Guide. Furthermore in 2009 the Council was instrumental in helping to pass several pieces of legislation, including: the requirement of *physical activity* for students (K-8, at least 30 minutes per day) and establishment of *School Health Advisory Councils* in each city, parish and other local public school board; an amendment to the 2005 Act 331 *School Vending* Bill to provide 100% (previously 50%) high school beverages adhere to healthy guidelines; providing for *health-related fitness assessments* (Fitnessgram) to determine physical fitness levels of students in schools; and *Healthy Food Retail*

Act to stimulate investment in healthy food retail outlets in underserved areas. Program created in the Department of Agriculture and Forestry and currently not funded.

Conferences on childhood obesity have targeted school staff as well as worksite wellness with the emphasis on obesity. In 2008 the Obesity Council partnered with Pennington Biomedical Research Center (PBRC) to conduct a statewide conference to educate health practitioners, professionals, educators and policy makers in the recognition, prevention and management of childhood obesity. More than 350 stakeholders in various fields of children's health traveled from all regions of the state to participate in the conference where the first ever Louisiana Report Card on children's physical activity and health was released. Based on the success of the conference, this will be an annual event. Since 2008 LA AFHK has conducted an annual state meeting, where team members and stakeholders gather to collaborate and discuss childhood obesity initiatives occurring in the state. This meeting also provides an opportunity for individuals from the same geographical area of the state to identify resources and barriers in their region and to formulate a regional plan to move forward in addressing childhood obesity.

### *Workforce Development*

The MCH program has developed a 30-hour training in infant mental health that is offered semi-annually to all clinical services staff, and is required for Nurse Family Partnership Program. This training provides an overview of the importance of early experience on later behavioral, social, emotional, and cognitive development. Attachment theory is emphasized. Trainees learn about the impact of various parent-infant attachment relationships and implications for future development. Other topics include recognizing psychopathology in infancy and early childhood; the impact of cultural and ethnic influences on parenting; parenting styles; assessment of factors that impact early social and emotional development (environmental, infant, maternal—including depression, substance abuse and domestic violence—and relationship), and brief intervention strategies. Personal, professional, and cultural values are discussed as they may impact the professional's ability to work effectively with clients. Over 800 public health and other maternal child health professionals have attended this program.

NFP nurses are required to become reliable in parent-infant interaction assessment via the Nursing Child Assessment Satellite Training (NCAST) program. This six-day training, developed by the University of Washington, School of Nursing, enables the NFP nurse to assess systematically parent-infant relationships through observations of feeding or teaching interactions. The MCH program now has five certified NCAST instructors who provide this training. NFP mental health consultants receive intensive infant mental health training through the Tulane University Department of Psychiatry's Institute for Infant and Early Childhood Mental Health. This training program is aimed at licensed mental health clinicians and develops skills and knowledge in evidence-based assessment and treatment approaches for infants, young children and their families.

Educational programs on cultural competence, focusing on racial, economic and linguistic issues, are provided to staff of MCH programs including Nurse Family Partnership, child care health consultants, and other program staff who work within MCH.

The Tulane Maternal and Child Health Leadership Training Grant funds ongoing training to MCH staff and stakeholders statewide, via teleconference in order to develop MCH competencies. The topics of training include leadership, student and staff mentoring, and staff management/supervision.

The MCH Child Safety Coordinators are required to obtain certification in Injury Prevention through the online training from the University of Delaware and to obtain/maintain certification as a National Child Passenger Safety Technician and as a Louisiana Child Care Health Consultant. They also receive training in motor vehicle safety, pedestrian safety, bicycle safety, ATV safety, hunting and gun safety, fire safety, water safety, poison prevention (including lead poisoning prevention), playground safety, home safety, outdoor safety (including sun safety) SIDS risk reduction and infant safe sleep environments.

Via continuing education programs, professional conferences, and other public health training programs, MCH has provided clinical mental health training to public health professionals. In collaboration with BrightStart, intensive infant mental health trainings were offered across systems of care to health professionals in the Department of Health and Hospital's Office of Public Health and Office for Citizens with Developmental Disabilities, Part C-Early Steps and in the Department of Social Services' Office of Community Services and Division of Child Care and Early Childhood Education. Presentations on perinatal depression were given to OPH staff, NFP, FIMR, and numerous non-profit and public mental health / health clinicians throughout the state to enhance and expand clinical mental health services to this population. Presentations focusing on perinatal loss and grief, unique aspects of grief with Sudden Unexpected Infant Deaths, and grief support have also been provided to FIMR, NFP, child death/child safety staff, and other public health professionals.

Ongoing collaboration exists between the MCH program and the Office of Public Health, Nursing Continuing Education (CE) Program. Numerous CE programs pertinent to MCH have been included in the quarterly CE statewide videoconferences, including substance use in pregnancy, infant mortality, and others. The Child Health Medical Director and the Maternity Medical Director serve on the OPH Nursing and Medical Continuing Education (CE) Program's quality assurance committee.

The Oral Health Program offers educational courses on dental topics. These courses have been provided to childcare providers, nurses, teachers and other professionals that work with children. With the addition of a Fluoridation Engineer, the program has developed a training course for water operators addressing the safe delivery of optimally fluoridated water.

### *Coordination*

MCH coordinates with the state Ryan White and Title IV AIDS through joint planning and assessment of the perinatal population. Both programs participate in the regional infant mortality review process (FIMR). Maternity team members provided technical assistance to the Baton Rouge project and now is involved with the initiation of the New Orleans FIMR-HIV program, a collaborative of American College of Obstetricians and Gynecologists, CityMatCH, and Centers for Disease Control. Through the FIMR-HIV program, pregnant women who are HIV positive are interviewed, with the purpose of identifying psycho-social issues that impact this target population and to take the woman's comments and recommendations to a Community Action Team.

MCH has a longstanding cooperation with the OPH-STD program, identifying and reviewing records of infants born with syphilis and HIV, as well as coordinating programmatic aspects of sexually transmitted diseases that impact birth outcomes. Louisiana's high Chlamydia and gonorrhea rates are brought to the attention of the regional FIMR Case Review Team and Community Action Team members.

Coordination with other programs and agencies is a necessity for the MCH Program in order to serve the multiple needs of Louisiana's child population. The MCH program works with the existing system for the provision of prevention and primary services for children, consisting of the publicly supported local public health units, state supported hospitals, rural health clinics, the 27 Federally Qualified Health Centers, and the Community Care Program, a program which links Medicaid enrolled children to a primary care provider.

MCH's Child Death Review relies on its collaboration with the Bureau of Emergency Medical Services (EMS) for data, surveillance and for implementing effective injury prevention initiatives to reduce fatal and non-fatal injuries among the children of Louisiana. EMS/Injury Research Prevention Program (IRPP) manages the Child Death Review Surveillance System, performs data analysis; and produces an annual Child Death Review Panel report. An IRPP staff member serves on the State CDRP. The Child Health Medical Director served on the IRPP Planning Group to assist in the development of the State Injury Prevention Strategic Plan. The Child Health Medical Director serves on Emergency Medical Services for Children (EMSC) Advisory Council. Also, EMSC partners with the MCH Child Safety Coordinators to host the annual EMSC day.

MCH's Child Death Review contracts with Children's Bureau –Project Last to carry out support services to families who have experienced a loss of an infant. Public Health Nursing Services, Public Health Social Work, and Children's Bureau Project Last provide Bereavement Support Home Visits to families who have lost an infant to SIDS. The Children's Bureau, a New Orleans not-for-profit social services agency, also provides counseling to children who have been affected by violent deaths and families who have lost children unexpectedly.

The MCH Program works closely with the Office of Community Services (OCS) within the Department of Social Services (DSS) to prevent child abuse and neglect. A Memorandum of Understanding (MOU) between the agencies exists to provide public health nursing assessments for children under investigation by the Office of Community Services (OCS) for suspected failure to thrive, malnutrition, or other medical neglect. The MCH Program works their High Risk Infant strategic planning committee to reduce infant morbidity and mortality due to intentional and unintentional injuries. Also, MCH collaborates with the Department of Social Services Child Care Licensing Section and the Office of Public Health Center on Environmental Health to ensure that child care centers continue to receive the three hours of DHH-mandated health and safety training, which is required to obtain and retain their child care license. Also, the MCH Program works collaboratively with OCS in the promoting awareness of Louisiana's Safe Haven Law, which provides a legal means for parents to safely relinquish custody of unwanted infants up to 31 days of age without the threat of prosecution for neglect, abandonment or child cruelty. An OCS staff is a member of the Louisiana Child Death Review Panel and works at the State and local levels to address the issues of preventable child deaths.

The MCH Program collaborates with the Children's Justice Act (CJA) Taskforce within the Department of Social Services. The Child Health Medical Director serves as a member of the CJA Taskforce, which works to improve the investigation, prosecution and judicial handling of cases of child abuse and neglect, particularly child sexual abuse and exploitation, in a manner that limits additional trauma to the child victim. This also includes the handling of child fatality cases in which child abuse or neglect is suspected and some cases of children with disabilities and serious health problems who also are victims of abuse and neglect. The CJA Taskforce funded the Child Death Review Panel (CDRP) Coordinator for Northern Louisiana through 2008 and continues to support the efforts of Louisiana CDRP.

The State Medicaid Program and the MCH Program in the Office of Public Health are both located within the Department of Health and Hospitals. The MCH Program Director along with executive staff of the State Medicaid Program are members of the Advisory Committee for the Louisiana Covering Kids and Families Coalition, which works toward increasing outreach efforts for LaCHIP and other Medicaid eligibility for women and children. Representatives of the Medicaid Program have been ongoing participants in BrightStart (Louisiana Early Childhood Comprehensive Systems Building Initiative) and address issues of access to care and medical homes. The State Medicaid EPSDT Coordinator has been a member of the Louisiana Childhood Lead Poisoning Prevention Program Advisory Committee to facilitate the efforts of both programs to address lead poisoning in the Medicaid population.

The Special Supplemental Nutrition Program for Woman, Infants, and Children (WIC) and the MCH Program are closely coordinated at the state and local levels. At the local level, public health units are the primary providers of WIC Services in the State. There is an opportunity to provide MCH-funded health education services provided by public health unit staff in addition to nutrition education to users of WIC services who receive their health services from private providers. At the State level, the Child Health Medical Director serves as the Medical Consultant for the WIC Special Formulas Program, and the MCH Program provides funding for a Nutrition Consultant, who works in the MCH office. The MCH Nutrition Consultant actively participates with the Louisiana Obesity Council and is the co-chair of the council subcommittee Louisiana Action for Healthy Kids (LA AFHK). LA AFHK addresses the epidemic of childhood obesity by focusing on changes in schools to improve nutrition and increase physical activity. LA AFHK partners with families, community members, professionals and business to support schools in the effort to help kids learn to eat right and be active every day. The LA AFHK team has developed five regional teams across the state and recruited over 200 members to the state team. Projects include partnering with the NFL New Orleans Saints and the Southeast United Dairy Industry Association for the distribution of 200 Re-Charge Kits to Louisiana schools to assist with increasing physical activity in after school programs.

The MCH Program provides funding to support the efforts of the Louisiana Childhood Lead Poisoning Prevention Program (LACLPPP). Since the inception of LACLPPP, the Child Health Medical Director served as the principal investigator of the CDC grant funding for the program. However, the new Program Director is now the principal investigator, and the Child Health Medical Director continues to serve as the medical consultant to LACLPPP.

MCH has worked closely with the Office of Mental Health (OMH) in supporting the expansion of the Early Childhood Supports and Services (ECSS) Program, which provides assessment and intervention services for young children to age 6 who are at risk for poor psychosocial and developmental outcomes. This program currently operates in 12 parishes of the State. MCH is represented on the Louisiana Partnership for Youth Suicide Prevention Taskforce and has participated in the strategic planning for reducing youth suicide deaths in Louisiana. MCH Epidemiology provides data to the Louisiana Partnership for Youth Suicide Prevention.

Child Health collaborates with the Chronic Disease Prevention and Control Program within the Louisiana Department of Health and Hospitals (DHH) to improve the quality of life for children with asthma through participation in its Childhood Asthma Surveillance Collaborative. With funds from the U.S. Environmental Protection Agency, the Bureau's Asthma Control Program developed one of the state's first surveillance systems to focus on children with asthma. The Louisiana Childhood Asthma Surveillance Collaborative (LASC), formally known as the Childhood Asthma Surveillance Collaborative (CASC), was created to provide guidance and assist DHH in assessing, evaluating, and determining correlations with current Department of

Environmental Quality (DEQ) data, Louisiana Hospital Inpatient Discharge Database (LAHIDD) data, and emergency room data regarding asthma triggers and asthma related emergency room visits. The information collected will be used to improve community collaborations; advocate for an asthma-friendly environment; and developing a comprehensive asthma education program for schools, providers, and other members of the community. LASC received a grant to fund regional coordinators to provide community education and outreach. MCH participated in the development of the Asthma Program plan and in the program evaluation.

The MCH Program's contractual partnership with Tulane University School of Medicine, Department of Psychiatry and Neurology and Louisiana State University Medical Center, School of Public Health is to provide consultants who have expertise in early childhood and infant/child behavioral health issues. Tulane provides program coordinators to carry out the efforts of the BrightStart (Louisiana Early Childhood Comprehensive Systems Grant Initiative) Strategic Plan. The partnership will expand to include a parenting education coordinator of an evidenced-based parenting education model. The MCH child mental health consultant provides consultation to the State Child Death Review Panel, SIDS Risk Reduction and Safe Sleep Program, BrightStart (ECCS) Initiative, the Child Health subgroup and core group, LAPEN (Louisiana Parenting Education Network) and other MCH supported programs.

Collaboration with the Louisiana Chapter of the American Academy of Pediatrics (LA AAP), and contractual partnerships with hospitals, community agencies, and the Louisiana Public Health Institute (LPHI) enable MCH to carry out its health and safety efforts. The Child Health Medical Director has been an active member of the Louisiana Chapter of the American Academy of Pediatrics Executive Committee. MCH contractual partners for the MCH Child Safety Coordinators/Local Child Death Review Panel Coordinators include Children's Hospital in New Orleans, MCH Coalition in Baton Rouge, Options for Independence in Lafourche Parish, Area Health Education Centers of Southeast, Southwest, and North Louisiana, and Christus Cabrini Hospital in Alexandria. The regional Fetal-Infant Mortality Review network contractors include Healthy Start Programs in New Orleans, Baton Rouge, and Lafayette regions, Southeast Louisiana's Options for Independence, Southwest Louisiana Area Health Education Center, Alexandria region's Extra Mile, Louisiana State University Health Sciences Center, and Northeast Louisiana Children's Coalition. LPHI provides staff to serve within the MCH Program policy planning, the State Child Death Review Panel/MCH Child Safety Initiative, and the MCH Needs Assessment process.

#### Information Systems, Data Analysis, Needs Assessment

The development of information systems that are capable of providing timely and appropriate data for planning and evaluation of programs and policies is a key component of MCH. In 1996, the MCH Program became a recipient of a Center for Disease Control & Prevention (CDC) MCH Epidemiology Grant. This grant helped establish the Epidemiology, Assessment, and Evaluation (EAE) unit within the MCH Program. The EAE unit is currently composed of a CDC assigned MCH Epidemiologist, a State Systems Development Initiative (SSDI) Coordinator/ senior MCH Epidemiologist, a Needs Assessment Epidemiology Coordinator, a Louisiana Pregnancy Risk Assessment Monitoring System (PRAMS) Coordinator, a PRAMS Operations Assistant, and various interns and graduate master level students of Tulane and LSU schools of public health. The EAE unit holds ultimate responsibility for facilitating appropriate access to, analyzing, and translating program-relevant data. The unit actively participates in MCH epidemiological studies; Block Grant data analysis and translation; objective data preparation for policy-building process and other specific projects; analyses of data from a variety of data sources, including national and state-based data. Ongoing agreements are in place to obtain annual data files from Louisiana



sources, including vital records (births, deaths, fetal deaths, and inpatient hospital discharge), Medicaid eligibility files, WIC eligibility files, newborn screening data, and birth defects surveillance data.

The MCH and CYSHCN epidemiology programs work with program coordinators, providers, and other stakeholders to share information obtained from the analysis of surveillance system data, linked data sets, and other MCH relevant surveys, and to seek program input on the policy implications of the findings. The MCH EAE unit works closely with internal partners at the Department of Health and Hospitals (DHH) to establish and improve linkages between vital records surveillance files and the MCH related databases. The results are MCH-related surveys and registries and improved access to information to monitor health.

The Louisiana SSDI program focuses on increasing the data/epidemiologic capacity of Louisiana's MCH and CYSHCN programs to monitor and address MCH health problems. The project improves data linkages and surveillance systems outlined in the Title V Block Grant Health System Capacity Indicator #9A. Access to existing and newly acquired data sets and information provided by their analyses and linkages allow MCH and CYSHCN Programs to identify priority needs through needs assessment processes, report on national and state performance measures, target resources, and develop and evaluate programs. The joint effort between epidemiologists and program staff help develop future interventions for these programs as well as assess their respective National and State Performance Measures. The main goals of the project are to: (1) improve the data linkages, analyses, and dissemination utilizing birth records linked with the data sources listed above; and (2) establish to access to and analyze data of the state Office of Addictive Disorders' Caring Community Youth Survey. The new availability of these bi-annually collected data provides new opportunities to gain better insight into the behavior of Louisiana children in the 6<sup>th</sup>, 8<sup>th</sup>, 10<sup>th</sup>, and 12<sup>th</sup> grades.

From the linked data, surveys, and registries, MCH epidemiologists conduct studies and evaluations that provide relevant information to program staff and policy makers in order to develop interventions that will help the state to meet national and state performance targets. The SSDI program is responsible for maintaining all MCH related data obtained through these various programs and assuring that the MCH program has access to the most recent data available for each data source. SSDI program and EAE unit analyses and results are disseminated at the state and local levels in the form of: 1) presentations to the State Perinatal Commission, the MCH Coalition, and internal and external meetings and conferences (e.g., MCH EPI conference), 2) publications, such as peer reviewed journals, the Louisiana State Medical Society Journal, Baby Talk Newsletter, and The Louisiana Morbidity Report, and 3) data and information on the state intranet and internet sites.

In addition to the data sources listed, the MCH Epidemiology program collects Louisiana-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. The Louisiana Pregnancy Risk Assessment Monitoring System (LaPRAMS), which began in Louisiana in 1997, provides data for planning and assessing health programs and for describing maternal experiences that may contribute to maternal and infant health. The goal of LaPRAMS is to reduce infant morbidity and mortality by impacting maternal and child health programs, policies, and maternal behaviors during pregnancy and early infancy. Findings from LaPRAMS are used to enhance the understanding of maternal behaviors and their relationship with adverse pregnancy outcomes and aid in the development and assessment of programs designed to identify high-risk pregnancies and reduce adverse pregnancy outcomes.

Monitoring the development of community-based service systems

The Maternity program monitors all contracts on a monthly basis, and ongoing telephone conferences address issues of concern. Quarterly FIMR teleconferences update and inform both regions and state efforts.

Child Health monitors the development of community-based service systems through BrightStart, the Children's Cabinet Advisory Board, the Louisiana American Academy of Pediatrics, and its participation on state boards, coalitions, and committees that also provide services at the community level. BrightStart's efforts are monitored by the Louisiana Legislature with the submission of progress reports every 6 months, as mandated by the 2008 Senate Concurrent Resolution No. 83. Efforts of the Louisiana Child Death Review Panels are monitored by the Louisiana Legislature with the submission of an annual CDRP report, in accordance with RS 40: 2019

Child Safety monitors the development of community-based service systems through the efforts of the Regional Child Death Review Panels and the MCH Child Safety Coordinators. Efforts are tracked by their written monthly activity reports which have performance measures, monthly group telephone conference calls, and quarterly face-to-face meetings.

NFP Program effectiveness is monitored by extensive data collection by the direct service staff during each home visit. Data regarding program participants is entered and collated within the NFP clinical information system database. NFP National Office generates quarterly and annual evaluation reports from the clinical information system data. The reports are disseminated to each NFP site and the NFP state management team to inform operational and clinical quality improvement plans, as well as to demonstrate attainment of programmatic goals and outcomes. In addition, MCH NFP management staff collects monthly reports from each local site regarding productivity and efficiency. Annual site visits are conducted with a continuous quality improvement system.

## **Needs Assessment of the Children with Special Health Care Needs Population**

### **1. Process for Conducting Needs Assessment**

#### **Goals/Vision**

The CSHS Program Needs Assessment began with a comprehensive review of regional, state, and national data, followed by a systematic review of the literature on the Medical Home, Care Coordination, Systems of Care, Health Disparities, and Family impact for caring for CYSHCN, as well a thorough identification of state and national goals. The information gained from these two steps was correlated with the pertinent goals in order to link the target population needs within the context of the broader service system framework. In early summer 2009, following this initial process, CSHS staff that represents the perspectives of medical, public health administration, nursing, social work, care coordination, parents/families, and public health epidemiology met to discuss the findings and to identify the conceptual framework for the 2010 Needs Assessment. From this meeting CSHS determined there were two overarching important themes: the Medical Home and the burden placed upon families to navigate the complex systems of care. Subsequently, a problem oriented conceptual framework was adopted with the purpose of capturing the following:

- The Medical Home infrastructure capacity among primary care providers in Louisiana

- The coordination of enabling services among CYSHCN stakeholder agencies

Three stakeholder groups were identified as key contributors to the Needs Assessment process. These were primary care pediatricians and family practice physicians, agencies/programs that provide direct care and coordination of services for Louisiana's CYSHCN population and their families, and the families with CYSHCN.

### **Leadership**

Three work groups were created and all CSHS staff mentioned above were members and/or had different leadership roles corresponding to their field of expertise. The Medical team, led by the CSHS Director, was responsible for engaging the Louisiana chapter presidents of pediatricians and family physicians. The Family team, led by two CSHS parent consultants, was responsible for engaging directors and staff from state family organizations. The Agency team, led by the CSHS Program Manager, was responsible for engaging directors and staff from all programs within the Louisiana Department of Health and Hospitals (DHH) and the Department of Social Services (DSS) that provide direct services to Louisiana's CYSHCN population, and state-wide family organizations. Lastly, CSHS employed the Policy and Research Group (PRG) who was an essential contributor to the Medical and Agency leadership teams by providing technical assistance and feedback. Each team met at least monthly to discuss progress and, when necessary, identify ways to improve the Needs Assessment process.

### **Methodology**

Three stakeholder groups were identified that corresponded to the work groups described earlier. Background data was collected, analyzed, and presented to the chapter presidents for each physician academy, as well as to program managers for the selected agencies and organizations. Survey development was conducted collaboratively with CSHS team members, physicians, program managers, and selected pre-testers. Peer reviewed literature provided the framework and theory for survey design. Data that described direct, enabling, population-based, and infrastructure building services further guided the formulation of questions. Lastly, survey protocol, introduction, dissemination, and incentives for completion were established in order to minimize information and response biases. Review of findings was conducted with reference to national and state data to determine concordance between stakeholders, as well as data sources with regard to emerging needs and priorities. This was done collaboratively with stakeholders. Determination of action plans, allocation of resources, and monitoring and evaluation of program activities were developed systematically using public health program planning methodology.

### **Methods for Assessing the CYSHCN Population**

#### *Families*

The CSHS epidemiologist conducted multiple analyses using data from the 2005/6 National Survey of Children with Special Health Care Needs (NS-CSHCN) to determine Louisiana specific consistent and emerging needs in order to identify factors that needed further investigation. It was decided to compare outcomes by Medicaid eligibility status since health care insurance coverage influences access, system use, satisfaction with the health system, needs, and health outcomes. A similar analysis was done using data from the 2007 National Survey of Children's Health (NSCH). The information gleaned from these analyses were compared to the Louisiana Families Helping Families (FHF) organizations' yearly activity summary reports, and the Louisiana Department of Education (DOE), Special Education section report in order to

provide further insight into the statistical picture. Based on all the information obtained it was determined that obstacles which impede attaining better health outcomes for Louisiana's CYSHCN population were the product of the complexity of the service system and providers' dependency on the family to navigate the system and to explain critical health/educational information to providers. Consequently, many of Louisiana's families with CYSHCN experience redundant services, incomplete care, and both time and financial constraints.

Based on the results of the analyses it was agreed that more specific information was needed to supplement the statistics generated. The needed information was the knowledge, use, satisfaction, and needs for community resources among Louisiana's CYSHCN and their families. It was noted however, that capturing a comprehensive list of all CSYCHN and their families was neither logistically nor financially feasible. Through discussions, it was decided that the best source to gather the data on family perspectives was from collaboration with each of the ten FHF regional offices, and therefore obtain feedback from a convenience sample.

In September 2009, the statewide nurse consultant and epidemiologist collaboratively developed a brief 3-paged survey that covered the content areas of access, knowledge, use, and satisfaction with services, as well as transition benchmark measures. An individual eligible to answer the survey was either from a family with at least one CYSHCN living in their household, or was a YSHCN. The CSHS statewide parent liaison consultant and statewide parent training coordinator reviewed the survey for clarity and content prior to dissemination. Both contacted each FHF regional office and briefly explained the CSHS 2010 Needs Assessment process and the Family Survey in order to garner collaboration with disseminating and promoting the survey. The survey was published in the winter publication of the quarterly newsletter, *Family Matters*. This publication is spearheaded by the CSHS statewide parent training coordinator, and is produced in collaboration with a diverse group of parents with CYSHCN, physicians, nurses, social workers, and CSHS Central Office staff. Distribution of the publication is through many means. The editor mails approximately 60 hard copies to each regional FHF parent liaison. These are copied and displayed at each of the nine CSHS statewide subspecialty clinics. The surveys were displayed in each FHF regional office, and at community outreach events. The editor has a subscriber list of 100 persons and groups who receive editions by email. Lastly, the publication was posted on two sections of the CSHS Program website beginning on October 7, 2009, and remained until January 14, 2010; on the family and the current highlights section. Respondents either could complete the survey on their own or with help from anyone requested. Respondents also had choices with how to submit their surveys. They could either mail their survey directly to CSHS or request the FHF regional office do so. The mailed surveys were given to the CSHS epidemiologist who recorded the results in a password protected Excel spreadsheet. Results were presented to stakeholders in a collaborative meeting. A more detailed description of the Family Survey is found in Appendix F.

#### *Primary Care Physicians-Medical Home*

In the fall of 2009, the CSHS Director and epidemiologist had informal meetings with Louisiana chapter presidents for the American Academy of Pediatricians, and the American Academy of Family Physicians. The meeting involved an introduction to the CSHS Program, a brief description of the Title V Program, the 2010 Needs Assessment, national, state, and programmatic data, and a request to collaborate with CSHS to conduct a Physician Survey among chapter members. Alliance was adopted, and survey guidelines were established. Each chapter provided a list of current members' names, addresses, and email contact information (Fiscal Year 2009) to PRG, which were used only for the survey. The Physician Survey was intended to operationalize the AAP Medical Home criteria, and was produced in collaboration with PRG and CSHS Central Office staff.

Based on our goal it was determined that the tool had two significant threats for misclassification. It was decided that question formation would focus on content validity since, on average, there were many concepts described for each Medical Home criterion. In order to minimize respondent information bias, we acknowledged that the target group were already familiar with the criteria that defined the Medical Home, and thus if the survey specified expressions reminiscent of care coordination or the Medical Home, this would result in responses that could either inflate or deflate the estimate. For potential respondents, we prefaced that the survey aimed to assess the key components of medical care that Louisiana physicians provided for children and adolescents, including CYSHCN. The Medical Home concept was specified only at the very end of the survey when respondents were asked if they would like to receive technical assistance from CSHS on Medical Home activities. The panel of professionals who contributed with the tool design provided feedback to ensure questions were covering the broad content areas for selected criteria. Pre-testing was conducted after in-house tests were done to identify programming bugs for the on-line version. Volunteer pre-tests not involved in the survey design (3 pediatricians, 1 family physician), were asked to comment on questions that seemed inappropriate, irrelevant, or otherwise confusing, as well as the length of time required to complete.

Prior to sending the survey, an announcement in the Louisiana chapter for the AAP Winter newsletter was made that briefly explained CSHS, the survey, and when the survey would be mailed. Each invitation to complete the survey included a cover letter composed by the CSHS Director, which recapped what had been published. For those who received a paper survey, the packet included the cover letter, the survey, a self-addressed stamped return envelope, and a postcard with which the respondent could request information for Medical Home technical assistance training. The survey was disseminated for approximately six weeks, between November 23, 2009 and January 15, 2010, an extension of four weeks from the originally proposed time frame. Four reminder emails were sent for non-respondents through an automated process that ensured anonymity. On-line data was downloaded weekly from the web server for backup purposes. A random drawing for a \$100 American Express gift card incentive was promoted the last week of survey completion.

Physicians eligible to complete the survey were those who provided primary care for children and/or adolescents at least three days a week in an outpatient setting, and provided primary care for CYSHCN. Some general questions were asked of all surveyed regardless of eligibility determination. Because the target group was small, the survey was disseminated to all members on the roster. A more detailed description of the Physician Survey is found in Appendix F.

#### *State Organizations and Agencies-Care Coordination*

Following the initial Needs Assessment planning meeting with CSHS leaders, the CSHS Program Manager conducted a systematic review of all DHH and DSS agencies and programs, and key non-governmental organizations in Louisiana that provide direct services to CYSHCN and their families. The initial stakeholders identified were the following:

- DHH
  - Office of Public Health (OPH)
    - Children's Special Health Services Program\*
    - Hearing, Speech, and Vision Program\*
  - Office for Citizens with Developmental Disabilities (OCDD)
    - Early Steps Program\*
    - Supports and Services\*

- Greater New Orleans (GNO) Resource Centers on Developmental Disabilities Program\*
- DSS
  - Louisiana Rehabilitation Services (LRS)
    - Vocational Rehabilitation Program\*
    - Independent Living Program\*
  - Office of Community Services (OCS)
    - Foster Care\*
    - Family Services\*
    - Child Protection and Investigation Program
  - Office of Family Support (OFS)
    - Disability Determinations
- Non-Governmental Organizations (NGO)
  - Families Helping Families\*
  - Family to Family Health Information Centers

*\*- indicates program staff were surveyed*

The CSHS Director contacted each agency's Assistant Secretary to explain the 2010 Needs Assessment, with the goal to garner buy-in and allowance to contact each office director and corresponding program manager, and to obtain staff email lists.

In early Fall 2009, each of the program managers listed attended a brief focus group meeting with CSHS and PRG. Prior to the meeting, the CSHS Program Manager provided each invited stakeholder with a list of six questions. These questions facilitated a description of each programs' services, including eligibility criteria, direct services provided and by whom, the number of clients served annually, and funding and reimbursement streams. The meeting took place in a centralized location in order to accommodate each program. The CSHS Director presented background on the 2010 Title V Block Grant Needs Assessment process and the CSHS Program. The CSHS epidemiologist presented data on Louisiana's CYSHCN population emphasizing the contrasting care coordination needs between the Medicaid eligible and ineligible populations. The CSHS Program Manager introduced PRG and described in detail what would be asked of each stakeholder during the remaining part of the meeting. Beginning with the CSHS Program, each program manager read aloud their answers to the six questions sent prior to the meeting in order to ensure that all participants had the same universal knowledge of each program. Additionally, written answers to the questions for each program were provided to the CSHS Program Manager. The last hour of the meeting was dedicated to the PRG led focus group process. One staff member led and tape-recorded the discussion, while another took detailed notes.

The focus group was designed to capture the following information in order to develop a survey salient to programmatic operations:

- Assess the knowledge among program managers of the available services for CYSHCN and their families in Louisiana
- Assess the current collaboration that exists between agencies/program that provide direct services for CYSHCN and their families in Louisiana
- Identify the perceived barriers to collaboration between the agencies/programs that provide the direct services

Following the focus group, the CSHS Program Manager requested that the stakeholder managers provide PRG a list of their staff that provides direct services for CYSHCN and their families. The requested list included the name, email address, and agency/program for which the person works. To reduce response and information bias, program staff were told the list would not be provided to any CSHS staff member and was solely for disseminating an anonymous and confidential on-line survey.

Based on the information obtained from each program manager, the final agency stakeholder group included all programs listed above except staff members from the disabilities determinations services, and the child protection and investigation (CPI) programs. The former program did not provide direct services, and the latter did not specifically identify CYSHCN as a component of their investigation process. Based on conversations with the OCS stakeholder, it was decided that *Foster Care and Family Services* staff would be surveyed since staff members are more likely than CPI staff to collaborate with other agencies and make referrals. (CSHS is currently collaborating with other programs to adopt a special health care need screener as part of the CPI process).

The CSHS Director again contacted the Assistant Secretaries for each state department to reiterate the 2010 Needs Assessment and to relay the outcome and next steps that evolved from the focus group meeting. The final tally of programs surveyed was ten: five from DHH, four from DSS, and one from an NGO.

Based on the focus group discussion, PRG developed a rough draft framework for the survey, which aimed to measure three objectives:

1. The extent to which frontline staff members serving CYSHCN have knowledge of the range of services available and agencies and programs providing those services to CYSHCN and their families
2. The extent to which frontline staff members serving CYSHCN perceive that they collaborate with other agencies and programs
3. The extent to which frontline staff members' perceive barriers to collaboration between agencies and programs that serve CYSHCN

The initial draft went through rounds of revisions based on feedback from CSHS staff, stakeholder program managers, and pre-testers. The final version included 36 close-ended questions which took up to 35 minutes to complete if all branching questions were answered. Two CSHS staff members not involved in survey design were selected to conduct pre-testing. Minor modifications of question wording and answer options were made based on their feedback.

All staff identified by their program managers were sent an email invitation to conduct the on-line survey. Respondents were eligible to complete the survey if they provided direct services to children and/or youth including CYSHCN, and their families. The survey hyperlink was active beginning February 17, 2010 through April 2, 2010. This period was extended from the original one-month time frame in order to increase the response rate. Three reminder emails were sent to all staff that had not already completed the survey. After the second reminder email, the CSHS Program Manager contacted the respective stakeholder managers to ask that they encourage their staff to complete the survey. A more detailed description of the Agency Survey is found in Appendix F.

## **Methods for Assessing State Capacity**

Methods to determine the need for and provision of direct services for Louisiana's CYSHCN population came from data analyses from the 2005/6 NS-CSHCN, the 2007 NSCH, the FHF parent liaison activity database, and the Department of Education (DOE) Special Education Data Profile. The information from these disparate sources provided the framework to determine specific questions to include in each of the 2010 CSHS Needs Assessment surveys. The questions about direct care were focused on barriers to access, whether financial or geographic, knowledge of, satisfaction with, and use of services, and provision of transition services among YSHCN. These questions were asked from the perspectives of the direct consumer, the primary care provider, and the community-based support program staff.

Methods to determine the state's capacity for enabling services included analyses of FHF data for State Fiscal Years 2006 to 2008. The aggregate data provided information on activities done by FHF staff within their specific target regions, as well as statewide and nationally. The information gathered was assessed within the context of each organization's mission statement. Data were analyzed by region, year, referral type provided, health condition classification, age, race/ethnicity, patient and family needs, consumer outreach events, and the source (person, profession) that initiated the contact with the respective FHF organization. These analyses were compared to CSHS Program and national data to estimate the statewide impact of FHF concerning this tier of the pyramid. Areas where there were gaps in both need and provision of consumer outreach helped to formulate the specific survey questions that were included in each of the three 2010 Needs Assessment questionnaires.

Methods to determine the population-based services capacity were based on review of programmatic data for both CSHS subspecialty clinics and for clinics supported by CSHS contracts. CSHS subspecialty clinic information was also obtained through program surveys of CSHS staff. Clinics supported by CSHS contracts included a Metropolitan region diabetes clinic, the states' two certified cystic fibrosis clinics, Neonatal Intensive Care Unit (NICU) follow-up clinics, and Medical Homes supported by CSHS care coordinators. For these clinics, patient volume was considered an indicator of demand for services. Data from CSHS surveillance programs were also reviewed, including the state's newborn hearing screening program and Louisiana's Birth Defects Monitoring Network (LBDMN). Hearing, Speech, and Vision (HSV) program statistics also indicate areas of the state where audiologists who fit hearing aids are lacking, as well as need for audiology assessments. LBDMN data is of limited use because it is not yet statewide.

Methods to determine the infrastructure building capacity were based on data from the 2005-2006 NS-CSHCN, the 2007 NSCH, and DOE, Special Education Profile 2007. Data from the first source was used to identify the magnitude with which certain subgroups of the CYSHCN population were not meeting each of the six National Performance Measures. Each measure was stratified by race/ethnicity, household income, Medicaid eligibility status, sex, health condition, and type of special health care need. The 2007 NSCH was used to compare non-CYSHCN to CYSHCN based on service system need, use, and satisfaction, as well as family characteristics. Lastly, DOE data provided information on use of services and outcomes among those enrolled in special education. This information was stratified by race/ethnicity, disability classification, age, and sex. The information gathered from these sources provided the framework for specific questions included in each of the three questionnaires.

## **Data Sources**



As stated earlier, the initial information gathering step to identify themes and develop the conceptual framework for the CSHS 2010 Needs Assessment involved analyses of national, state, and local data sets that described the demographic, health, service use, and needs among Louisiana's CYSHCN population and their families. A brief description of each data source used and the analysis methodology are described below. The results for each data source, as well as for each of the three Needs Assessment surveys are shown in section 3.

**NS-CSHCN 2005-2006:**

NS-CSHCN provides both national and state specific prevalence estimates on the demographic and family characteristics, health status and function, service system use, and needs for the CYSHCN population and their families. Since it is a cross-sectional survey, the results cannot be interpreted as causal. The analysis involved first limiting the observations to Louisiana respondents, and then grouping CYSHCN according to private or publically insured status. CYSHCN and household characteristics were described for the respective groups. Chi-square and logistic regression were conducted to determine if differences between groups were significant for each characteristic. Causal relationships, as well as both information and response biases, are noteworthy limitations to recognize when interpreting results from these analyses.

**NSCH 2007:**

This cross-sectional survey provides national and state specific prevalence estimates of demographic and family characteristics, health (physical, emotional, behavioral) status indicators, and service system experiences for non-institutionalized children and youth (birth through 17 years old) in the United States. Analyses involved limiting responses to Louisiana, and grouping respondents according to two criteria: 1) publically insured; and, 2) Special Health Care Need status. Child/Youth and family (household) characteristics were compared for each group. Chi-square and logistic regression were used to determine if differences were significant. Similar limitations as the ones described for the NS-CSHCN are also applicable to the NSCH.

**FHF:**

Regional FHF offices provided aggregate data for State Fiscal Years 2006, 2007, and 2008 of both the regional office and CSHS parent liaison activities. The reports provide descriptive data on the interests and needs for regionally based families with CYSHCN, as well as local community, regional, and state outreach, education, information/referral, and support activities done by each regional FHF staff. Comparisons over the three years were made both within and between regions to assess if changes over time occurred, and where need/focus was most acute. There were limitations associated with these data. The data provided was aggregate and therefore the magnitude of interest and need by individual or by family could not be identified, nor could we account for multiple encounters by the same individuals/families. Data quality and reporting protocol varied and was dependent upon the regional FHF Directors' instruction.

**DOE:**

The Louisiana 2007 Special Education Data Profile provides regional/parish, personnel, and child/youth information for students with exceptionalities (gifted, disability) receiving education in the Louisiana public school system, with some information on those enrolled in private schools. Limitations for interpretation are associated with the inability to correlate individual characteristics with outcomes since the data were compiled as aggregate statistics.

**Linkages between Assessment, Capacity, and Priorities**

The results of the family, physician, and agency questionnaires were analyzed and stratified to examine gaps by race/ethnicity, age, and provider type. The additional data sources utilized in

framing the Needs Assessment were compared to survey findings. From this exercise, CSHS determined gaps, concordant perceived needs by different groups, estimated Medical Home capacity statewide, and knowledge of community-based resources among CYSHCN and families. In a meeting with stakeholders, CSHS collaboratively identified two priorities and outlined a five-year action plan. There are three tiers of action plans as they reflect the three-stakeholder group's capacity to address the identified needs.

### **Dissemination**

The Agency Survey results were shared during the agency stakeholder meeting that took place in April to collaboratively determine priority areas and to develop the 5-year action plan to address gaps in coordination of care between programs that provide direct services for Louisiana's CYSHCN and their families. FHF and F2FHICs were represented in that group. The results for all but the Agency Survey were presented to the entire MCH and CSHS Program leaders during a strategic priority-planning meeting also in April. The results of the Physician Survey will be published in the newsletters of the Louisiana chapters of the AAP and the LAFP. Results of the Family Survey will be submitted to the editor of the Family Matters quarterly publication and published in the summer edition. Results will also be disseminated to the CSHS parent liaisons. Furthermore, a manuscript based on the survey results will be submitted to a peer reviewed journal.

### **Strengths and Weaknesses of the Process**

#### *Family Survey*

The survey was designed with input from the CSHS parent liaisons. Hence, parent perspectives helped to guide the formulation of questions and content. The questions were composed based on areas of interest and need as reflected in published literature and national data sets. The survey was disseminated through regional FHF offices and CSHS subspecialty clinics by parent liaisons, and to subscribers of the Family Matters quarterly publication, both by mail and on the CSHS website. This dissemination method may decrease the chance for response and information biases since a fellow parent may be more likely to respond to a survey given by a peer, and to answer questions about service knowledge, use, and need more honestly, if the interviewer was not a direct care provider.

A convenience sample of Louisiana families with CYSHCN provided responses. This poses a threat to the external validity of the findings since answers may only be reflective of families who are aware of and actively seek out their regional FHF office. If this is indeed the case, then the findings, which indicated a varied knowledge of community resources, reinforce the need to have stronger collaborations on information dissemination and clarification by CSHS and FHF. Relying on a convenience sample was the only logistically and economically viable option for surveying this population given that there is no well-established roster, which specifically identifies Louisiana families with CYSHCN. There may also be a threat to the internal validity since the manner in which respondents completed the survey may be different according to the FHF office staff that both disseminated and assisted clients with survey completion.

#### *Physician Survey*

The Physician Survey questions were designed to operationalize the AAP Medical Home concepts. The AAP Medical Home policy statement is considered the gold standard for defining pediatric Medical Home services, and as such served as an established framework to determine

question design, content, and validity. Formulated questions were compared to other surveys, critiqued by both the AAP and LAFP president chapters, and evaluated through a standardized methodology. This process helped to ensure a strong content validity. Access to a complete list of AAP and LAFP physicians enabled CSHS to determine the population size and design an appropriate sampling methodology. The screening questions and skip processes within the survey ensured that the survey answers reflected the true population of physicians to which CSHS would then design an intervention with features salient to the target needs. The skip pattern enabled CSHS to acquire additional information for overall physician pool regardless of survey eligibility. Initial collaboration with each physician chapter may have enhanced respondent compliance, since each chapter president promoted the survey.

However, despite the many strengths there are a few noteworthy limitations. The final response rate was disappointingly low (17.4%). Hence, the external validity of the survey results is low. Furthermore, since not all physicians listed on the roster met survey eligibility criteria, a true response rate could not be calculated since there is no manner in which to filter the original contact list. Therefore, the final response rate is an estimate. Not all criteria of the AAP Medical Home guidelines could be operationalized. Thus, the survey results do not quantify the Medical Home capacity itself, but rather reflects the provision of Medical Home services. Although the AAP Medical Home policy statement serves as a gold standard for Medical Home criteria, there exists no such standard for Medical Home questionnaires. Because of this, the survey questions formulated for this survey could not be compared to determine the degree of validity of answers.

### *Agency Survey*

The Agency Survey was collaboratively developed by CSHS stakeholders who serve CYSHCN through various service delivery systems. The stakeholders represented both governmental and community agencies. This broad perspective assured a comprehensive assessment of knowledge, barriers and collaboration among agencies. Survey questions were developed using comments from the focus group discussion during the first meeting of the stakeholders. This facilitated buy-in and ensured that language and terminology could be easily understood by program staff. Lastly, the collaborative review of the survey results and subsequent identification of need and plan to address gaps helps to reduce risk for type III error i.e. program failure despite patent and salient program development.

The response rate, 28.5%, was on par with what is typically seen for online surveys i.e., 20-30%. Despite the concerted effort to increase participation, wide variation existed between programs. Some groups were disproportionately represented in comparison to others. This weakness was addressed in presentation of the data by separating responses according to respondent's program.

## **2. Partnership Building and Collaboration Efforts**

CSHS utilized its 2010 Needs Assessment as a unique opportunity to build and enhance partnerships with state programs at both the inter- and intra-departmental levels. Additionally, the stakeholder coalition involved two statewide non-governmental organizations that provide services to CYSHCN and families that interact with both the public and private sector service systems. The focus of the 2010 Needs Assessment has prompted CSHS to seek new partnerships with DSS programs, F2FHICs, and Louisiana Federally Qualified Health Centers. The Needs Assessment results highlighted the need to enhance existing partnerships with the LAFP, AAP, Louisiana School-Based Health Centers, FHF, and the Louisiana Office of Public Health. The contributions to the Needs Assessment process of both new and existing partners were necessary to identify and develop the action plan to address the priority needs of CYSHCN who both

interact with multiple public sector service systems, as well as those who seek only limited program services.

#### Provider Collaboration

CSHS partnered with the Louisiana AAP and LAFP to assess the state Medical Home capacity. The CSHS Director engaged in collaborative discussions with the chapter presidents, who engaged board members for both chapters. An informal presentation of the CSHS program, Title V program, the 2010 Needs Assessment, and statistics on the Louisiana CYSHCN population and their families was presented at each meeting. Stakeholder collaboration necessary for survey development and dissemination of results in the AAP and LAFP chapter newsletters was also established. A 2009 roster of current member names and contact information (phone number, email, address) was provided to PRG. Prior to disseminating the survey, each chapter announced either through a meeting or in their respective newsletters that a link to the online survey would be sent within the next few weeks. The survey additionally served as a means by which CSHS was able to identify specific primary care providers who were eligible and interested in receiving technical assistance with care coordination.

#### Family Collaboration

CSHS partnered with families and parent stakeholders to gather important information from the family perspective on community-based service systems. A brief survey was used to ascertain the content areas of access to services, knowledge, use, and satisfaction with services, and transition benchmark measures. The CSHS Statewide Parent Liaison Consultant and Statewide Parent Training Coordinator reviewed the survey for clarity and content prior to disseminating to the public. To garner collaboration with disseminating and promoting the survey, both the CSHS Statewide Parent Liaison Consultant and Statewide Parent Training Coordinator contacted each FHF regional office and briefly explained the CSHS 2010 Needs Assessment process and the Family Survey. The survey was published in Family Matters, a quarterly statewide newsletter distributed to CYSHCN and families through FHF offices, outreach events, CSHS regional clinics, and the CSHS website. The survey was also posted in the Current Highlights section of the CSHS website. CSHS parent liaisons assisted families with completing the surveys and mailing them to the CSHS Central Office, if requested.

#### Agency Collaboration

CSHS partnered with state agencies and non-governmental organizations to assess knowledge of, barriers to, and collaboration among front line staff that provide direct services to CYSHCN and their families. CSHS chose ten programs as stakeholders in the provision of services to CYSHCN (CSHS, HSV, Early Steps, Supports and Services, Greater New Orleans Resource Centers on Developmental Disabilities, Vocational Rehabilitation, Independent Living, Foster Care, Family Services, and FHF).

Eight of the ten stakeholder agencies were represented by their program managers during a focus group meeting on October 30, 2009. The focus group discussion provided insight on topics of interest and informed questions and response options for the development of the online survey that would be administered to stakeholder front line staff. Stakeholder program managers provided a list of 873 email addresses to PRG. Each Assistant Secretary and stakeholder program manager reviewed the survey before implementation.

On April 23, 2010, stakeholder program managers were invited to a follow-up meeting where PRG presented the survey results. Using the program planning process, the group determined that increased knowledge of each other's programs was needed among staff at the regional level. The group collaboratively identified the specific knowledge dissemination activities that were currently in place in order to determine how the existing infrastructure could be enhanced. Activities that would increase understanding of and referral to each other's programs were identified, and resources to implement the new activities were sought and allocated, thereby creating a collaborative stakeholder plan.

### Ongoing Collaboration

In addition to the newly formed stakeholder group, CSHS has maintained a long-standing partnership with many local and statewide public and private agencies and organizations to address the medical and community resource needs of Louisiana's CYSHCN. CSHS partners with Children's Hospital through its model program for specialized care of children with diabetes. CSHS assures a multi-disciplinary team of a pediatric diabetologist, pediatric diabetes nurse educator, pediatric nutritionist, pediatric psychologist, exercise trainer and visiting pediatric diabetes liaison nurse. The goal of the program is to reduce emergency room visits, improve growth and development of children, as well as decrease the average blood glucose level of the enrolled children. CSHS partners with Tulane University Hospital for Children to provide pediatric subspecialty medical treatment for CSHS eligible children who have or who are suspected of having Cystic Fibrosis. This program involves both inpatient and outpatient care. CSHS partners with LSUHSC at Earl K. Long Medical Center in Baton Rouge as well as LSUHSC Shreveport to provide in-hospital and discharge planning for infants who receive Neonatal Intensive Care following birth, as well as follow-up in High Risk Clinics after discharge. CSHS partners with Southeast Louisiana Area Health Education Center for a Statewide Parent Consultant who coordinates all aspects of family support and input into the CSHS program. CSHS partners with statewide FHF members to provide parent liaisons in each of its nine regional subspecialty clinics to link families with community resources. CSHS provides subspecialty care for CYSHCN and their families in its regional clinics through partnerships with LSUHSC, Tulane University Medical Center, Ochsner Hospital and Children's Hospital. CSHS regional subspecialty clinic staff collaborate with local agencies, including schools, hospitals, FHF, parent support groups, Office of Mental Health, Office for Citizens with Developmental Disabilities, and private sub-specialists. CSHS clinic staff collaborate with primary care physicians to ensure that subspecialty care is coordinated with the Medical Home. In partnership with both LSU and Tulane Schools of Medicine, CSHS ensures that all pediatric residents trained in Louisiana understand the Medical Home model of care for CYSHCN and are familiar with public health and community resources, to that their future practices provide comprehensive, family-centered, and coordinated care. Recently CSHS has expanded this partnership to the LSU Family Practice residency program as well.

CSHS consistently advocates for CYSHCN through representation on statewide councils and boards. The CSHS Director participates in the State Planning Council for Developmental Disabilities in Louisiana. Other members of this council include the Advocacy Center, LSUHSC Center for Excellence in Developmental Disabilities, self advocates, parents, State DOE, Office of Mental Health, Office for Citizens with Developmental Disabilities, Louisiana Rehabilitation Services, Governor's Office on Disability Affairs, Governor's Office on Elderly Affairs, and others. This ongoing collaboration addresses issues related to all aspects of life for persons with disabilities. The CSHS Director and the Statewide Care Coordinator Supervisor are members of the Advisory Board of the Louisiana Healthcare Quality Forum (LHCQF) Medical Home

Committee. The LHCQF has been legislatively mandated to implement the Medical Home in Louisiana.

CSHS provides a continuum of services beginning at birth with birth defects surveillance and screening for disabilities. CSHS is implementing the Louisiana Birth Defects Monitoring Network (LBDMN). The LBDMN Advisory Board consists of nine members including representatives from the Louisiana State Medical Society, Ochsner Foundation Medical Center, Tulane University Medical Center, LSUHSC, March of Dimes, MCH Coalition, OPH, a parent representative, and a consumer representative. LBDMN partners with Lake Charles Memorial Hospital and Louisiana Public Health Institute for surveillance staff and Spina Bifida Association of Greater New Orleans for its advisory board. LBDMN works closely with MCH for systems development.

The HSV Program within CSHS works closely with all birthing hospitals in the state to ensure hearing screening for all newborns. CSHS also collaborates with private audiologists and the medical community for follow-up evaluations as well as to provide needed services for families who lack insurance or have no access to local community services. The State Advisory Council for Newborn Hearing Screening is appointed by the Governor, and includes 14 stakeholders who advise the state's Early Hearing Detection and Intervention (EHDI) program. EHDI works with Louisiana chapters of the Association of the Deaf, Commission for the Deaf, Hospital Association, AAP, LAFP, Speech/Language Hearing Association, American Speech/Language Hearing Association, American Academy of Audiology, Speech Language Pathologists and Audiologists in Louisiana Schools, and Board of Examiners for Speech Language Pathology and Audiology. EHDI partners with Southeast Louisiana Area Health Education Center for its nine statewide regional taskforce leaders and a statewide parent consultant.

### **3. Strengths and Needs of the Maternal and Child Health Population Groups and Desired Outcomes**

#### ***Overall Population of CYSHCN in Louisiana***

Depending on the survey (NSCH or NS-CSHCN), the proportion of children (birth-17 years old) in Louisiana who have a special health care need ranges from 14.8% to 23.6%, which corresponds with either a little more than 162,000 or almost 255,000 children who met the special health care need criteria. The largest reported proportion of CYSHCN in Louisiana is 6-11 year olds, which is significantly higher than the same survey's national average (19.2%,  $p < .05$ ). According to both data sources, this is followed closely by 12-17 year olds. More males meet special health care need status than females, although the roughly five-point difference is not significant. The distribution of special health care need status varies by race and ethnicity group. A greater proportion of Non-Hispanic Multiple Race children are CYSHCN (23.7-25.2%), followed by Non-Hispanic White (15.7-24.0%). Roughly, 13% to 24% of Non-Hispanic Black children have a special health care need, and among Hispanic children, about 14% to 19% are CYSHCN. Among the Hispanic children, the majority report English as the household's primary language. Stratifying by household income, the proportion of households with CYSHCN does not drastically change, although it is higher among lower income families. About 13-25% of each income grade has a CYSHCN in the household.

#### ***Health Insurance Issues***

Almost 66% of families with CYSHCN were found to have adequate private and/or public insurance to pay for the services they needed, as reported at the time of the NS-CSHCN (National

Performance Measure #3). However, it was also found that 5.1% were not insured, 8.3% had experienced a disruption in insurance coverage at some point in the 12 months prior to the survey, and among those insured 28.2% said the coverage was inadequate. Among the Physician Survey respondents, 89.3% stated that they accept most forms of health insurance. Furthermore, a large proportion relayed that they were a Louisiana Medicaid Provider (92.9%). Although this estimate may not represent all primary care providers in the state, it may indicate that Medicaid providers are more likely to respond to public health surveys, and thus represents an opportunity for stronger collaborations between public health programs and Medicaid providers. This may be advantageous for the CYSHCN population considering approximately 45% are publically insured, a considerably much higher rate than the national average (28.6%,  $p<.05$ ).

Insurance is associated with many factors among Louisiana families with CYSHCN. Compared to the insured, the uninsured had more than two times the prevalence rate for reporting four or more functional difficulties. Overall, Louisiana's CYSHCN population is on par with the national average for continuous health insurance coverage (91.7% vs. 91.2%). Although the prevalence rate for being insured during an entire year improves as the household income increases, the differences between grades is not significant. Based on the Physician Survey results, approximately 70.5% of respondents stated they discussed the need for and helped with the acquisition of Louisiana Medicaid/LaCHIP. However, other sources for covering health services expenses, such as Supplemental Security Income (SSI), or SSI-Disability, and Title V programs, were not as frequently discussed (31.3%, and 36.6% respectively).

Compared to the national average, more of Louisiana's CYSHCN have health insurance that adequately meets their needs (66.9% vs. 71.8%). However, insurance adequacy is not uniformly experienced. CYSHCN with functional limitations have a significantly lower prevalence rate for adequacy compared to those whose condition is managed by prescription medication (56.2% vs. 79.8%,  $p<.05$ ). Adequacy is also related to whether the child/youth has one or more emotional, behavioral, or development issue(s), where higher rates for inadequate insurance exists for this group compared to those without the issue(s) (39.3% vs. 24.5%,  $p<.05$ ).

Results from the Family Survey indicated that the top four priority needs were providers (pediatricians, subspecialists, dentists, occupational/physical therapists) that both accepted Medicaid and CYSHCN. With a few exceptions, these needs were among the top five across all the different strata (age, race, region of residence). Among respondents from the Physician Survey, a concordance of family priority needs as perceived by physicians further emphasizes the universal need to expand the repertoire of Louisiana providers who accept both Medicaid and CYSHCN.

When questioned about difficulties associated with access to subspecialists, overall approximately one-fifth relayed that the subspecialist did not accept their type of health insurance.

### Morbidity

As might be expected, more parents with CYSHCN had one or more concern about their child/youth's physical, behavioral, or social development compared to parents of non-CYSHCN (71.0% vs. 41.1%,  $p<.05$ ). It is noteworthy to consider that two-fifths of parents with non-CYSHCN had concerns. However, this rate might seem appropriate considering that the percent at risk for developmental or behavioral problems is 35.2%, compared with only 26.4% for the US.

The distribution of functional difficulties in Louisiana's CYSHCN population is similar to that of the national average. However, almost one-quarter of Louisiana's CYSHCN population relayed that their health condition(s) consistently and often affect their daily activities. This is an interesting statistic given that results from the NSCH 2007 found more CYSHCN in Louisiana exercised everyday compared to non-CYSHCN (43.6% vs. 30.7%,  $p<.05$ ). The type of special health care need varies by multiple factors. Compared to White Non-Hispanic CYSHCN, Black non-Hispanic CYSHCN have half the prevalence rate for experiencing no functional difficulties (19.5% vs. 8.4%,  $p<.05$ ). Hence, a larger proportion of Black Non-Hispanic CYSHCN reported at least one functional difficulty. CYSHCN living at or below 99% FPL, and those living between 100-199% FPL reported more than twice the prevalence rate for more than four functional difficulties compared to CYSHCN living between 200-399% FPL, and those living at or above 400% FPL. These prevalence differences are statistically significant (38.6%, and 38.2% vs. 15.5%, and 16.4%,  $p<.05$ ).

Another significant difference by household income occurs between CYSHCN with and without an emotional, developmental, or behavioral issue(s). CYSHCN living at or below 99% FPL have a significantly greater prevalence rate for an emotional, developmental, or behavioral issue(s) compared to CYSHCN living between 200-399% FPL, and those living at or above 400% FPL. These differences are statistically significant (35.9% vs. 20.4%, and 19.0%,  $p<.05$ ). Another disparity exists for the same health condition, where significantly more Black Non-Hispanic CYSHCN reported the issue(s) than White Non-Hispanic CYSHCN (36.4% vs. 23.2%,  $p<.05$ ). Another significant trend is that as the child/youth ages, the prevalence rate for this health condition increases (0-5: 14.7%, 6-11: 28.9%, 12-17: 34.05,  $p<.05$ ).

Ease of service system use is related to whether the child/youth had one or more emotional, behavioral, or developmental issue. Louisiana's CYSHCN with this condition relayed about a threefold higher rate for experiencing the service systems as not organized, compared to those without the condition (21.1% vs. 7.1%,  $p<.05$ ). CYSHCN with one or more emotional, behavioral, or developmental issue(s) have about a 50% higher prevalence rate for need of provider communication with the child/youth's school and/or other programs (56.1% vs. 16.6%,  $p<.05$ ). Although the estimates for dissatisfaction do not meet standards for reliability or precision among those without the issue, and therefore the estimates could not be compared, there were higher prevalence rates for dissatisfaction among those with the condition.

Reviewing the state of health for Louisiana's CYSHCN population by specific condition, the data indicates a rather heterogeneous group. Allergies of any type was the most prevalent condition reported (54.5%). The condition is equally distributed by age, sex, and insurance type. Approximately 45% of CYSHCN with allergies receive SSI. Two or more co-occurring health conditions were most frequently reported, as well as either one, or four or more functional difficulties.

The second most frequently occurring condition was attention deficit disorder or attention deficit hyperactivity disorder (ADD/ADHD), where 40.5% of CYSHCN were reported to have this. The prevalence rate increases with age, where only 10.4% of CYSHCN 5 years and younger have been diagnosed with ADD/ADHD. Compare this to 46.4% of 6-11 year old, and 52.8% of 12-17 year old CYSHCN are diagnosed. About 12% more males report the condition than females (45.9% vs. 32.2%). The condition is lower among the privately insured (33.9%) than either the public only (45.7%) or those with both public and private (51.4%). About 36% of uninsured CYSHCN have ADD/ADHD. More than half of kids with this condition receive SSI (53.5%). This condition is associated with a number of co-morbidities, and with reporting four or more functional difficulties.



About 36% of CYSHCN have asthma. It is most frequent with younger children (0-5 years), higher among the publically, and both public and privately insured. Forty-three percent of asthmatic CYSHCN receive SSI. It is most associated with two other health conditions, and reporting one functional difficulty.

A little more than one-fifth or 33,108 CYSHCN reported depression, anxiety, an eating disorder, or other emotional problem. It is more common among older children/youth, females, and the uninsured. More than one-third receives SSI for their condition. Additionally, more report four or more co-occurring health conditions and four or more functional difficulties.

A similar proportion of CYSHCN reported migraine or frequent headaches (20.8%). Frequency increased with age, was 3% higher among females, and highest with the uninsured. Approximately one-quarter receives SSI for this condition. This condition is frequently associated with three or more health conditions, and four or more functional difficulties.

The last condition studied, and subsequently with the lowest prevalence rate, was mental retardation or developmental delay where a little more than 17,000 or 10.9% of Louisiana's CYSHCN population have this condition. The frequency varied by age, whereas it was equally distributed by sex. More publically insured and uninsured children/youth have the condition. Almost 50% are SSI recipients. Similar to the last condition, mental retardation or developmental delay is associated with four or more other health conditions, and four or more functional difficulties.

### Service Need

Approximately one-fifth of Louisiana's CYSHCN population reported the need for physical, occupational, or speech therapy in the 12 months prior to the NS-CSHCN. Louisiana's CYSHCN population fared better compared to the national average on the need for 2 or more unmet needs for health care services or equipment in the past 12 months (3.3% vs. 6.0%,  $p < .05$ ).

Compared to the national average, Louisiana's CYSHCN had a significantly higher proportion who needed other medical equipment (wheelchair, hospital bed, oxygen tank and pressure machine) during the 12 months prior to the survey (11.4% vs. 15.7%,  $p < .05$ ). CYSHCN between birth and 5 years had twice the prevalence rate for other medical equipment need compared to CYSHCN 6 to 11 years, and YSHCN 12 to 17 years (27.4% vs. 11.5% and 12.6%,  $p < .05$ ). Again looking at the same indicator, there is a two-fold gap for need between Black Non-Hispanic CYSHCN and their White Non-Hispanic counterparts (23.3% vs. 11.2% ,  $p < .05$ ). This need is also associated with type of health insurance coverage. A little more than one-fifth of Louisiana's publically insured CYSHCN cited a need for other medical equipment; a significant difference in proportions compared to those covered by a private insurer (22.6% vs. 9.8%,  $p < .05$ ).

Although the differences are not significant, there is almost a 27% gap in the prevalence rate for need of mental health services between CYSHCN and non-CYSHCN, where more of the latter group received the needed services (40.3% vs. 67.0%,  $p < .05$ ). Collectively, approximately 42,000 of Louisiana's children and youth did not receive the mental healthcare and/or counseling they needed.

Although it is not statistically significant, Louisiana's CYSHCN population experienced almost twice the prevalence rate for experiencing problems obtaining needed referrals compared to Louisiana's non-CYSHCN group (34.9% vs. 19.1%,  $p > .05$ ).

Service needs reported among the Family Survey respondents centered on providers who both accept Medicaid and CYSHCN. Twenty-four percent of respondents cited they could not see the needed subspecialist because the provider was not available in their geographic area. Although the sample sizes pose a risk for estimate precision, the proportions did vary by race, and region of residence. These results, when interpreted in the context of other data, indicates that provider shortages, and location of providers within the state continue to impede consumers from obtaining needed services. Indeed, from the perspective of the primary care providers, the Physician Survey respondents identified specific types of subspecialists to which they have difficulties accessing in order to provide their patients the needed referral. The subspecialties where more than 50% of the respondents relayed difficulties were psychiatry, developmental/behavioral pediatrician, neurology, orthopedic, and dermatology (75.0%, 67.4%, 63.0%, and 53.3% respectively). Although sample size artificially inflates the estimate, when stratified by the region the physician works, the proportions reporting difficulties vary (Appendix F, II).

### Home/Environment/Community

Exposure to tobacco has approximately equal prevalence rates for both non-CYSHCN and CYSHCN (32.0% and 38.2%). According to the 2007 NSCH, 19.4% of children in Louisiana live in neighborhoods with poorly kept or dilapidated housing (14.6% nationally), and only 82.6% live in neighborhoods deemed safe, compared with 86.1% US. Among the Physician Survey respondents, approximately 78% cited their practice was accessible by public transportation.

Comparing the National Performance Measures (NPMs) by metropolitan statistical area, defined as urban, suburban, large town, and small town/rural, the data indicates significant differences in proportions met. Overall 62.2% of families reported that they felt like partners in decision-making at all levels and were satisfied with services that they received (NPM #1). For suburban CYSHCN, 75.9% met this measure, which was significantly higher than urban CYSHCN (58.4%), and those living in large towns (51.9%). Rural residence was not any different (71.1%). Coordinated care in a Medical Home (NPM #2) was obtained by 49.6% of Louisiana's CYSHCN. Although both suburban and rural CYSHCN had higher rates (57.9% and 59.6%), neither was different from the other, as well as the other two groups (urban: 49.6%; large town: 48.2%). More than 65% reported adequate insurance coverage (NPM #3). Urban CYSHCN had the lowest rate (58.1%), but was not statistically different from the other three groups (Suburban: 72.7%; Large town: 74.2%; Rural: 74.0%). Early and continuous screening (NPM #4) was met by 54.3% of CYSHCN. Rates varied but were not significant. It was highest among suburban CYSHCN (60.4%), followed by rural respondents (58.5%), urban (55.7%), and lastly large town CYSHCN (40.7%). Both rural and suburban CYSHCN had the highest rates for reporting that services are organized in ways that make it easy for families to use (NPM #5) (94.1%, and 93.2% respectively). These rates are higher than the state average (89.3%). More than 90% of large town CYSHCN met this measure, and so did 86.5% of urban CYSHCN. Lastly, among youth with special health care needs (YSHCN), 40.9% received the transition services necessary to make the appropriate transitions to adult healthcare, work, and independence (NPM #6). This rate was highest for rural (58.5%), followed by suburban (48.6%), urban (36.5%), and large town youth (36.4%). None of the rates for each residence category was statistically different. In summary, percent CYSHCN meeting the NPM was lower in urban areas and large towns than suburban and rural areas for all five NPM's, although not all differences were statistically significant.

Almost one-quarter of Louisiana's CYSHCN reported that their condition(s) affected their daily activities usually, always, or a great deal. This rate does not significantly change based on region of residence. A higher prevalence of Louisiana's CYSHCN missed 11 or more school days due to illness than the national average (18.8% vs. 14.3%). The prevalence was lowest among urban CYSHCN (16.6%), then large town (19.0%). Suburban and rural CYSHCN had approximately equal rates (22.6% and 22.5%).

Both rural and urban CYSHCN had approximately one-tenth report to have been without insurance in the 12 months prior to the survey (10.9% and 10.1%). These rates were slightly higher for the whole state (8.3%), which is a reflection of the relatively lower rates for suburban (5.5%), and large town CYSHCN (2.8%). Subsequently, these same locations had the lowest rates for CYSHCN without insurance at the time of the survey (suburban: 2.2%, large town: 0.0%). Conversely, urban CYSHCN had the highest rate (8.8%), followed by rural CYSHCN (5.1%), where the latter's rate is also the state average. Urban CYSHCN had almost twice the rate of CYSHCN who reported their health insurance was inadequate than rural CYSHCN (34.4% vs. 17.2%,  $p < .05$ ). Both suburban and large town CYSHCN had rates comparable to the state average (22.4%, 23.0%, and 28.2%).

More than one-tenth of CYSHCN reported an unmet need for specific health care services (12.2%). This rate was almost double for rural CYSHCN (22.0%), on par with the average for suburban and large town CYSHCN (12.8% and 12.2%), and slightly lower for urban (9.8%). Unmet need for family support was low, both nationally and in Louisiana (4.9% and 4.0%). This did not vary significantly by state residence location. Experiencing difficulties getting a needed referral was almost 6% lower among Louisiana's CYSHCN compared to the national average (15.8% vs. 21.1%). Slight variations by residence location occurred, but these were not significant (urban: 19.1%, suburban: 11.5%, large town: 9.0%, and rural: 14.7%). There were significant differences in prevalence rates between urban and both suburban and rural CYSHCN for reporting there was no usual source of care when sick (or that they relied on the emergency room) (12.4% vs. 1.7%,  $p < .05$ ). The same outcome was reported by 10.5% of large town CYSHCN. For the entire state, 8.8% of CYSHCN do not have a usual source of care when sick. Rural and urban CYSHCN have higher rate than suburban and large town CYSHCN (8.3% and 7.1% vs. 4.4% and 4.0%; state average: 6.1%).

#### Financial/Family Burden

Compared to White Non-Hispanic families with CYSHCN, a higher prevalence of Black Non-Hispanic families with CYSHCN paid less than \$250 in out-of-pocket medical expenses per year for their child/youth (34.5% vs. 73.6%,  $p < .05$ ). Among the other race/ethnicity groups there were no other significant differences, although each group had a higher prevalence rate for paying less per year than White Non-Hispanic families (Hispanic: 57.1%; Non-Hispanic Multi-racial: 51.1%; Non-Hispanic Other: 61.2%).

For the same measure, there are significant differences by family structure. Fewer two-parent (biological/adoptive) families with CYSHCN than single mother households paid less than \$250 in out-of-pocket medical expenses (36.0% vs. 61.8%,  $p < .05$ ). Two-parent stepfamilies and other family structures were not different from the other two groups (50.5%, and 56.5% respectively).

Since public health insurance programs are income contingent, and these programs do not require enrollees to pay significant out-of-pocket medical expenses, it is not surprising to find that the group with the highest prevalence rate for the lowest out-of-pocket expenses were households living at or below 99% FPL (80.4%). This rate was significantly different from all other income

grades (100-199% FPL: 58.4%; 200-399% FPL: 27.8%; 400%+ FPL: 23.4%). The last two income grades were also significantly different from the second lowest income grade ( $p < .05$ ). As then might be expected, among the publically insured, approximately 79% paid less than \$250 in out-of-pocket medical expenses per year. This was not significantly different from CYSHCN covered by both public and private plans (69.8%), but was significantly different from those privately insured (19.6%,  $p < .05$ ).

Adequacy of insurance is a reflection of the magnitude for out-of-pocket expenses, and access to necessary providers. Among those whose insurance was inadequate, equal proportions paid less than \$250, and more than \$1,000 per year (38.5%, and 32.7% respectively). This lack of difference is then an indication that despite low out-of-pocket medical expenses, there remains a large number of insured CYSHCN in Louisiana, (approximately 16,000) who are experiencing difficulties accessing the needed providers and services. Among CYSHCN with adequate insurance, a larger share paid less than \$250 (55.4%), which is significantly different from those without adequate insurance. Additionally, significantly fewer pay more than \$1,000 than the inadequate insurance group (13.9% vs. 32.7%,  $p < .05$ ).

Louisiana has approximately the same prevalence rate as the national average for financial burden placed upon families to care for their child/youth's health condition (19.8% vs. 18.1%). Among Louisiana families, there was equally low distribution for rates of financial burden across all household income grades (0-99% FPL: 20.9%; 100-199% FPL: 20.3%; 200-399% FPL: 22.2%; and, 400%+: 13.1%). As would be expected, a higher proportion of uninsured CYSHCNs families' responded that the child/youth's health condition caused financial burden compared to those insured (54.5% vs. 17.9%,  $p < .05$ ). Similarly, comparing those with continuous coverage to those with disrupted coverage, the impact on finances was significant, where the insured have almost one-third the rate (17.3% vs. 47.8%,  $p < .05$ ). This supports the need to continue to provide families with information and referral about health insurance options, as well as to reinforce the importance of maintaining continuous coverage. Indeed, comparing financial burden prevalence rates by type of health insurance coverage, the data shows no significant differences (Private: 16.9%, Public: 17.9%, Both Private & Public: 22.2%). Likewise, financial burden is related to insurance adequacy, where a lower proportion of CYSHCN with adequate insurance reported having financial burden (14.5% vs. 26.7%,  $p \leq .05$ ).

Comparing financial burden rates by the type of special health care need, CYSHCN with functional limitation(s) had the highest rate (39.5%) which is significantly higher than CYSHCN whose condition is managed by prescription medication (7.5%). This latter group is also significantly different from CYSHCN who have above routine need and use of services (23.9%), and CYSHCN who have both above routine need and use of services and require prescription medication(s) (23.4%).

Lastly, financial burden is associated with presence of one or more emotional, behavioral, or developmental issue(s), where this group of CYSHCN have twice the rate than those without (32.4% vs. 15.4%,  $p < .05$ ). Children between birth and 5 years old who had a visit with a health professional sometime in the 12 months prior to the survey, had a relatively large number of respondents state that they were not asked about any concerns they had regarding their child's learning, development, or behavior. This rate was equally low for both CYSHCN and non-CYSHCN alike (41.6% vs. 58.8%,  $p > .05$ ). Conversely, the percent of Louisiana children screened is higher than the national average (28.7% vs. 19.5%). This rate is most likely due to the requirement of developmental screenings for Medicaid Community Care (Kidmed) reimbursement.

Since children grow and develop in the context of the family environment, the health and emotional well-being of their parents/guardians is an important indicator for many child outcome measures. Among CYSHCN, the need for mental healthcare and/or counseling among family members is disproportionately experienced. As might be expected, a higher prevalence of family members of CYSHCN without an emotional, behavioral, or developmental issue(s) did not have any need for mental healthcare counseling than those family members with CYSHCN who had the issue(s) (96.7% vs. 73.1%,  $p<.05$ ).

### Oral Health

Having a special health care need places one at an increased risk for oral health problems. Indeed, compared to non-CYSHCN, a lower prevalence of CYSHCN reported their teeth were in excellent or very good condition (71.4% vs. 63.5%,  $p>.05$ ); however, the difference was not significant. On the other hand, when the frequency for oral health care problems is compared between the two groups there are significant differences. More CYSHCN experienced two or more problems in the 6 months prior to the survey than non-CYSHCN (16.1% vs. 7.8%,  $p<.05$ ).

Despite the increased rate for problems, about one-fifth to one-quarter of Louisiana's child/youth population did not see a dentist for preventive dental care in the 12 months prior to the survey (non-CYSHCN: 24.6%, CYSHCN: 20.2%). Although, 97.3% of CYSHCN who cited a need, reported that they received the needed preventive dental care. Subsequently, about 3.4% or a little more than 4,000 CYSHCN did not receive all the needed care. Perhaps efforts to facilitate access to and receipt of comprehensive care (about 3,500 CYSHCN did not receive all needed services) can help to improve the oral health care indicator even more.

### Medical Home

Physician Survey results revealed that components of the Medical Home are not uniformly provided. Among the respondents, only 39.3% reported they provided their patients with a written plan of care that addresses the patients' and families' needs and improves collaboration of care among other providers, agencies, and organizations. As would be expected, only 49.1% reported that their patients' plans of care involve coordination with the patients' schools so that their special health care needs are addressed. Despite this low care plan rate, almost all respondents relayed that when they referred a patient for specialty care, they or their staff shared information with the family and sub-specialist that provided the specific reason for the referral (95.5%), and helped to assist the family with communicating clinical information to the sub-specialist (92.0%). As anticipated, most reported (93.5%) that they discuss results and recommendations from the sub-specialist visit with the child/youth and family, and integrate the recommendations in the child/youth's plan of care.

Equal proportions of CYSHCN and non-CYSHCN met the AAP definition of receiving care within a Medical Home (51.3% vs. 56.6%,  $p>.05$ ). Since the Medical Home is a model of primary care for all children, and to which certain components address the unique need for CYSHCN, it is not surprising that both groups have roughly the same rates. However, the overall low rates illuminate an area where healthcare capacity in Louisiana can be improved. The Medical Home is significantly related to use, need, and satisfaction for healthcare services. For example, compared to CYSHCN with a Medical Home, those without a Medical Home had more than three times the prevalence rate for experiencing the service system as not organized in a way that families could easily use (4.5% vs. 16.5%,  $p<.05$ ). Fewer CYSHCN relayed the need for other medical equipment (wheelchair, hospital bed, oxygen tank and pressure machine) if they had a Medical Home compared to those without a Medical Home, although the difference was not

significant (14.0% vs. 17.1%,  $p > .05$ ). Comparing Louisiana's CYSHCN by presence of a Medical Home, the data shows that those without one had a greater need for referrals (38.8% vs. 22.6%,  $p < .05$ ), and also experienced problems obtaining referrals (10.1% vs. 0.0%,  $p < .05$ ). CYSHCN with an emotional, behavioral, or developmental issue had a lower prevalence rate for receiving Medical Home services compared to those without the condition (33.6% vs. 55.2%,  $p < .05$ ).

The type of special health care need was also associated with Medical Home receipt. The lowest rate was among CYSHCN with functional limitation(s) (37.3%), which was significantly lower compared to CYSHCN whose health condition is managed by prescription medication (60.4%,  $p < .05$ ). CYSHCN that take prescription medication and also have an above routine need and use for health services also had a significant difference to the prescription medication only group (42.8% vs. 60.4%,  $p < .05$ ). No difference was seen for CYSHCN with above routine need and use for health services. There was a lack of association between need for routine care and the Medical Home status where CYSHCN with and without a Medical Home relayed approximately equal prevalence rates for need (70%).

An interesting finding for the amount paid in out-of-pocket medical expenses was that CYSHCN with a Medical Home did not pay any more or less out-of-pocket expenses than those without a Medical Home. Since discussion by the provider about insurance options, a transition measure, was considerably lower for Louisiana's YSHCN, it may be that Medical Home providers are not engaging in discussions about insurance as frequently as they could. Unlike the lack of impact by presence of a Medical Home with out-of-pocket expenses, financial burden was associated with this measure. CYSHCN with a Medical Home have less than half the rate for financial burden than those without (12.3% vs. 27.6%,  $p < .05$ ).

The degree to which families with CYSHCN relayed they were satisfied with the communication between doctors and other health care providers is an important indicator since CYSHCN are known to use many different service providers, which places them at risk for an array of associated problems (duplication of services, financial/insurance/time demands, etc.). Data indicates that satisfaction with provider communication is significantly higher if the child/youth has a Medical Home (97.8% vs. 48.9%,  $p < .05$ ). The Medical Home is also associated with need for and satisfaction with doctors' communication with the child/youth's schools and/or other programs. This is important considering 18.8% of CYSHCN missed 11 or more days of school due to illness, 4% higher than the national average. Significantly more CYSHCN without a Medical Home needed their providers to communicate with their schools/other programs (34.3% vs. 18.4%,  $p < .05$ ), and had higher prevalence rates for being somewhat satisfied (12.3% vs. 0.0%,  $p < .05$ ), or dissatisfied (11.6% vs. 0.0%,  $p < .05$ ).

Among CYSHCN with a Medical Home, fewer respondents reported that family members needed mental healthcare and/or counseling compared to those without one (94.7% vs. 86.2%,  $p < .05$ ). Linking the Medical Home with family composition, the data shows that compared to CYSHCN living with a single mother, those residing with two parents (biological/adoptive) had more than double the prevalence rate for receipt of Medical Home services (64.3% vs. 31.3%,  $p < .05$ ). Grouping by household income, the rate for Medical Home receipt increased with income, and was significantly different from the lowest level compared to the two highest grades (34.6% vs. 56.7%, and 60.8%,  $p < .05$ ). Insurance type showed similar differences. Only 44.0% of publically insured, and 30.8% of CYSHCN with both private and public insurance received Medical Home services, compared to 61.1% of privately insured CYSHCN ( $p < .05$ ). .

#### Usual Source of Care

Approximately 88.6% of Louisiana children/youth received a preventive healthcare visit in the past year, a statistic on par with the national average (88.5%). Unfortunately, perception of need for routine preventive care was lower than the national average where 69.8% of Louisiana's CYSHCN parents responded that their child/youth needed routine preventive care, such as a physical examination or well child check-up in the 12 months prior to the survey (Nation: 77.9%,  $p < .05$ ). A lower prevalence of families with male CYSHCN reported the need for routine preventive care, compared to families with female CYSHCN (64.5% vs. 77.8%,  $p < .05$ ). Although none of the proportions were significantly different, the need for routine care differed by family structure, where other family structures, and two-parent stepfamilies had the lowest rates (41.8%, and 57.3% respectively), followed by single mothers (67.9%). The highest rate was by two-parent biological/adoptive families (75.3%).

A significantly larger proportion of Louisiana's CYSHCN had two or more visits to a hospital emergency room (19.3% vs. 26.1%,  $p < .05$ ). Source of usual care when sick differs by race/ethnicity among Louisiana's CYSHCN population. A larger number of Black Non-Hispanic children and youth have no regular place for sick care or rely on the emergency room for their care, as compared to their White Non-Hispanic peers (18.7% vs. 2.9%,  $p < .05$ ). Comparisons by other race/ethnicity groups could not be made since the sample sizes were not sufficient to meet requirements for precise/reliable estimates. Usual source of care when sick also varies by insurance type. Sixty-six percent of publically insured CYSHCN used a doctor's office, whereas 89.3% of privately insured relayed the same ( $p < .05$ ). Significant differences were also seen for these two groups for citing a clinic, health center, or other regular source (22.7% vs. 7.4%,  $p < .05$ ). No other differences were found for CYSHCN covered by both private and public plans, or were uninsured at the time of the survey.

Unfortunately, Louisiana is not faring well compared to the national average in terms of source for sick and routine preventive health care. Among Louisiana's CYSHCN population, the prevalence rate for those who do not have a usual source for sick and/or preventive care is significantly higher than that nationwide (10.1% vs. 6.4%,  $p < .05$ ). Within Louisiana, there are differences noted by race/ethnicity group. Compared to White Non-Hispanic CYSHCN, Black Non-Hispanic CYSHCN have a significantly lower prevalence rate for having the same source for care (89.2% vs. 73.6%,  $p < .05$ ). There were no other significant differences found for the other race/ethnicity groups, although each were lower compared to White Non-Hispanic CYSHCN (Hispanic: 76.3%; Multi-racial Non-Hispanic: 79.8%; Other Non-Hispanic: 73.5%).

Differences were also found according to family composition. For CYSHCN who live in a single mother household, a lower proportion had the same source compared to CYSHCN living with two parents (biological/adoptive) (73.0% vs. 89.2%,  $p < .05$ ). The other two family structures, two-parent stepfamily, and other were not different (82.6%, and 96.8% respectively).

Having the same source of care is also related to household income. The lowest prevalence rate was among families living at or below 99% FPL (66.9%), which was significantly lower compared to all other income grades which ranged from the lowest at 88.6% (100-199% FPL), to highest at 91.1% (200-399% FPL). As might then be expected based on the income results, those with public insurance were significantly different from the privately insured (77.5% vs. 89.6%,  $p < .05$ ). The other two types of health insurance coverage were not different (both private and public: 88.6% and uninsured: 69.4%).

Alarming, CYSHCN with functional limitation(s) had the lowest rate for same care source for sick and routine healthcare (69.8%). This rate was significantly different from CYSHCN who

have their condition managed by prescription medication(s) (87.0%), and among those who have above routine need, use of health services, and use prescription medication (90.0%). There was no difference for CYSHCN who have above need and use of healthcare services (87.0%).

### Provider Cultural Competence

The Physician Survey assessed a number of components of medical service provision that details the degree to which providers incorporate patient and family culture as a part of their medical practice. Respondents were asked to identify from a list of six patient/family characteristics, which (one or all) they took into consideration when communicating health information. Overall, five of the six were reported to be frequently considered. About 94% of respondents said they considered their patient/family's educational level, their cultural background, (89.3%), their socioeconomic status (83.9%), household composition (single parent, stepfamily, etc) (83.9%), and other important characteristics such as religion, gender roles, ethnicity, and language (83.0%). Least likely to be considered was the Louisiana residential status (31.3%). Another cultural competency factor that was similarly low was whether the physician provided his/her patients with interpreters/translators (29.5%). Lastly, the degree to which the physician was easily accessible to the patient/family was assessed by whether patients could speak directly to the physician when needed. Approximately 78.5% of respondents indicated they were accessible, a positive finding.

The degree to which families report that the health care provider spent enough time with them serves as a proxy for determining whether the family felt as though they understood the outcome of the medical encounter. Results from the Physician Survey indicate that 65.1% of respondents schedule extra time or extend the office visit time for their CYSHCN patients. Compared to family practitioners, significantly more pediatricians reported they did this. Based on data for Louisiana from the NS-CSHCN, a greater proportion of Black Non-Hispanic CYSHCN felt as though their doctors and other healthcare providers sometimes or never spent enough time with them, compared to their White Non-Hispanic counterparts (47.3% vs. 12.7%,  $p < .05$ ). Comparisons between other race/ethnicity groups could not be made because the sample sizes were too small to meet standards for reliability or precision.

Comparing CYSHCN by household income for appropriate level of time spent by the doctors and other healthcare providers, there exist stark differences between the lowest income level and the upper two. Thirty-six percent of CYSHCN living at or below 99% FPL relayed sometimes or never enough time was spent, whereas, 18.7% of CYSHCN living between 200-399% FPL, and 12.3% of CYSHCN living at or above 400% FPL had the same response ( $p < .05$ ). Perception of appropriate length of time spent also varied by insurance type. CYSHCN covered by both private and public health insurance had the highest prevalence rate for citing sometime or never enough time spent, followed by publically insured CYSHCN (46.8%, 28.8%). Although neither of these two groups were significantly different from the other, they both had significantly higher rates compared to privately insured CYSHCN (14.8%,  $p < .05$ ). This indicator was also associated with the Medical Home measure. Approximately 33% of CYSHCN without a Medical Home stated their doctor and other healthcare providers always spent enough time, whereas almost 85% of those with a Medical Home felt the same ( $p < .05$ ). Comparing CYSHCN to non-CYSHCN, each group relayed roughly the same prevalence rates for spending enough time with them in the 12 months prior to the survey (56.1% vs. 55.7%,  $p > .05$ ). Given that CYSHCN by definition have a greater number of medical encounters and cases that are more complex, it is interesting that no significant difference was found.



The perception by families of the degree to which their child/youth's doctors or other health care providers listened to them carefully captures another component of the Medical Home. The prevalence rates for this indicator varied by CYSHCN characteristics. More Black Non-Hispanic than White Non-Hispanic CYSHCN relayed that their doctors or other health care providers sometimes or never listened carefully to them (20.6% vs. 8.8%,  $p<.05$ ). Similar to other measures comparing CYSHCN outcomes by race/ethnicity groups, the sample sizes for the other categories did not meet standards for reliability or precision of estimates. Comparing CYSHCN who live in single mother households to those who live in two-parent households (biological/adoptive, or stepfamily), fewer stated they always were listened to carefully (59.4% vs. 74.8% and 79.0%,  $p<.05$ ). Differences were also seen by the type of special health care need. A smaller proportion of CYSHCN with functional limitation(s), and above routine need/use of health services stated they always were listened to carefully, compared to CYSHCN whose condition is managed by prescription medication(s) (56.7%, and 52.4% vs. 78.3%,  $p<.05$ ). CYSHCN with Medical Homes have a significantly higher prevalence rate compared those without one for reporting their doctors or other health care providers always listen carefully to them (88.4% vs. 49.3%,  $p<.05$ ).

### Care Coordination

Coordinating the medical care for CYSHCN is more demanding than for non-CYSHCN; additionally, the magnitude for care coordination demands and needs varies within the CYSHCN group. Overall, 49.6% of Louisiana's CYSHCN population received coordinated, ongoing, comprehensive care within a Medical Home. Compared to non-CYSHCN, CYSHCN had almost 5 times the prevalence rate for not receiving comprehensive care coordination (7.9% vs. 34.4%,  $p<.05$ ).

Within the CYSHCN group, it is valuable to determine where there are gaps in need according to various child and family characteristics. About 13% or 10,000 more CYSHCN and their families received help coordinating care if the child/youth was covered by public health insurance than those covered by a private insurer; however, this difference is not significant. Although care coordination is a vital component of the Medical Home model, the data shows there were no differences in receipt of help with arranging or coordinating care by Medical Home status; those without a Medical Home have a 7.5% decreased rate for help compared to those with a Medical Home (32.5% vs. 40.0%,  $p>.05$ ).

Compared to the rest of the nation, Louisiana's CYSHCN families spend significantly more hours each week providing and/or coordinating their child/youth's health care (5-10 hours/week: 12.9% vs. 8.9%;  $p<.05$ ). Among Louisiana's CYSHCN families, the magnitude of time spent is associated with the child/youth's age. Among families with YSHCN, a little more than half spend less than hour each week, a rate that is significantly different from families with a child 5 years or younger (50.7% vs. 23.8%,  $p<.05$ ). Alternatively, only a small proportion of families with YSHCN will spend 11+ hours each week providing or coordinating health care compared to the families with a child 5 years or younger (6.7% vs. 25.7%,  $p<.05$ ). Differences by race/ethnicity group could not be determined since the sample sizes were too small for precise estimates and reliable comparisons.

Insurance type was associated with care coordination where publically insured CYSHCNs' families have a disproportionately higher prevalence rate for 11+ hours each week spent coordinating care compared to those privately insured (18.9% vs. 4.9%,  $p<.05$ ). The type of special health care need was also associated with time spent. CYSHCN with functional limitations required the most time (27.0% spent 11+ hours each week), whereas CYSHCN whose

condition is managed with prescription medication required the least (51.2% spent < 1 hour each week).

### Transition

With advances in medical care and technology, CYSHCN are living longer and therefore the demand for appropriate transition services has increased. Thus, an important indicator to determine whether YSHCN have their needs met is the degree to which they receive the services necessary to make appropriate transitions to adult healthcare, work, and independence. Based on data from the NS-CSHCN 40.9% of Louisiana's YSHCN receive transition services. This estimate was only slightly below the national average (41.2%).

The transition outcome results from the Family Survey mirror the NS-CSHCN estimate, however instead of creating a composite measure, the CSHS transition outcome is reflected by five transition service questions. Additionally, the CSHS transition measure differs slightly from the NS-CSHCN measure because the responses for each of the five transition questions are from respondents who relayed they had a Primary Care Physician (PCP). CSHS made these amendments to ensure the transition outcome reflected transition services that are within the AAP Medical Home model. The Family Survey results indicate that approximately 87% of YSHCN have a PCP. Among this group, only 47% said their PCP discussed their health and dental insurance options. Thirty-four percent reported their PCP discussed finding an adult PCP. Only about 29% relayed that their PCP discussed type and eligibility criteria of community-based resources. This was the lowest reported transition service. The second least frequently reported result was whether the PCP discussed future work and/or education choices with the YSHCN and/or their family. Lastly, 42.1% reported that their PCP discussed the youth's role in managing his/her health care routine. This indicates great variation in provision of transition services. When answers were stratified by race, the data showed an interesting picture. Among African-American/Black YSHCN, fewer reported they had a PCP than White YSHCN; however, Black YSHCN with a PCP reported higher prevalence rates for each of the five transition questions than their White counterparts.

The proportion of YSHCN who reported having a PCP varies greatly by region. Region 5 was the lowest (61.5%), and region 7 the highest (100%). For the remaining regions the proportions ranged from 71.6% to 85.4%. This indicates a need to increase the rate at which YSHCN are linked to a PCP, and subsequently potentially increase receipt of transition services.

Similar to the Family Survey results, findings from the Physician Survey reveal that transition services are not provided uniformly. Interestingly, 72.0% of family practitioners, and 10.7% of pediatricians relayed that transition services were not applicable because they serve patients from childhood through adulthood. This response is unfortunate considering transition services provided by the PCP are not necessarily contingent upon the patient transferring from their care. Less than one-fifth of physicians reported that they discussed all the independent living skills with their YSHCN patients (16.9%). Of these three skills, less than one-quarter relayed that they discussed community-based resources, 45.4% said they discussed educational/vocation choices, while 61.0% discussed with the patient his/her role in managing their health care. Discussion about health/dental insurance options was also low (36.4%). The more frequently reported transition services were providing developmentally appropriate counseling directly to their YSHCN patients (64.9%), and ensuring that their patients have established an adult PCP (79.2%).

The NS-CSHCN can provide reliable state estimates for which subgroups of YSHCN experience disproportionately lower rates of receipt of transition services. Comparing YSHCN by

race/ethnicity, data showed that more Black Non-Hispanic YSHCN did not receive the needed transition services compared to their White Non-Hispanic counterparts (78.4% vs. 47.5%,  $p<.05$ ). Unfortunately, the sample sizes for the other race/ethnicity categories were not large enough to meet standards for reliability or precision and thus, comparisons could not be made. Comparing youth who live at or below 99% FPL, and between 100%-199% FPL to those at or above 400% FPL, the data shows the latter group had a significantly higher proportion who received the needed transition services (29.9%, and 29.0% vs. 59.1%,  $p<.05$ ). Comparing YSHCN covered by a private insurer to those with public insurance, a larger proportion of the former group received the needed transition services; however, this almost 20% difference was not statistically significant (51.1% vs. 33.7%,  $p>.05$ ).

As might be expected, receipt of transition services is associated with the type of special health care need. The groups that had the smallest proportion receive the services were YSHCN with a functional limitation(s), followed by those who have an above routine need and/or use of services (76.9%, 71.9%). An approximate 20% difference in prevalence rates separated YSHCN who have their condition managed by prescription medication(s), and those who have their condition managed by prescription medication(s) and above routine service use (51.4%, 49.3%). The only significant differences found were between the functional limitation and the prescription medication(s) groups ( $p<.05$ ).

NS-CSHCN survey results indicate that YSHCN in Louisiana with a Medical Home have a 30% higher prevalence rate for receipt of transition services compared to those without (59.4% vs. 27.1%,  $p<.05$ ). A component of transition is provider discussion with the youth and/or family about health insurance options when the youth becomes an adult. To continue receipt of Medical Home services, continued health insurance coverage is essential. The NS-CSHCN survey asked families with YSHCN whether anyone had discussed with them how to obtain or keep some type of health insurance. Unfortunately, this measure was alarmingly low at only 27.9%. Considering the highest proportion of CYSHCN in Louisiana is YSHCN (38.4%), and the second largest proportion is CYSHCN aged 6-11 years who will be entering transition in the near future, improved transition services in the Medical Home including discussion of insurance options is imperative.

### Community / Service System

FHF is a parent driven and staffed organization that provides information and referral for Louisiana's families with CYSHCN. Compiled data from FHF showed that the majority of consumer contacts with each office were by either a parent/guardian of a CYSHCN, or a professional. Similar to the racial/ethnicity make up of Louisiana, a higher proportion of White and African-American consumers contacted and received services from FHF. Also similar to the distribution of CYSHCN in Louisiana, the largest proportion of families who contacted FHF had children between 6 and 12 years old; followed closely by YSHCN, and adults with special health care needs. The smallest proportion were families with children 5 years and younger. This data could elucidate many scenarios for information and resource need. For example, there may be a greater need for community-based resources by families with older CYSHCN, or it may be that this subgroup is more knowledgeable about resources like FHF compared to families with young CYSHCN, who may not know that FHF exists.

FHF tracks the health condition classification based on the categories used in the school system. Most families had children/youth with a health impairment, followed by orthopedic impairment, then a condition that fell into the "does not apply category", and then multiple disabilities. Falling five percentage points were infants and toddlers with disabilities, hearing/vision

impairment, learning disability, emotional disturbances, autism, and ADD/ADHD. Contact was predominately by phone, in person, or by mail/email. Most information was provided verbally, and less frequently provided were printed materials, research materials, and tapes/books/videos.

FHF tracks information and referral for six resources and one category, “other”. Although the majority of the information and referral fell into the latter group, many consumers received information about developmental disability programs, rehabilitation services, and policy action alerts. FHF provides information outreach to consumers in multiple ways. These include informal and formal presentation, workshops, conferences, support groups, sibshops (sibling support groups), parent-to-parent meetings, peer parent trainings, peer support, and case consults and conferences. Although the type of outreach varied by region, the majority of regions predominately provided information by presentation and peer support; conferences, workshops, case consult and conferences, and support groups followed. The least used means to conduct outreach were sibshops, parent-to-parent meetings, and peer parent training.

Since FHF consumer contact data does not represent all of Louisiana’s CYSHCN population, it is important to determine the extent to which other providers are enabling information exchange. Among PCPs, results from the Physician Survey indicate that less than one-third of respondents or their staff discussed with their CYSHCN patients and/or families about the need for and acquisition of services from FHF or other family/parent support groups. Comparing the referral rate between provider types, pediatricians were significantly more likely to refer than were family practitioners. When looking at referral to other resources, physicians discussed the following from most frequently to least: occupational, physical, and speech therapies (84.8%), the WIC nutritional assistance program (81.3%), durable medical equipment (76.8%), Early Steps early intervention program (74.1%), Louisiana Medicaid (70.5%), Head Start (67.9%), Individualized Education Plans (IEPs) (52.7%), 504 Accommodations (50.0%), assistive transportation (38.4%), state Title V programs (36.6%), SSI/SSI-DI (31.3%), respite care (27.7%), Louisiana Rehabilitation Services program (23.2%), and Family Supports and Services/Waiver programs (16.1%). Pediatricians were significantly more likely to discuss referral for therapies, WIC, Early Steps, Head Start, IEPs, and 504 Accommodations. Family practitioners were significantly more likely to discuss referral for Medicaid. In line with the rate at which PCPs provide referrals it is interesting to see that Family Survey results indicate that almost two-fifths of families reported difficulties accessing community resources/supports because their doctor did not know about any resources nearby, and/or did not know the eligibility requirements of the nearby resources.

NS-CSHCN data identifies specific factors associated with experiencing difficulties with ease of service system use, despite an overall high rate (89.3%) for Louisiana CYSHCN reporting that they felt the services were organized in ways that families could easily use. About 12,823 CYSHCN experienced difficulty trying to use any service because the family could not get the service(s) when needed. This type of difficulty is experienced equally for all income levels. Although not significantly different, there was a higher rate for this difficulty among publically, and both publically and privately insured CYSHCN compared to those with private insurance, and the uninsured (85.7%, and 100.0%, vs. 68.6%, and 63.5%). This finding may in part be explained by the results of the Agency Survey where results have implications among the publically insured CYSHCN population. Among the nine programs surveyed to determine their degree of collaboration with other programs (*collaboration, coalition, coordination, cooperation, networking, or no collaboration*), FHF was the only program to which all other program staff reported they predominately *collaborated*. The Supports and Services program was considered to predominately *cooperate* with other program staff. Lastly, Family Care and Foster Services were reported to predominately *network*. For all other programs, staff reported they predominately did

not have collaboration with or did not know of the program. These results are reported in Appendix E, Table 2, which was shared with program representatives during the second stakeholder meeting.

Service system difficulty is related to not getting the information needed. Based on Louisiana data from the NS-CSHCN, approximately 12,078 (7.5%) CYSHCN experienced this problem. More Non-Hispanic Black, Non-Hispanic Multi-racial, and Hispanic CYSHCN had this problem compared to Non-Hispanic White and Non-Hispanic Other (93.0%, 94.8%, 100.0%, vs. 54.6%, and 12.9% respectively,  $p>.05$ ). Family structure was also related, and was highest among single mother households (85.4%) relative to two-parent stepfamily (62.1%), and two-parent biological/adoptive (47.6%). Household income level was associated with lack of information. Families living at or below 99% FPL were significantly different from the other three levels (91.2% vs. 52.6% (100-199%), 52.5% (200-399%), and 41.4% (400%+),  $p<.05$ ). An uninsured status resulted in a significant 32.0% difference from those insured (96.4% vs. 64.4%,  $p<.05$ ). Comparing insurance type, the privately insured had less difficulty compared to publically, and those both publically and privately insured (52.9% vs. 76.8% and 65.0%, respectively,  $p>.05$ ).

Similar to the results from the Agency Survey mentioned above, the source for program information among state program direct service staff originates almost equally from trainings through work (87.4%), through word of mouth (82.6%), and/or personal contacts (81.6%). It is therefore not surprising there are significant differences by insurance type for receipt of needed information since state direct service staff are the providers who interact with the publically insured CYSHCN population. Furthermore, considering this sub-group experiences challenges with obtaining the needed information, it is alarming to find that 58.0% of state direct service staff reported they learned about other agencies or programs through their own clients.

Again referring to population based data from the NS-CSHCN, other sources for experiencing difficulties were: too much paperwork required (4,382 CYSHCN (2.7%)), not enough money to pay for the needed service (7,055 CYSHCN (4.4%)), a transportation problem (6,854 CYSHCN (4.2%)), a long waiting list (5,940 CYSHCN (3.7%)), communication problems between service providers (9,846 CYSHCN (6.1%)), unable to find providers with the necessary skills (8,542 CYSHCN (5.3%)), did not meet eligibility requirements (7,716 CYSHCN (4.8%)), service(s) not available in my area (8,543 CYSHCN (5.3%)), had a language, communication, or cultural barrier (2,737 CYSHCN (1.7%)), lack of time available to figure all the service system/process all out (6,108 CYSHCN (3.8%)), and lastly, because all the eligibility benefits were exhausted (938 (0.6%)).

From another perspective, barriers for program collaboration among state direct service staff were citing that the services their clients needed were not available, lack of transportation for clients to get to the program/services, service shortage in rural areas, staff burden/high case and work load, funding issues related to Medicaid/health insurance, and lack of communication between programs. On average, about one-fifth of respondents cited they lack of knowledge about other programs as a reason for why they rarely or never referred clients to other programs' services.

### Special Education

Children with disabilities represented 13.0% of the Louisiana schoolchildren. Among the public school students, 16.3% were enrolled in special education, whereas among private school students, only 2.5% were enrolled. The most common type of disability was a specific learning disability, followed by a speech or language impairment. Equal proportions were represented for developmental delay, other health impairment, and mental disability. Among the hearing

impaired, most are hard of hearing (63.7%), and deaf (36.3%). There are approximately equal proportions of blind or partial sight designations for those students identified as having a visual impairment. Speech or language impairment was most frequently manifested as an articulation problem (64.2%). Of the students categorized as having a mental disability, most were reported mild (62.9%), followed by moderate (29.1%).

The DOE reported the educational environments in their 2007 Special Education Profile report. The most common was within the regular classroom where 59.3% of special education students fell into this category. About one-fifth had a resource within the regular class environment, and 16.1% had a self-contained day. Of the number of students served in extended school year program, the greatest percentage were categorized as having a developmental delay (22.4%), followed by autism (15.4%), a specific learning disability (11.8%), multiple disabilities (9.3%), and a speech or language impairment (8.3%).

Among the public school students, the prevalence rates for special education enrollment differed by race/ethnicity category. Among American-Indian students, almost 14% were in special education, shortly followed by African-American students. The third highest rate was 12.6% among White students. Approximately 7.2% of Hispanic and slightly fewer than 5% of Asian students received special education. Although there were equal proportions of males and females in the public school population, males made up two-thirds of those enrolled in special education.

The type of disability a student had varied by age and both sex and race. Among children aged 3 to 5 years old, the majority were diagnosed with a developmental delay or speech/language impairment. Comparatively, for students between 6 and 21 years old, most were designated to have a specific learning disability, or speech/language impairment.

Among males, there were approximately equal prevalence rates for each race (Black, White, Other) for autism, and developmental delay. More Black males were diagnosed with a mild mental disability than either White or other race males (8.7% vs. 3.0%, and 2.9%). White males had almost twice the rate for other health impairment than the other two groups. All three groups shared specific learning disability, and speech/language impairment(s) as the most frequently occurring disability, however the former group is higher among Black males (37.2%) than White (26.5%), or other race (30.9%) males. Whereas, other race males had the highest rate for speech/language impairment(s) (33.3%) compared to White (31.3%), and Black (19.9%) males.

Similar distribution patterns were seen when comparisons were made among females by race group. Although the rates were low, White and other race females had almost twice the frequency of autism compared to Black females (1.8%, and 1.7% vs. 0.9%). Conversely, emotional disturbance was higher for Black females (2.6%), than for either White (1.4%), or other race (1.2%) females. This was also the case for mild mental disability (Black: 10.5%, White: 4.6%, other: 4.2%). Similar to White males, a higher frequency of White females were designated with other health impairment (11.9%) compared to their Black (7.0%), and other race (6.0%) counterparts. Specific learning disability was the most commonly occurring condition among Black (37.6%), and was the second most for White (27.1%), and other race (26.6%) females. Speech/language impairment(s) was more common for White and other race females (32.6%, and 32.9%, respectively), and was second most for Black females (19.6%).

Based on the Federal Office of Special Education Programs (OSEP) school exit categories, 45.0% of special education students dropped out of school for the 2006-2007 year, while the other half received either their high school diploma or a certificate. Comparisons of school exit outcomes according to disability group elucidate some informative differences. Among students with

emotional disturbance, almost three-quarters dropped out (72.2%). Similarly, among students with profound mental disabilities, 66.7% or two-thirds did not complete school. Approximately equal rates for completion and non-completion occur for with specific learning disability (52.5% vs. 47.5%), speech/language impairment (54.5% vs. 45.5%), other health impairment (57.4% vs. 42.6%), and mild mental disability (58.9% vs. 41.1%). The remaining disability categories have a dropout rate which ranges from a little more than one-third (severe mental disability: 38.1%) to 12.2% (autism).

#### *CYSHCN Areas to Continue and Areas to Enhance*

Between the two NS-CSHCN survey years health outcomes among Louisiana's CYSHCN population, as reflected by the Maternal and Child Health Bureau Core Outcome Measures, have greatly improved. Louisiana has moved from below the national average in all six NPM's to above the national average in four of the six NPM's. One factor that may have influenced this is the exodus of CYSHCN with more severe problems from the state after Hurricane Katrina, when healthcare resources were greatly disrupted. However, changes in the healthcare system have also improved access. Probably the most significant change is expansion of the state's public health insurance programs, including outreach initiatives for LaCHIP and Medicaid, and the additions of the Medicaid Purchase Plan, LaCHIP Affordable plan, and Children's Opportunity Act. These have increased the proportion of CYSHCN who have adequate insurance and continuous coverage, thereby improving access. CSHS will continue to assist families in identifying appropriate health insurance options since coverage addresses a myriad of important factors that relate to health, wellness, family and financial stability, and independence.

It is important to note that although Louisiana's CYSHCN have experienced improved insurance coverage, access to providers as well as quality of care coordination services vary greatly by type of insurance (public vs. private), and therefore is an ongoing concern. Recent budget cuts have reduced Medicaid reimbursement to physicians, further decreasing the number of Medicaid providers. Therefore, CSHS will continue to sustain a small but important role as safety net provider for select subspecialty care.

Some important statistics reveal that Louisiana needs to improve the service system as it relates to health condition management and collaboration between families and social service, educational, and medical providers. Less than half of Louisiana's CYSHCN meet all NS-CSHCN criteria for receipt of care in a Medical Home. Similarly, physicians report varying compliance in meeting Medical Home criteria in their practices. Only two-fifths of YSHCN received the needed transition services. Family practitioners did not recognize the need to provide transition services for YSHCN that would remain in their practices. With these facts in mind, CSHS will continue to increase the Medical Home capacity by improving care coordination and transition services in pediatric Medical Homes and CSHS clinics statewide. CSHS activities will reflect a stronger focus on infrastructure building and enabling service activities aimed to improve the knowledge, skill, and ability among providers to meet care coordination, transition and Medical Home criteria. Since the Medical Home builds on a partnership with families, CSHS will work to improve the experience and satisfaction of service use among Louisiana families with CYSHCN by working with FHF and F2FHICs to provide enabling services related to advocacy and service system navigation and to improve coordination and knowledge of services among regional program staff. CSHS will continue to explore ways to link population based databases such as those of LBDMN, Early Steps, and CSHS to provide seamless care coordination for families. CSHS will continue to improve collaboration between agency programs through its stakeholder group and work to develop the DSS-DHH Master Patient Database. Finally, CSHS will continue to promote coordinated systems of care and adequate reimbursement for Medical Home activities

such as care coordination through involvement in health care reform committees and initiatives as they evolve, such as the LHCQF Medical Home committee.

#### **4. Program Capacity by Pyramid Levels- CYSHCN**

##### **Direct Health Services**

###### **Need**

While the percent of CYSHCN whose families report they have adequate insurance has increased steadily from 51.9% in 2001 to 65.5% in 2005/06 leaving only 5.1% of CYSHCN in Louisiana without insurance, access to providers who take Medicaid is a continuing priority among families of CYSHCN; a sentiment concurred from the perceptions of primary care physicians. According to the NS-CSHCN, 28.2% of respondents said their coverage was inadequate. Among CYSHCN families surveyed by CSHS, the top four priorities were access to pediatricians, subspecialists, occupation, and physical Therapists (OT/PT), and dentists who accept CYSHCN with Medicaid. These priorities remained static when stratified by age, race, and region of residence. The most common barriers to accessing services listed were no resources nearby or no resources taking on new clients. Among subspecialists, more than half of primary care providers listed psychiatry (75%), developmental pediatrician (67.4%), neurology (62.0%), and orthopedics (53.3%) as difficult to access. These were followed by dermatology (45.7%), endocrine (41.3%), rheumatology (39.1%), and neurosurgery (25%). Although the number of physician responses was small when broken down by region, shortage patterns were remarkably similar across regions (Appendix E, Table 1). For the most part access is easier in New Orleans than in other parishes, although 55% had difficulty getting a neurology consult even in New Orleans. When asked to rank their perception of CYSHCN family needs, pediatricians and family practitioners ranked lack of mental health providers as the top priority and lack of access to subspecialists, OT/PT, and pediatric dental providers as the next three, respectively, mirroring what families said.

Interestingly, in the Physician Survey, pediatricians who accept Medicaid was listed as sixth, behind care coordination by primary care providers. Yet a recent survey by the Louisiana chapter of the AAP found that only 58% of pediatricians surveyed were taking new Medicaid patients. In all parishes surveyed except New Orleans, the majority of pediatricians were not accepting new Medicaid patients (Baton Rouge, Lafayette, Shreveport and Lake Charles). NS-CSHCN data indicate 8.8% of CYSHCN do not have a usual source of care when sick (8.8% vs. 5.7% US). While this has always been an issue in Louisiana, recent Medicaid reimbursement cuts have made this even more of a re-emerging issue.

###### **Capacity**

CSHS has traditionally held subspecialty clinics in all nine regions of the state for CYSHCN who meet both medical and financial eligibility as mandated by the state. CSHS will continue to provide subspecialty medical services as an important gap filling entity since access to providers varies according to state location and insurance provider acceptance on behalf of the practice. As CYSHCN have obtained Medicaid, many have moved into the private sector seeing Medicaid providers. CSHS has a policy that when the number of patients in a clinic decreases to 10 or less, CSHS staff transition the remaining children to private providers and the clinic is closed. This has resulted in the cancellation of a few subspecialty clinics in the Metropolitan region (cardiology, ENT, arthritis, hand). Children's Hospital New Orleans has a program for uninsured children that cover all services provided at the hospital. However, CSHS continues to provide neurology, orthopedic, otology, neurosurgery, rheumatology, cleft lip and palate, spina bifida,



cystic fibrosis, scoliosis, audiology, nephrology, spinal cord, reconstructive surgery, cardiology, cerebral palsy, ophthalmology, and urology clinics throughout the state, according to both need and physician availability. Nutritionists attend CSHS clinics in seven regions. Physicians are paid a monthly honorarium to travel to regions where the need exists. When clinic numbers or physician availability does not permit a clinic in one region, families are directed to a nearby region that offers the needed service. Clinic numbers continue to decrease as insurance coverage increases (from 4,656 CYSHCN in 2007 to 4,585 in 2009), and it is our hope that one day CSHS clinics will not be required to fill this gap.

CSHS funds dental services for CYSHCN at Children's Hospital in the Metropolitan region (four parishes) provided by the Louisiana State University (LSU) Dental School, and limited OT/PT services when required post-operatively in all regions. OT/PT is provided through Early Steps and the public school system (IDEA Parts B and C), although shortages of providers especially in rural areas of the state make provision of these services an ongoing concern.

CSHS holds audiology clinics for children with identified hearing loss, which provide hearing assessments and hearing aids throughout the state. With the expansion in Medicaid coverage, access to audiologists in the private sector has increased steadily and the number of audiologists employed by CSHS has decreased to only two. The audiologist in the Southeast region (five parishes) currently travels to two other regions thereby capturing twenty-one parishes. The audiologist in the Acadiana region (seven parishes) also covers the Southwest region (five parishes). The LSU School of Allied Health, private audiologists at Children's Hospital of New Orleans, and Ochsner Hospital and Clinic, cover the Metropolitan region. A private audiologist covers the Central region (eight parishes). Not all private audiologists dispense hearing aids (especially in the Acadiana region) and not all CYSHCN have insurance. For these situations, the CSHS audiologists travel as needed to meet the child's need.

Traditionally, shortages of primary care physicians who take Medicaid combined with a cultural dependence on public hospitals for emergency room access have made linkage to Medical Homes difficult in Louisiana. However, Community Care requires children covered by Medicaid to be linked to a Medical Home; a mandate that has greatly improved access for CYSHCN. All children coming to CSHS clinics are assessed for Medical Home status. Social workers work with families to identify a source of primary care if none exists. Currently, ninety-eight percent of CYSHCN attending CSHS clinics are connected to a Medical Home. Subspecialty clinic notes are transcribed after each clinic and sent to the Medical Home provider. According to the NS-CSHCN, only 6.1% of Louisiana's CYSHCN population are without a personal doctor or nurse. However, the survey results indicate that only 66% of those with public insurance attended a doctor's office compared with 89.3% of the privately insured, inferring that barriers to access exist.

CSHS pays insurance co-pays over \$25 for children with private insurance and LaCHIP Affordable Plan. This is to encourage families to obtain insurance while permitting CSHS to bill insurance.

### **Enabling Services**

#### **Need:**

Overall, 49.6% of CYSHCN receive coordinated, comprehensive care in a Medical Home, which is above the national average of 47.1%. While most CYSHCN have a primary care provider, the NS-CSHCN suggests that care coordination services are greatly needed among Louisiana

CYSHCN and their families. Compared to non-CYSHCN, CYSHCN in Louisiana have five times the prevalence rate for not receiving needed comprehensive care coordination (7.9% vs. 34.4%). Compared to the national average, families with CYSHCN spend significantly more time coordinating care, and Medicaid families spend more time coordinating care than non-Medicaid families (11+ hours per week, 18.9% vs. 4.9%,  $p < .05$ ). Twice as many Medicaid families had a family member stop working due to their child's health condition (20% vs. 10%). Almost twice as many Medicaid families say they had difficulty using services (13.0% vs. 7.6%). Families of young children and families of CYSHCN with functional limitations spend more time coordinating their child's care than children requiring only medication.

In Physician Surveys, physicians report that they regularly share information with other providers and that more than half refer for occupational, physical, and/or speech therapies, WIC services, durable medical equipment, Part C Early Intervention services, Medicaid, Head Start, and Special Education. However, only 50% report that they refer for 504 Accommodations, and less than half report they provide a written plan of care, coordinate their plan of care with schools, discuss insurance options with families, or refer for assistive transportation, Title V programs, SSI or SSI Disability, respite care, or Louisiana Rehabilitation Services. Only 29.5% refer to family support organizations; this was more common among pediatricians. Only 29.5% report that they provide access to translators in their practices. These percentages may be inflated, since physicians who do these things may be more likely to complete a questionnaire. In addition, 89.3% of physicians answering the survey reported to be a Louisiana Medicaid provider, while only 58% in a survey done by the Louisiana AAP in May 2008 reported this same. However, neither survey can be generalized to the overall target population. Questions regarding cultural sensitivity suggest that physicians do consider patient educational level, cultural background, socioeconomic status, household composition, and religion, gender roles, ethnicity and language (range 93.8% to 83.0%) when communicating health information and forming a plan of care.

Agency Surveys indicate a great need for increased collaboration between public health agencies and programs. This lack of collaboration means there is no single point of entry for families into public health services, making it difficult for families to navigate the system and learn about other health services. Despite this identified priority area, 89.3% of families with CYSHCN in Louisiana said services were easy to use (US 89.1%).

Another priority for CYSHCN is transition services for YSHCN. Louisiana ranked below the national average for the Transition NPM, while above the national average in the other four NPM addressed by CSHS programmatic activities. This need was echoed in the Family Surveys, where transition services were ranked sixth, after access to Medicaid providers (top 4) and prescription coverage. Physician Surveys indicate that the majority report they establish an adult healthcare provider and discuss the youth's role in managing their healthcare, but only 45.6% discuss vocational choices, 24% discuss community resources, and only 16.9% report addressing all independent living skills. Agency Surveys indicate little collaboration between CSHS and other program staff regarding transition needs, including supports and services, vocational rehabilitation, and independent living.

#### Capacity:

CSHS subspecialty clinics are staffed with social workers, social service counselors, and parent liaisons that provide care coordination for CSHS families. Parent liaisons ensure that care is family-centered while linking families with needed community resources, and social service staff assist in identifying needs and services. Parent liaisons work with both FHF staff and Family to Family Health Information Centers (F2FHICs), located in each regional FHF office, to identify

appropriate resources for families. FHF's and F2FHICs are an invaluable resource for CYSHCN in Louisiana and for CSHS clinic staff as they work to address family needs. Parents are active in decision-making at all levels of CSHS.

Medicaid outreach campaigns as well as newer options for public insurance including the LaCHIP Affordable Plan, the Family Opportunity Act, and the Medicaid Purchase Plan have given Louisiana's CYSHCN families a rate of insurance coverage that is higher than the national average. Social workers help families to identify appropriate sources of health insurance, including new Medicaid options. CSHS has a new liaison with Medicaid to assist with clients who are denied SSI Disability, which is necessary to receive continued Medicaid benefits past the age of 19. A new brochure will be developed listing current public insurance options. When necessary, families are referred to the Advocacy Center for assistance in negotiating eligibility for various public options/ insurance claims and issues.

In the Central and Metropolitan regions of the state a new more systematic, comprehensive care coordination program targeting YSHCN in transition was piloted over the past two years utilizing a new care coordination software and an interdisciplinary team including a nurse, nutritionist, audiologist (if applicable), parent liaison, and social service staff. However, staff shortages due to state budget cuts and unannounced lay-offs of employees who did not receive permanent civil service status have made implementing this systematic care coordination program impractical. Therefore, to both meet patient and family needs in the context of staff challenges, the care coordination program was simplified. The result is a flexible efficient program that provides a needs assessment for each family, prioritizes needs, identifies complex cases, and links families with needed resources. Families with complex needs receive a written plan of care that is shared with the Medical Home. The revised care coordination program is ready for implementation in additional regions. Transition brochures for families outlining areas to be addressed for complete and successful transition will also be developed. A new transition section will be added to the CSHS website.

## **Population Based**

### **Need**

Providers are located in the major metropolitan areas and the major medical schools, which are located in New Orleans and Shreveport. Providers are also more prevalent in Lafayette. In the rest of the state, shortages prevail. Even New Orleans has a true shortage of neurologists. For families with Medicaid, access to Medicaid providers is their priority need.

As a result, families of CYSHCN need care coordination services, as discussed above. Physicians need greater appreciation of the importance of public health and community resources for families of CYSHCN, especially among those with Medicaid. This lack of appreciation and knowledge presents a barrier to effective care coordination in Medical Homes. Finally, public health and community resources are not coordinated, making it difficult for families to take full advantage of them. There is no single point of entry into public health and/or community services, and program staff have insufficient knowledge of each other to refer to each other appropriately. Data sets are not linked, limiting coordination between programs.

### **Capacity**

To address subspecialist shortages, CSHS collaborates with both medical schools and with private providers to send subspecialists to shortage areas. CSHS also funds two certified cystic fibrosis centers. The center in Shreveport is a joint CSHS- LSU Medical School clinic; the center in New Orleans is a Tulane clinic that CSHS funds. CSHS also funds a diabetes clinic at Children's Hospital and two NICU follow-up clinics, one in Baton Rouge and one in Shreveport, to improve care coordination for these populations.

CSHS has initiated a successful care coordination program in pediatric Medical Homes to improve knowledge of community and public health resources among physicians and families. This began with two Medical Homes that participated in a National Initiative for Children's Healthcare Quality (NICHQ) sponsored Medical Home learning collaborative in 2003. A third residency teaching practice was added after the collaborative ended that attempted to measure the success of the project using the Medical Home Index and the Medical Home Family Index. This New Orleans based practice was forced to address care coordination needs of CYSHCN in post-Hurricane Katrina New Orleans, resulting in the development of a very efficient and effective care coordination system in a busy practice for an underserved population.

CSHS then hired a care coordinator supervisor to provide technical assistance for care coordinators in additional practices. The model has since been replicated in two additional practices. To make expansion economically feasible, CSHS changed the model from full funding of a care coordinator to a model where practices must designate an existing staff member as the care coordinator. CSHS will provide \$20,000 toward their salary if they will spend at least 50% of their time care coordinating and allow CSHS to assist with implementation of the model. Resources and ongoing technical assistance are provided to the practice. Teaching practices are given priority so that future pediatricians will incorporate care coordination into their Medical Homes, although large private practices that accept Medicaid patients are targeted as well. CSHS has targeted up to five new practices for care coordination in fiscal year 2011, including two family practice teaching practices. Transition services are not yet targeted by the care coordination technical assistance, but will be added in the future. Differences in pediatrician and family practice medical home capacity as evidenced by the physician surveys will be considered in designing intervention strategies.

CSHS has recently developed 9 different laminated one-page (front and back) region-specific resource guides targeted for physicians, which will serve as a quick reference to aid in referral to public health and community resources. This resource provides a description of services, the eligibility requirements, and contact information for key public health and community resources (including educational) as well as FHF and F2FHICs. The guides were mailed to physicians who answered the survey. The guides will be updated annually, and disseminated to physicians and CSHS clinics. In addition, orthopedists and neurologists who treat adult patients will be targeted for future mailings to assist with transition of youth into these clinics. Guides will also be available to families and physicians through the CSHS website. CSHS will also submit articles on care coordination, transition, and community and public health resources to the AAP and AAFP newsletters.

There is potential for linkage of several statewide data systems that could improve follow-up for CYSHCN. These include the LBDMN, Newborn Hearing Screening, Early Steps, and CSHS. Children identified in the two newborn surveillance systems need access to subspecialty care and early intervention. HSV works with Early Steps to improve its follow-up data. The Louisiana Birth Defects Monitoring Network (LBDMN) is under CSHS. This surveillance system identifies children with specific birth conditions and currently covers 80% of births in Louisiana. A new \$947,403 CDC grant will permit expansion of the LBDMN to track all births. Among the

identified children, those who need access to healthcare and early intervention resources are provided with a resource booklet that was developed by LBDMN, which will assist the family to more readily understand and navigate the healthcare service system. A new brochure informing parents of the resource guide will be sent to birthing hospitals for distribution to parents of infants born with birth defects to alleviate delays in identification through the registry. As LBDMN becomes a statewide web-based system, new opportunities for program referral and collaboration will develop.

As a result of this Needs Assessment, CSHS has a new stakeholder group comprised of program managers of the various public health programs that serve CYSHCN in DHH and DSS, as well as representatives from FHF and F2FHICS. Initial meetings helped to address gaps in knowledge among program managers. Survey results identifying gaps in referral patterns between programs were then presented to the group, and goals for addressing those gaps at the regional program staff level have been developed. CSHS will amend its contract with Bayou Land FHF to provide workshops for program staff to learn about each other's programs and eligibility. In addition, CSHS will disseminate CSHS and FHF brochures and regional resource guides to FQHC's and SBHC's. Finally, CSHS will engage a social marketing firm to design a poster informing families of FHF services for placement in clinics that serve CYSHCN with Medicaid. Improvements in coordination between programs via the stakeholder group and these activities should make accessing these resources easier for all families of CYSHCN.

### **Infrastructure Building**

#### **CYSHCN Service System Need**

Louisiana has traditionally invested in a tertiary system of care, funding public hospitals across the state as opposed to preventive outpatient clinics. Healthcare dollars have therefore been spent disproportionately on hospitalizations and emergency room visits, rather than on prevention, leading to a system of care that is expensive and ineffective. Resulting low Medicaid reimbursement rates and low percent of claims paid have led to many physicians refusing to take Medicaid patients. Because of health care shortages throughout the state particularly in rural areas, many physicians have full patient caseloads without taking Medicaid patients.

In addition, CPT codes for care coordination that could be paid by Medicaid to encourage physicians to provide the needed services are not reimbursed. These CPT codes include prolonged physician service with direct contact (99354-99356), prolonged physician service without direct patient contact (99358-99359), medical team conference with qualified health care professional (99366-8), care plan oversight services (99374-99375), special services: for modification of care plans and other services involving communication to patient/family (99091), telephone services (99441-99443), special reports (99429), and administration of health risk assessment instrument (99420). Reimbursement for these essential activities would encourage physicians to incorporate more care coordination services within their practices. Louisiana Medicaid provides a \$3 per month care coordination fee to physicians for care coordination, however because this is not linked to any specific activities, physicians receive this regardless of whether care coordination is done.

Physicians in Louisiana must begin to see care coordination as part of their responsibility. Medical education must teach physicians to care for children in their communities, as is embraced by the Future of Pediatric Education II, which determines pediatric residency curriculum. Physicians need to be aware of the difficulties all families of CYSHCN face, but in particular, families who are Medicaid eligible and have a CYSHCN.

Finally, a single point of entry is needed to access public health and community resources. Lack of coordination between public health programs makes navigating the system difficult for physicians, families, and program staff alike. The result is a system with both duplication and omission of needed services at the family level, resulting in higher cost with less efficiency.

### Capacity

In 2007 Louisiana passed a Health Care Reform Act, requiring the DHH to redesign Louisiana's healthcare system based on the Medical Home model. A waiver was submitted to the Centers for Medicaid and Medicare Services (CMS) in December of 2006, which detailed a managed plan for a system of coordinated care networks to be piloted in several regions of the state. To date this plan is still pending CMS approval, and hence has not been implemented. CSHS is active on the state's legislated stakeholder group, the HealthCare Quality Forum, and participates in its Medical Home Advisory Committee. The Committee held a Medical Home Summit for key healthcare leaders and stakeholders in Louisiana in May 2008, to which CSHS presented its care coordination pilot data (recently accepted for publication in the MCH Journal). The committee also adopted the Patient Centered Medical Home Principles and National Committee for Quality Assurance (NCQA) criteria for Medical Homes in Louisiana. With the help of a HRSA Primary Care Access Stabilization Grant, many Medical Homes in Louisiana became NCQA certified. The Forum has also investigated possible electronic medical record software systems for adoption by DHH so that Medicaid providers statewide could share the same electronic medical record system.

CSHS is also in active discussions with Medicaid regarding reimbursement for care coordination activities. Recently, the Medicaid Director was promoted to Undersecretary of DHH and the Deputy Director moved to another agency, slowing these discussions. They will become relevant again when requirements for care coordination networks (CCNs) for a managed care model are discussed, and CSHS has made known its desire to be at the table with Medicaid for these discussions. CSHS has also stressed the importance of involving primary care physicians in CCN development so that requirements are realistic for practices and reimbursed appropriately to create desired changes in healthcare delivery to CYSHCN.

CSHS has a long history of collaboration with the La AAP chapter. The CSHS Director is an AAP member and has been active in the CYSHCN Healthcare Reform workgroup. The quarterly AAP chapter newsletter has served as a regular vehicle for dissemination of public health information. The chapter has shared member email and mailing address lists for numerous OPH mail-outs and most recently for its Needs Assessment surveys. Recently CSHS has begun to collaborate with the AAFP as well, since family practitioners comprise approximately 50% of pediatric primary care providers in Louisiana. While pediatricians are located in metropolitan areas, family practitioners tend to be located in the state's rural areas. The Family Practitioners were included in the 2010 Needs Assessment Physician Surveys. Care coordinators will begin in Family Practice teaching clinics in 2011.

CSHS is active in resident medical education. The Director of CSHS is the director of the development rotation for both Tulane and LSU medical schools, and therefore has the opportunity to teach Medical Home principles to all Louisiana pediatric residents. Residents participate in numerous activities to increase their sensitivity to family needs and learn about community and public health resources. Residents also participate in a program called "Operation House Call", where they visit a family of a CYSHCN in their home and conduct a structured interview to learn about that family's experience. Results of the interview are then discussed in a group didactic

session with other residents and faculty. The Care Coordinator Supervisor provides a didactic session on Medical Home. Residents are required to give a “Medical Home presentation” of a child they saw in clinic that month, including a discussion of appropriate community and public health resources, and plans for future educational, vocational, and independence needs. In addition to the pediatric development rotation, CSHS sponsored care coordinators are placed in pediatric and continuity clinics so that residents become aware of community resources and how to refer to them appropriately. CSHS is now expanding selected program activities to family practice residents as well. Operation House Call has been extended to family practice residents in two regions of the state, and contracts for 2010 include care coordination in two family resident continuity clinics.

CSHS’s new stakeholder group is designed to improve collaboration between public health programs from other agencies (see population based capacity). Represented on the stakeholder group are: Early Steps, Supports and Services Center, Resource Centers, CSHS (all from DHH) and Independent Living Program, Vocational Rehabilitation Program, Disability Determinations Services Program, Child Protection Services (all from DSS), and Families Helping Families and Family to Family Health Information Centers (F2F HICs). While regional CSHS offices collaborate to varying degrees with all of these programs, the stakeholder group is intended to increase coordination between these services for families at the community level. FHF is the one agency that already actively collaborates with all programs and hence the CSHS FHF contract will be expanded to include provision of workshops for staff from all programs on program services and eligibility criteria.

Finally, CSHS has been active in (and actively promoting) the Data Integration Project between DHH and DSS, which has a goal to create a master patient index where patient information from various programs is merged and data is accessible by all participating programs. By accessing the database, program staff would be able to determine what programs the family is already linked to and which programs the family may be eligible for. This project has been slow to develop because of many infrastructure changes that DHH is currently undergoing. Over the past two years almost all of the personnel above the Office of Public Health, Preventive Medicine Center Director have changed as administration attempts to reduce the budget shortfalls and streamline activities. The CSHS Director recently met with the new DHH Policy Director to encourage further development of the database. She was met with enthusiastic support.

#### *Developing an Action Plan & Monitoring and Evaluating CSHS Programmatic Activities*

The CSHS program met in spring 2010 to identify key programmatic activities for each level of the MCH pyramid that would address the national and state performance measures and thereby priority needs for the CYSHCN population. The meeting was led by the CSHS Program Manager and Epidemiologist. Comprehensive data on the state of needs, risk factors and markers, and outcomes were provided to key team members of the CSHS program. A brief review of the five types of needs as described in the “Workshop on State Title V Needs Assessment Practice” (14<sup>th</sup> Annual MCH Epidemiology Conference, Atlanta, GA December 2008) were explained (standards, demands, population at risk, relative to another type of population, and perceptions). Meeting leaders led the group through a problem map; a technique used to identify how and why predisposing factors are interconnected to a problem, and the resulting interconnected consequences. From identifying the linked factors, programs are able to recognize areas where intervention actions can take place to reduce the frequency and/or risk for a specific health related problem.

A problem map was constructed for each of the five NPMs, and the one State Performance Measure (SPM). The current rate for the performance measure was provided to the group, and the problem was defined as the negative outcome for a NPM or SPM. As a group, precursors and consequences for each problem were identified by reviewing the provided data. Group discussion took place to determine how and why precursor and consequence factors were related, and from these the group identified links and the potential actions to improve outcomes. Activities were then determined for inclusion in FFY 2011 MCH Block Grant activities. These activities were summarized in the sections above and are discussed in more depth in the 2011 MCH Block Grant narrative.

To determine how each activity would be measured, a process evaluation template was provided to each meeting attendee. The meeting leaders provided an example for each of the five components that define a process evaluation. The leaders then had the group focus on the activities and measureable outcomes for each activity. A consensus approach was used to identify the appropriate sources for which activities could be measured. Spreadsheets outlining activities for each performance measure are presented in Appendix E.

After all process evaluation templates were completed for each of the five NPMs and the one SPM, the CSHS Program Manager and Epidemiologist reviewed all the activities to identify activities that addressed more than one NPMs or SPM, as well as those that were unique to the specific measure. The CSHS Program Manager and Epidemiologist led a follow-up meeting with the same key CSHS staff where they presented a poster of all programmatic activities described in the process evaluation format. During this meeting, CSHS staff identified the specific required resources needed to ensure success with completing each programmatic activity. This process involved designating key personnel to lead specific activities, amending contracts, developing a comprehensive roster of selected providers identified to receive the programmatic intervention(s), identification of data resources, and descriptions of how the relevant data-tracking tools would need to be amended. The process evaluation information was documented on the poster-sized template that will be displayed in the CSHS central office. Quarterly meetings during the FFY were scheduled. These monitoring meetings will serve to update the process evaluation template throughout the year.

## **5. Selection of State Priority Needs**

### **List of Potential Priorities**

The MCH program convened a meeting of each of the program's subgroups as well as stakeholders involved in the needs assessment process to determine the MCH program's state priorities. This meeting was facilitated by the LPHI liaison. The meeting began with an overview of the purpose of the Title V Needs Assessment, followed by brief introductions of meeting participants. MCH program subgroup leaders presented 3 to 5 priority needs that represented the top priority areas of their respective subprograms. In addition to identifying their top priority areas, the presentations also detailed the methodology used to identify subprogram priority needs. Subgroups were instructed to use data describing why the 3 to 5 top priority needs should be included among the state's top ten priority needs. Following each presentation, participants were allowed an opportunity to ask the subgroup questions. The presentations served as the primary method by which subgroup participants determined the state's top priority needs.



Following subgroup presentations, the LPHI liaison facilitated a discussion among participants in which priority needs identified in the presentations were evaluated to determine which should be included among the state's top priority needs. The following are a list of the preliminary priority needs identified by the subgroup presentations; 1) Increase care coordination capacity statewide for children with special health care needs, 2) Increase access to and knowledge of services available to CYSHCN covered by Medicaid, 3) Preconception/ Interconception care, 4) Prematurity, 5) Address health disparities in birth outcomes, 6) Increase access to Behavioral Health, 6) Breastfeeding , 7) Obesity/Healthy eating, 8) Unintentional/intentional injuries, 9) Parenting education/Family support, 10) Behavioral Health, 11) Teen Pregnancy, 12) Reproductive Health, 13) Substance Use/Abuse, 15) Misuse of Cyberspace, 16) Education and Awareness of the importance of oral health, 17) Increase Preventative Oral Health Services- fluoride varnish, sealants, 18) Fluoridation, 19) Increase Oral Health workforce, 20) Improve/create reimbursement for Dental Services in Medicaid settings.

### **Methodologies for Ranking/Selecting Priorities**

The LPHI liaison explained the criteria to be followed in selecting the state's top ten priority needs. These criteria were largely based on those criteria established to select the top state priorities in the 2005 Needs Assessment. Developing a set criteria for participants to evaluate priority needs provided a means of standardizing the selection process. These criteria included the following; 1) Ask participants to think about where overlaps exist among priority needs identified by each subgroup, 2) determine whether the issue is data driven, 3) Is there a large population affected by the issue?, 4) Is the issue generally recognized as a need by providers and recipients?, 5) Is the need not adequately addressed by others?, 6) Is this a realistic/feasible issue to address?, 6) Evaluate the impact of the issue. What is the likelihood of success?, 7) Is it sustainable?, 8) Is the issue consistent with MCH Title V Block Grant law?, 9) Is there or will there be MCH/CSHS capacity to address each priority need?

The priority needs selected by participants to be included as state priority needs were: 1)Preconception/Interconception care, 2)Obesity prevention, 3)Breastfeeding , 4)Pre-term birth, 5) Reduce intentional and unintentional injuries among children, 6) Expand care coordination for children with special health care needs 7) Assure that health education strategies and methods in MCH programming are culturally sensitive and designed to reduce race-based health disparities, 8)Improve Oral Health of MCH population, 9)Improve Behavioral Health of MCH populations, 10 Increase Preventative Health Services for adolescents and Transition Services for Adolescents with Special Health Care Needs. Each of these areas generated discussion that allowed participants to weigh the advantages and disadvantages of including each item as a priority need. Below is a summary of how participants evaluated priority needs and selected these priorities.

Breastfeeding was nominated and discussed as a potential state priority need. The discussion to include breastfeeding as a priority need largely centered on data which show that Louisiana continues to have low rates of breastfeeding and evidence that rates of breastfeeding initiation are well below the national average and the Healthy People 2010 objective. Participants also referenced the large disparity between Black and White rates of breastfeeding initiation as evidence of the importance of including breastfeeding as a priority need. Widespread agreement

of the nutritional benefit of breastfeeding segued into a discussion of the inclusion of breastfeeding under the larger category of nutrition. However, the debate to include nutrition as a priority need was primarily based on obesity data. In particular, data from the BRFSS showing high rates of obesity among women of reproductive age in Louisiana were alluded to as evidence of the importance of including nutrition as a priority need. Moreover, data from the child health subgroup which show that Louisiana has one of the highest rates of childhood obesity in the country was also mentioned as evidence to support the inclusion of nutrition as a priority need. Concern by some that breastfeeding initiatives may be lost or minimized if included under a nutrition category led to further conversation on whether breastfeeding should be included as a separate priority need. It was ultimately believed that including breastfeeding and nutrition under the same priority need would not jeopardize breastfeeding initiatives. Because of this the group decided to merge the two into a single priority need.

Preconception and Interconception Health was also discussed as a potential state priority need. Group discussion of Preconception and Interconception health centered on birth spacing, folic acid supplementation, unintended pregnancy and extending Medicaid coverage to women after pregnancy to improve health outcomes among women with chronic conditions. There was considerable support for including this particular need as a state priority need. This was largely due to a general consensus by all to support initiatives that focus on improving the health of women of reproductive age.

Behavioral health was considered important to include as a state priority need by all. Much of the discussion on behavioral health was based on an acknowledged lack of behavioral health service availability to the states' MCH populations. Participants discussed current initiatives such as SBIRT (screening, brief intervention, referral, and treatment for substance use, depression, and domestic violence) and how its expansion across the state represents one of the important initiatives spearheaded by the MCH program that may help address this identified need. Some discussion entailed how transportation is one barrier to accessing services when behavioral health care is available.

Transportation was discussed as a barrier to accessing not only behavioral health services, but health care across a range of services. This led to an expanded discussion of how transportation is but one of a number of barriers to accessing care. Another discussed barrier to health care access was a lack of providers who accept Medicaid coverage. Participants indicated that even among providers who accept Medicaid that some only offer services to Medicaid patients on select days or at select times. This particular issue of the limitations of Medicaid coverage was articulated by the oral health leaders as one of the factors that affect access to oral health care. In addition, the oral health leaders argued that many dentist do not accept Medicaid at all because of low reimbursement rates. These data were identified as evidence of the importance of including oral health as a state priority. There was however, limited discussion of whether oral health should be included as a separate state priority need. The alternative argued by some was to include it among another of the state's top priority needs. However, the oral health program leader argued the importance of oral health's inclusion as a separate priority need by highlighting more data which show the need for improvement. For example, nearly 60% of Louisiana citizens do not have access to fluoridated water, and Louisiana continues to have a low rate of dental sealants among 3<sup>rd</sup> grade children. It was also argued that many dentists do not except Medicaid. Taken together these data helped to move the group to consensus on including oral health as a separate priority need.

Addressing high rates of preterm birth received a high level of support to include as a priority need. That preterm/low birth weight was identified as the leading cause of infant mortality in the

state was mentioned as one of the primary reasons why it deserved to be among the state's top priority needs. In addition, the rate of preterm birth among African American Americans is 4 times higher than that of Whites.

Unintentional and intentional injury was nominated for inclusion as a state priority need. This particular priority was suggested for inclusion because unintentional and intentional injury remains a leading cause of mortality for children 1 to 14 and children 15 to 19. There was also limited discussion of how intentional injuries are an issue for children special health care needs as well. There was no opposition to the inclusion of unintentional and intentional injury as a state priority need.

Racially based health disparities were also nominated as a state priority need. There was general agreement that reducing race based health disparities should be included among the states priority needs. The fundamental argument for including the reduction of race based health disparities as a priority need are the many Black White disparities observed across most of the health indicators examined by each of the subgroups. It was conveyed by some that reducing health disparities was an essential part of the work that we do in the MCH program. Much discussion was generated around how to properly articulate and structure a statement of how the MCH program would address race based health disparities.

Increasing care coordination for children with special health care needs was nominated as a state priority need. While access to Medicaid providers is still a priority reflected in both the physician survey and the family survey, improved insurance coverage continues to steadily improve access to care over time. The need for CSHS subspecialty clinics, while still present, is decreasing. As they gain access to care, CYSCHN, and in particular those with Medicaid, have a greater need for care coordination to increase their knowledge of healthcare services, including primary care, sub-specialty care, and public health and community resources. By improving care coordination in the Medical Home, families of CYSHCN will learn to depend on their MH for preventive care and support, thereby decreasing dependence on emergency rooms and hospital tertiary care and improving outcomes at lower expense.

Following the discussion of priority needs the LPHI liaison assisted participants through an exercise designed to help participants more fully develop identified priorities into priority need statements. The LPHI liaison provided two examples of priority needs statements to help participants in formulating and structuring need statements. Participants were encouraged to offer priority needs statements. Following a first attempt at formulating a needs statement other participants were allowed to modify statements until the group reached agreement on the statement. The following statements comprise the 2010 state priority needs: 1. Decrease infant mortality through reduction of preterm births in the African American population, 2. Decrease intentional and unintentional injuries in the maternal, child, adolescent, and CYSHCN populations, 3. Improve preconception and interconception health among Louisiana women, 4. Reduce unintended pregnancies and reduce births spaced less than 24 months apart, 5. Increase care coordination for CYSHCN and their families, 6. Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding, 7. Assure that strategies and methods in MCH and CYSHCN programs are culturally competent to reduce racial disparities, 8. Improve oral health of MCH and CYSHCN population by increasing access to preventive measures and access to oral health care, 9. Improve the behavioral health of the MCH and CYSHCN population through prevention, early intervention, screening, referral, and treatment, where appropriate, and 10. Increase preventive services for adolescents and transition services for youth with special health care needs (YSHCN).

### **Priorities Compared with Prior Needs Assessment**

The ten Title V priority needs for the MCH Block Grant Program created in 2005 were: (1) Decrease infant mortality and morbidity in collaboration with regional coalitions comprised of public and private health and social service providers; (2) Decrease intentional and unintentional injuries in the maternal, child, adolescent, and children with special health care needs (CYSHCN) populations; (3) Assure access to quality health care for the maternal, child, adolescent, and children with special health care needs populations, addressing barriers including Medicaid provider availability and lack of transportation; (4) Address the mental health needs of the maternal, child, adolescent, and CYSHCN populations, through prevention and early intervention, screening, referral, and where appropriate, treatment; (5) Address the substance abuse related needs of the maternal and adolescent population, through prevention and early intervention, screening, and referral; (6) Promote comprehensive systems of care and seamless transition to adult services for the CYSHCN population by providing care coordination. (7) Promote pre-conceptional and interconceptional health care including family planning and folic acid education; (8) Address the oral health needs of the maternal, child, adolescent, and CYSHCN populations; (9) Improve the health behaviors of the maternal, child, adolescent, and CYSHCN, addressing healthy nutrition, proper prenatal weight gain, breastfeeding, and physical activity; (10) Obtain and utilize reliable evidence to: a) identify preventable causes of maternal, child and adolescent mortality and morbidity, b) develop preventive public health campaigns targeting high risk populations, and c) perform process and outcome evaluation.

Following the 2010 needs assessment process the MCH and CSHS staff created the following new priority needs for Louisiana's Title V Block Grant program: 1) Decrease infant mortality through reduction of preterm births in the African-American population; 2) Decrease intentional and unintentional injuries in the maternal, child, adolescent, and CYSHCN populations. 3) Improve preconception and interconception health among Louisiana women; 4) Reduce unintended pregnancies and reduce births spaced less than 24 months apart; 5) Increase care coordination for CYSHCN and their families; 6) Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding; 7) Assure that strategies and methods in MCH programs are culturally competent to reduce racial disparities; 8) Improve oral health of MCH population by increasing access to preventive measures and access to oral health care; 9) Improve the behavioral health of the MCH population through prevention, early intervention, screening, referral, and treatment where appropriate; 10) Increase preventive services for adolescents and transition services for youth with special health care needs (YSHCN).

While many of Louisiana's maternal and child health problems identified in 2005 persist, obesity prevention and interconceptional health care have risen to the top priorities for the MCH Program. The percent of pregnant women and children with health insurance coverage has improved greatly, resulting in improved access to care for all MCH populations, including CYSHCN. Problems in navigating the system persist however for Medicaid-eligible CYSHCN who have increased need for healthcare services combined with a relative lack of providers who take Medicaid. The following factors have brought changes in the priorities since 2005.

Priority Need 1. Decrease infant mortality through the reduction of preterm births in the African-American population. The 2005 priority "decrease infant mortality and morbidity in collaboration with regional coalitions comprised of public and private health and social service providers" was replaced with this new focus on the primary contributing cause of infant mortality, preterm birth. Additionally, the large racial disparity in preterm births between African Americans and Whites

coupled with the large proportion of Louisiana births to African Americans (40%) makes clear where the focus of the MCH Program efforts should be.

Priority Need 2. Decrease intentional and unintentional injuries in the maternal, child, adolescent, and children with special health care needs populations. This priority was continued since injury remains as the leading cause of death among maternal, children and adolescent populations.

Priority Need 3. Improve preconception and interconception health among Louisiana women. The 2005 priority “Promote pre-conceptional and inter-conceptional health care including family planning and folic acid education” was replaced due to Louisiana’s MCH Program’s increasing focus on preconception and interconception health through the management of chronic diseases. Louisiana’s nine regional Fetal-Infant Mortality Review Panels’ featured Dr. Michael Lu, a leading expert on interconceptional health, at two of their annual conferences. Six of the nine regions ranked preconception and interconceptional health as a top priority need in 2010. The 2009 Louisiana Legislature passed a resolution for the development of interconceptional health coverage for Medicaid eligible women with chronic conditions and previous preterm births.

Priority Need 4. Reduce unintended pregnancies and reduce births spaced less than 24 months apart. The 2005 priority “Promote pre-conceptional and inter-conceptional health care including family planning and folic acid education” was replaced due to the findings from a Louisiana study that showed 3 times the odds of subsequent preterm births if pregnancy spacing was less than 18 months. Additionally, since 2005 a Family Planning Medicaid Waiver was approved for Louisiana and the MCH Program provided folic acid for Family Planning Program clients.

Priority Need 5. Increase care coordination statewide for CYSHCN and their families. The 2005 priority “Assure access to quality health care for the maternal, child, adolescent, and children with special health care needs populations, addressing barriers including Medicaid provider availability and lack of transportation” was replaced due to the decreasing need for MCH to provide prenatal and preventive pediatric care and the greatly improved insurance coverage of Louisiana’s children. Louisiana leads the nation in adequate prenatal care and according to a December 2009 Louisiana Health Insurance Survey, the 2009 estimate for uninsured children (under age 19 years) was 5.3%. Similarly, according to NS-CSHCN the percent of CYSHCN without health insurance at the time of the survey was only 5.1% (US 3.5%), and between 2001 and 2005/06 the percent of CYSHCN with Medicaid increased from 51.9% to 65.5%. However, data indicate twice the unmet need for care coordination among Medicaid eligible CYSHCN than those with private insurance (22.4% vs. 11.0%). According to 2007 NSCH, CYSHCN have almost 5 times the prevalence rate for not receiving comprehensive care coordination than children generally (7.9% vs. 34.4%) and have more difficulty getting referrals (34.9% vs. 7.9%). Both the family survey and the physician survey indicate that lack of Medicaid providers continues to be a top priority need among CYSHCN.

Priority Need 6. Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding. The 2005 priority “Improve the health behaviors of the maternal, child, adolescent, and children with special health care needs populations, addressing healthy nutrition, proper prenatal weight gain, breastfeeding, and physical activity” was replaced due to Louisiana’s low rate of breastfeeding and high rate of childhood obesity and the need for effective interventions.

Priority Need 7. Assure that strategies and methods in MCH programming are culturally competent to reduce racial disparities. The 2005 priority “Obtain and utilize reliable evidence to: a) identify preventable causes of maternal, child and adolescent mortality and morbidity, b)

develop preventive public health campaigns targeting high risk populations, and c) perform process and outcome evaluation” was replaced in order to highlight the wide racial disparities in health outcomes among the 2 main racial groups in the state, African Americans and Whites, and to target MCH resources to close this gap. The preterm and low birth weight rate among African Americans is four times the rate for Whites.

Priority Need 8. Improve oral health of MCH population by increasing access to preventive measures and access to oral health care. The 2005 priority need “Address the oral health needs of the maternal, child, adolescent, and children with special health care needs populations” was replaced due to low rates of Medicaid eligible children accessing any dental services (32.5%) and the low rate of dental sealants among 3<sup>rd</sup> grade children in Louisiana (33.2%).

Priority Need 9. Improve the behavioral health of the MCH population through prevention, early intervention, screening, referral, and treatment where appropriate. The 2005 priorities “Address the mental health needs of the maternal, child, adolescent, and children with special health care needs populations, through prevention and early intervention, screening, referral, and where appropriate, treatment” and “Address the substance abuse related needs of the maternal and adolescent population, through prevention and early intervention, screening, and referral” were combined to be consistent with Louisiana’s merger of the state Office of Mental Health and Office of Addictive Disorders into one Office of Behavioral Health.

Priority Need 10. Increase preventive services for adolescents and transition services for adolescents with special health care needs. The 2005 priority need “Promote comprehensive systems of care and seamless transition to adult services for the Children with Special Health Care Needs population by providing care coordination” was replaced due to the consensus of the priority-setting group to include a priority need targeting adolescents. Care coordination for CYSHCN was included in the Priority Need #5 above.

### **Priority Needs and Capacity**

The relationship between MCH’s priority needs and the four service levels of the pyramid is described below.

- 1) Decrease infant mortality through the reduction of preterm births in the African-American population

Infrastructure-Building services include the Epidemiology, Assessment, and Evaluation (EAE) section of Louisiana’s MCH Program. EAE includes four epidemiologists who provide the preterm and race specific data and analyses that guide the program development. MCH Fetal-Infant Mortality Review programs in each of the nine regions of the state are the hub of the maternal and infant component of the MCH program at the community level, providing the coordination of public and private health and related social services partners. Population-Based services include the Partners for Healthy Babies social marketing campaign addressing preterm birth prevention and promoting the toll free hotline linking women to prenatal care and other sources of preterm birth prevention services. Enabling Services include the Nurse Family Partnership Program and outreach and case management services funded by MCH to supplement the Healthy Start Programs in Louisiana. Direct Services include the provision of prenatal care in communities with poor access to private obstetric providers.

- 2) Decrease intentional and unintentional injuries in the maternal, child, adolescent, and children with special health care needs populations

Infrastructure-Building services include the EAE section of Louisiana's MCH Program. EAE includes an epidemiologist who coordinates with the OPH Injury Prevention Program to provide injury data and analyses that guide MCH's Child Safety program development. MCH provides the coordination of the Louisiana Child Death Review Panel that performs multi-disciplinary, multi-agency reviews of unexpected, unintentional child deaths of children under 15 years of age to develop a greater understanding of the causes of child deaths, the methods for preventing such deaths, and the gaps in services to reduce the incidence of injury and death to infants and children. A component of the Early Childhood Comprehensive Systems initiative established the Louisiana Parenting Education Network to prevent intentional and unintentional injuries by setting standards and competencies for parenting education in the state. MCH provides Infant Mental Health training for professionals working with children birth to age five, including children with special health care needs. Population-Based services include a statewide infant safe-sleep social marketing campaign and nine regional child safety coordinators providing health promotion and coordinating local child death review panels. Enabling services include the Nurse Family Partnership Program proven to reduce child abuse and emergency room visits for childhood injury.

### 3) Improve preconception and interconception health among Louisiana women

Infrastructure-Building services include Louisiana's Children's Cabinet Advisory Board's priorities to reduce infant mortality by addressing interconceptional health of women with chronic diseases. The 2009 Louisiana Legislature passed a resolution for the development of a demonstration project to cover inter-conceptional care of Medicaid eligible women with previous preterm birth and chronic disease. Six of the nine regional FIMR Programs identified preconception and inter-conception health as a top priority in the MCH 2010 needs assessment and serve as the coordinating body for program development. Population-Based services include a social marketing campaign promoting preconception and inter-conception health entitled *The Stork Reality*. Enabling Services include Nurse Family Partnership and case management programs in Healthy Start agencies expanded by MCH funding. Direct Services include enhanced funding from MCH to the Family Planning program for the distribution of folic acid to their patient population.

### 4) Reduce unintended pregnancies and reduce births spaced less than 24 months apart.

Infrastructure-Building services include Infrastructure-Building services include the Epidemiology, Assessment, and Evaluation (EAE) section of Louisiana's MCH Program. EAE includes four epidemiologists, including the Pregnancy Risk Assessment Monitoring System (PRAMS) that provide the specific data and analyses that guide the program development. One of the MCH epidemiologists is conducting the Louisiana Family Planning Medicaid waiver evaluation. Population Based services include the social marketing campaign *The Stork Reality*, that educates the public about the high rate of unintended pregnancies in the state. Enabling Services include the Nurse Family Partnership Program that is proven to increase pregnancy spacing. Direct Services include funding for the OPH Family Planning Program for delivery of direct patient care.

### 5) Increase care coordination for CYSHCN and their families.

Infrastructure- CSHS has engaged stakeholders in its new Advisory Group, which represents all key public health agencies that provide care coordination to CYSHCN, Families Helping Families (FHF), and Family to Family Health Information Centers (F2FHICs). CSHS has hired a

statewide care coordinator supervisor, who is a nurse and a certified case manager to teach care coordinators in pediatric practices to make referrals to public health and community resources. CSHS has developed region-specific resource guides to aid practices in care coordination. The CSHS Director leads a development rotation for all pediatric residents trained in Louisiana, emphasizing their role as medical home providers and teaching them about resources for CYSHCN. CSHS is also represented on Louisiana's Advisory Board for the Healthcare Quality Forum Medical Home Committee. Population-based services include a new care coordination initiative with web-based software in CSHS regional subspecialty clinics to address transition needs of YSHCN. CSHS provides funding and technical assistance for care coordinators in pediatric practices. CSHS also has the ability to identify children born with birth defects through the Louisiana Birth Defects Monitoring System, and has developed a resource book for families identified through this surveillance system. Children with hearing loss are identified through its newborn screening program, which assists in linking children with care coordination services through Early Steps and the Parent Pupil Education Program of the School for the Deaf. Direct and Enabling Services – CSHS partners with FHF and the F2FHICsto provide care coordination to families with CYSHCN coming to CSHS clinics. CSHS regional clinics are staffed with parent liaisons, social workers, social service counselors, nutritionists, audiologists, and contracted subspecialists who work together to provide care coordination for CSHS families.

6) Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding

Infrastructure –Building services include a childhood obesity prevention program, Nutrition and Physical Activity Self- Assessment for Child Care program, an evidence-based program designed to enhance policies, practices, and environments in child care settings by improving the nutritional quality of food served, the amount and quality of physical activity, staff-child interactions, and the facility nutrition and physical activity policies and practices and related environmental characteristics. MCH will also collaborate with Louisiana Department of Social Services to ensure Louisiana childcare licensure regulations include strong nutrition and physical activity policies. The MCH Program is represented on the Louisiana Council on Obesity Prevention and Management, a council mandated by state legislation. The MCH representative serves as co-chair of the Obesity Council's subcommittee Louisiana Action for Healthy Kids (LA AFHK). LA AFHK addresses the epidemic of childhood obesity by focusing on changes in schools to improve nutrition and increase physical activity. LA AFHK partners with families, community members, professionals and business to support schools in the effort to help children learn to eat right and be active every day. MCH funds *The GIFT* Program that supports birthing facilities in improving breastfeeding policies and practices by providing technical support and training to increase Louisiana's breastfeeding initiation and duration rates. Population-Based services include the Partners for Healthy Babies social marketing campaign which included breast feeding promotion and referral to resources at the community level. Enabling Services include the Nurse Family Partnership Program with a strong focus and success on clients opting to breast feed their infants.

7) Assure that strategies and methods in MCH programs are culturally competent to reduce racial disparities

Infrastructure-Building services include the Epidemiology, Assessment, and Evaluation (EAE) section of Louisiana's MCH Program. EAE includes four epidemiologists who provide the race specific data and analyses that target program development to the highest risk populations. Methods to increase sensitivity to interpersonal attitudes and behaviors that may reflect negative



cultural biases take place periodically with the MCH administrative staff. Educational programs on cultural competence, focusing on racial, economic and linguistic issues, are provided to staff of MCH programs including Nurse Family Partnership, child care health consultants, and other program staff who work within MCH. Population-Based services include health education strategies including Partners for Healthy Babies and the Safe Sleep social marketing campaigns, and the Happy and Healthy Kids parenting newsletter. Prior to implementing MCH health education strategies, formative and evaluative research is conducted with consumers to receive feedback on specific messages and to test relevance, appropriateness, and effectiveness of campaigns and materials. The campaigns and materials are simultaneously developed, produced and printed for Spanish-speaking audiences.

8) Improve oral health of MCH/CHSCN population by increasing access to preventive measures and access to oral health care

Infrastructure Building services include surveillance, epidemiology and evaluation to identify oral health needs and set priorities for the MCH/CHSCH population. The state-wide Oral Health Coalition, a diverse stakeholder group, addresses the issues of prevention, access, education and policy; and identifies strategies to improve the state's oral health indicators. Community Water Fluoridation (CWF) is a population-based preventive initiative that is promoted by the program and its partners. Future plans include the launching of an Oral Health web site and the development of communication plans for both CWF and dental sealants. Direct services include the school-based dental sealant program, applying dental sealants to the first molars of 2<sup>nd</sup> grade students in schools with 50% or more of the students on free or reduced lunch. This program initiative utilizes program partners, dental professionals and regional assistants to deliver this preventive service. Children Special Health Services contracts with the Louisiana State University Dental School to provide dental services at Children's Hospital in New Orleans for children with special health care needs.

9) Improve the behavioral health of the MCH population through prevention, early intervention, screening, referral, and treatment where appropriate

Infrastructure-Building Services include training in infant mental health and perinatal depression to numerous non-profit and public mental health clinicians throughout the state to enhance and expand clinical mental health services to this population. Population-Based services include a parenting newsletter consisting of 28 newsletters focusing on social-emotional health, mailed to Louisiana parents of children birth to age 5. Direct services include several behavioral health screening and intervention efforts. The Screening, Brief Intervention, Referral and Treatment initiative uses the *4PsPlus* validated screening tool to identify women at risk for substance use, domestic violence, and depression. If a need is determined by the health provider, the woman is referred for further evaluation and treatment when appropriate. Specially trained licensed mental health clinicians provide direct and consultative services to seven of the 17 Nurse Family Partnership (NFP) teams. In addition, there are clinical services for perinatal depression to participants of Nurse Family Partnership and Healthy Start in Orleans Parish and in the Lake Charles area. MCH has developed a Bereavement Support program, provided by specifically trained nurses and/or social workers to provide information to families regarding grief reactions, local support services, and referral, if needed, for further grief counseling. MCH funds Project LAST to provide grief and trauma intervention services to families who have lost an infant to SIDS, and to children ages infancy through 17 years who have experienced trauma/loss, violence, or disaster.

10) Increase preventive services for adolescents and transition services for YSHCN.

YSCHN Infrastructure - See #5 above for infrastructure for care coordination. The new CSHS stakeholder advisory group includes representatives from the Louisiana Rehabilitation Services' Independent Living Program, and the Vocational Rehabilitation Program, who assist with transition services for CYSHCN. Population-Based Services: Transition services for YSHCN are incorporated into CSHS care coordination in pediatric practices. In addition, CSHS has a long history of providing transition services in CSHS clinics. Recent pilots of a new web-based software system for developing care coordination plans have focused solely on youth in transition. Expertise on transition gained from CSHS clinics can be incorporated into resident teaching and recommendations for pediatric practices. Direct and Enabling: CSHS has a long history of providing transition services in CSHS clinics. Recent pilots of a new web-based software system for developing care coordination plans have focused solely on youth in transition.

Infrastructure-Building services include collaboration between the OPH Adolescent and School Health Program (ASHP) with the Department of Education and Louisiana Obesity Council on coordinated school health and obesity issues. ASPH provides training and technical assistance to all 58 School Based Health Center (SBHC) sites. Because most SBHCs are SCHIP/Medicaid application centers, SBHC staff conducts outreach that resulted in decreasing the percentage of uninsured students enrolled in SBHCs from 8% in 2006-2007 to 7% in 2007-2008. Population-Based services include the Partners for Healthy Babies and Stork Reality social marketing campaigns that address reproductive health promotion targeting adolescents. Enabling services include the Nurse Family Partnership Program with a median age of 19 years among program participants. Direct Services include the funding of 58 SBHCs providing comprehensive physical and mental health services to more than 56,000 students annually. MCH funding for the OPH Family Planning Program provides services for adolescents.

### **Priority Needs and MCH Program Capacity**

The relationship between MCH's priority needs and capacity is described below.

- 1) Decrease infant mortality through the reduction of preterm births in the African-American population

MCH staff and contracts dedicated to reducing infant mortality and preterm births include Maternal Health Medical Director, Nurse Consultant, Health Communication Coordinator, four Epidemiologists, two program managers, nine regional nurse coordinators of the Fetal Infant Mortality Review program and a contract for the social marketing campaign Partners for Healthy Babies. Other contracts with Healthy Start agencies and Office of Addictive Disorders address preterm prevention.

- 2) Decrease intentional and unintentional injuries in the maternal, child, adolescent, and children with special health care needs populations

MCH staff and contracts dedicated to injury prevention include Child Health Medical Director, two program managers, nine regional Child Safety Coordinators, three injury prevention program managers, two epidemiologists, over 100 Nurse Family Partnership nurses addressing intentional and unintentional injury, and a contract for social marketing campaign addressing safe sleep environments for infants.

- 3) Improve preconception and interconception health among Louisiana women

MCH staff and contracts dedicated to preconception and interconception health include Maternal Health Medical Director, Nurse Consultant, Health Communication Coordinator, four Epidemiologists, two program managers, nine regional nurse coordinators of the Fetal Infant Mortality Review program and a contract for the social marketing preconception health *The Stork Reality*. A new initiative at the Department of Health and Hospitals to improve birth outcomes will allow for more resources to address this important area of unmet need.

4) Reduce unintended pregnancies and reduce births spaced less than 24 months apart

MCH funds OPH Family Planning Program infrastructure at local and state health department. Four MCH epidemiologists address this subject and one is responsible for the Family Planning Medicaid Waiver evaluation. A contract for the social marketing preconception health *The Stork Reality* educates the public on the high unintended pregnancy rate. The Nurse Family Partnership Program is a proven to increase pregnancy spacing.

5) Increase care coordination for CYSHCN and their families.

CSHS central office staff include the director who is a board certified developmental pediatrician, a nurse consultant with over 30 years experience with CYSHCN, a social worker specializing in CYSHCN, a nurse certified case manager, a nutritionist, an audiologist who directs the hearing, speech, and vision program (HSV), and parent consultants for both the CSHS and HSV programs, and a strong public health program planning and epidemiology section. The Newborn Hearing Screening Program and the Louisiana Birth Defects Monitoring Network are programs within CSHS, permitting early identification of infants born with hearing loss and infants with birth defects for provision of care coordination. CSHS contracts with FHF to place parent liaisons in all CSHS clinics who meet with families to identify need for community resources. Collaboration with F2FHICs provides additional support for parent liaisons and families with CYSHCN requiring access to care coordination resources. CSHS has formed a new stakeholder advisory group with representatives from all public health programs from both Department of Health and Hospitals and the Department of Social Services that provide services for CYSHCN and their families, permitting improved coordination between programs.

6) Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding

MCH staff and contracts dedicated to nutritional health include an MCH Registered Dietician, a program manager of the breastfeeding promotion program in delivery hospitals, the Maternal and Child Health Medical Directors, the social marketing campaign Partners for Healthy Babies, the WIC Program, Louisiana Obesity Council, and collaborative initiatives with Tulane University School of Public Health and Louisiana State University (LSU) School of Public Health. A contract is being developed with LSU to establish an early childhood obesity prevention program through child care centers and the Louisiana Department of Social Services who administers child care quality assurance and licensing.

7) Assure that strategies and methods in MCH programs are culturally competent to reduce racial disparities

MCH contracts and staff dedicated to providing culturally relevant and appropriate resources include the Partners for Health Babies and Safe Sleep social marketing campaigns, Nurse Family Partnership program, tobacco control initiative, child care health consultant initiative, and obesity

prevention initiative. In addition, MCH staff and contracts dedicated to assuring cultural competency of its programming include four epidemiologists who provide the race specific data and analyses that guide program development.

8) Improve oral health of MCH population by increasing access to preventive measures and access to oral health care

MCH staff and contracts dedicated to oral health include two program managers, an epidemiologist, a health educator, fluoridation engineer, an Oral Health Advisory Council, and contracts for dentists and dental hygienists to apply dental sealants in elementary schools.

9) Improve the behavioral health of the MCH population through prevention, early intervention, screening, referral, and treatment where appropriate

MCH staff and contracts dedicated to behavioral health include Maternal Health Medical Director, Nurse Consultant, Health Communication Coordinator, four Epidemiologists, two program managers, a state Medical Director and nine regional coordinators of the Screening, Brief Intervention, Referral and Treatment program, and a contract for the social marketing campaign Partners for Healthy Babies.

10) Increase preventive services for adolescents and transition services for adolescents with special health care needs.

The Adolescent and School Health Program staff and contracts include a Program Manager, five Contract Monitors, a data manager, and contracts for operation of 58 School Based Health Centers statewide.

See #5 for capacity of CSHS program staff, contracts, and collaborations to provide care coordination services. New care coordination initiatives offer opportunities for improving transition services through contracts with pediatric offices for the provision of care coordination and incorporating transition needs into pediatric resident training. The CSHS Advisory Group also includes representatives from the Louisiana Rehabilitation Services' Independent Living Program, and Vocational Rehabilitation Program.

### **MCH Population Groups**

A concerted effort was made to assure that State priority needs identified represented the three major MCH population groups. As a result, priority needs could be categorized into one of three categories; 1) the priority need exclusively focused on one major MCH population group, 2) the priority need covered two major MCH population groups, 3) the priority need was relevant to all MCH population groups. Based on this categorization, increasing care coordination for CYSHCN and their families was the only priority need that exclusively focused on one population group. The remaining priority needs identified focused on more than one MCH population group.

There were several priority needs that represented two major MCH population groups. The following priority needs represent both maternal and infant population groups; 1. Decrease infant mortality through reduction of preterm births in the African American population, 2. Improve preconception and interconception health among Louisiana women, 3. Reduce the rate of unintended pregnancies and pregnancies spaced at less than 18 months, 4. Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding.

Lastly, the following priority need represented children and CYSHCN; Increasing preventive services for adolescents and transition services for youth with special health care needs.

Priority needs representing all three population groups included; 1. Decrease intentional and unintentional injuries in the maternal, child, adolescent, and CYSHCN populations, 2. Assure that strategies and methods in MCH and CYSHCN programs are culturally competent to reduce racial disparities, 3. Improve oral health of MCH and CHSCN populations by increasing access to preventive measures and access to oral health care, 4. Improve the behavioral health of the MCH population through prevention, early intervention screening, referral, and treatment, where appropriate.

### **Priority Needs and State Performance Measures**

The MCH program convened a meeting of the MCH program subgroup leaders, the MCH epidemiology staff, and other MCH staff that played an integral role in the needs assessment process to identify state performance measures for the state priority needs. The process of identifying state performance measures and linking these measures to priority needs relied on the expertise of subprogram leaders and the MCH epidemiology staff's knowledge of available data sources and expertise in research measurement methods. A list of current national performance measures (NPM) and previous state performance measures (SPM) were disseminated to all, allowing participants the opportunity to evaluate whether these performance measures would be useful in measuring success in meeting each priority need. As a result, a number of performance measures were linked to priority needs. In some instances, new performance measures were created and linked to priority needs if it was determined that previous performance measures would be insufficient in measuring success of a priority need. For the majority of priority needs there were multiple performance measures identified to measure success in meeting each priority need.

Priority Need 1. Decrease Infant mortality through reduction of preterm births in the African American population.

NPM's 8, 15, 17, and 18 were linked to priority need 1. NPM 8 measures the birth rate for teenagers aged 15 through 17. Teens have higher rates of premature birth than women over 20. In Louisiana, the teen birth rate among African American's is nearly 2 times higher than that of Whites. Because prematurity increases the risk of infant death, monitoring the teen birth rate is important in planning efforts to reduce infant mortality among African Americans. NPM 15 measures the percentage of women who smoke in the last three months of pregnancy. National performance measure 18 was selected because it provides an assessment of whether prenatal care is initiated early in pregnancy, increasing the likelihood of positive birth outcomes. NPM 17 measures the percent of very low birth weight infants delivered at facilities for high risk deliveries and neonates. This performance measure was linked with priority 1 because increasing the percentage of low birth weight deliveries at facilities with staff who have specialized training and technology to care for very low birth weight infants decreases the risk of infant death. SPM 5 measures the percent of late preterm births, those occurring at 34-36 weeks gestation. SPM 6 measures the percentage of women giving birth who have been screened for substance use, depression and domestic violence. SPM 7 measures the percent of women who use alcohol during pregnancy. These have all been shown to have a negative effect on birth outcomes. SMP8 measures the percent of African American women who most often lay their baby on their back to sleep.

Priority Need 2. Decrease intentional and unintentional injuries in the maternal, child adolescent and CYSHCN populations.

NPM's 10, 16 and SPM 3, 6 and 8 were linked to priority need 2. NPM 10 assesses the rate of deaths to children aged 14 years and younger caused by motor vehicle crashes. This measure was linked to priority need 2 because motor vehicles are the leading external cause of injury related mortality among children. NPM 16 measures the rate of suicide deaths among youth ages 15 to 19. Suicide is the third leading cause of injury related mortality among children in this age range. SPM 3 measures the rate of children under 18 who have been abused or neglected. This performance measure was selected as a result of data which show that nearly 10% of children in Louisiana are reported to be abused or neglected. SMP8 measures the percent of African American women who most often lay their baby on their back to sleep. SPM 6 measures the percentage of women giving birth who have been screened for substance use, depression and domestic violence.

Priority Need 3. Improve preconception and interconception health among Louisiana women.

NPM 15 and SPM's 7 and 9 were linked to priority need 3. NPM 15 and SPM 7 assess the percent of women who smoke and drink in the last trimester of pregnancy respectively. As such they provide an assessment of the risky behaviors among women during pregnancy. SPM 9 measures the percent of women who visited a healthcare worker to be checked or treated for high blood pressure during the 12 months before pregnancy. This performance measure was linked to priority need 3 as it is a direct measure of the health of women prior to pregnancy.

Priority Need 4. Reduce unintended pregnancies and reduce births spaced less than 24 months apart.

SPM 2 measures the percent of unintended pregnancies among women who had a live birth. SPM 2 is linked to priority need 4 because it provides a direct measure of pregnancy intention. SPM 10 measures the percent of women delivering a live birth in less than 24 months of a previous live birth.

Priority Need 5. Increase care coordination for CYSHCN and their families.

SPM4 measures the difference in the percent of publicly insured and percent of privately insured CYSHCN in Louisiana who need more care coordination services. NPM 2 measures the percent of children with special health care needs age 0 to 18 whose families partner in decision-making at all levels and are satisfied with the services they receive. NPM 3 measures the percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. NPM 5- The percent of children with special health care needs age 0 to 5 whose families report the community-based service system are organized so that they can use them easily.

Priority Need 6. Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding.

NPM's 11 and 14 were linked to priority need 6. NPM 11 assesses the percentage of mothers who breastfeed their infants at 6 months of age. This performance measure was linked to priority need 6 because it provides an assessment of breastfeeding duration. NPM 14 measures the percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index at or above the

85<sup>th</sup> percentile. This measure provides insight into the percentage of obese children receiving WIC services. As such, this performance measure provides information important to developing interventions early in development that may stem the tide of obesity later in life.

Priority Need 7. Assure that strategies and methods in MCH programs are culturally competent to reduce racial disparities.

SPM 8 was linked to Priority Need 7. It measures the percentage of African American women who most often lay their baby on their back to sleep. This measure assess MCH's efforts to increase back sleeping among the African American population through targeted initiatives including the Safe Sleep social marketing campaign.

Priority Need 8. Improve oral health of MCH and CYSHCN populations by increasing access to preventive measures and access to oral health care.

NPM 9 was linked to priority need 8. NPM 9 measures the percent of third grade children who received protective sealants on at least one permanent molar tooth. This variable is a standard oral health measure collected by the state oral health program and used to examine the oral health of children. It is also a measure collected across states allowing for cross state comparisons.

Priority Need 9. Improve the behavioral health of MCH and CYSHCN populations through prevention, screening referral, and treatment, where appropriate.

NPM 15 and SPM's 6 and 7 were linked to priority need 9. NPM 15 and SPM 7 measure the percentage of women who smoke and drink in the last 3 months of pregnancy respectively. These performance measures provide some indication of the extent to which behavioral health services and interventions are needed. SPM 6 measures the percent of Louisiana women giving birth who are screened for substance use, depression and domestic violence using SBIRT. This particular measure was selected because it provides an assessment of the magnitude of behavioral problems that affect Louisiana women.

Priority Need 10. Increase preventive services for adolescents and transition services for youth with special health care needs.

NPM 6 and SPM 1 were linked to priority need 10. NPM 6 measures the percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. This measure comes from the CYSHCN survey and is worded to be identical to priority need 10. SPM1 measures the percent of all children and adolescents enrolled in public schools in Louisiana that have access to school based health center services. This measure was linked to priority need 10 because it provides some data on the extent to which preventive services are available in school based health centers. As such it is also an indirect assessment of preventive services needed.

## **Section 6 Outcome Measures – Federal and State**

Priority Need 1: Decrease infant mortality through reduction of preterm births in the African American population

Related Performance Measures (PM):  
National Performance Measures:

NPM 8-The birth rate (per 1,000) for teenagers aged 15 through 17 years  
NPM 15- Percentage of women who smoke in the last three months of pregnancy  
NPM 17-Percent of very low birth weight infant delivered at facilities for high-risk deliveries and neonates  
NPM 18- Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester

**State Performance Measures:**

SPM 5 (new) – Percent of late preterm births, those occurring at 34-36 weeks gestation  
SPM 6 – Percent of women giving birth who undergo screening for substance abuse, depression and domestic violence using SBIRT approved methods  
SPM 7 – Percent of women who use alcohol during pregnancy  
SPM 8- Percent of African American women who most often lay their baby on their back to sleep.

**Outcome Measures:**

OM 1- The infant mortality rate per 1,000 live births  
OM 2- The ratio of the Black infant mortality rate to the White infant mortality rate  
OM 3- The neonatal mortality rate per 1,000 live births  
OM 4- The post-neonatal mortality rate per 1,000 live births

**Existing Activities:**

MCH assists parish, regional, and state MCH and public health leaders to address infant mortality through data analysis, technical assistance and funding of interventions. MCH funds Infant Mortality Reduction coordinators in each of the 9 regions to assure the infrastructure and capacity is in place to address this problem. In order to gather more detailed information on perinatal deaths, OPH funds the Fetal-Infant Mortality Review (FIMR) in all regions. MCH funds community-based outreach, case management and home visiting programs statewide and prenatal care in areas with limited access. In addition, MCH administers public information and media campaigns to reduce infant mortality promoting early prenatal care and healthy behaviors, and SIDS risk reduction. Communication is population-based and includes multi-media presentation and direct presentations (speeches, health fairs). MCH co-funds the SBIRT-Screening, Brief Intervention, Referral, and Treatment program with the state Office of Behavioral Health which addresses maternal substance use, depression, and domestic violence. The MCH Director serves on the state Commission on Perinatal Care and Prevention of Infant Mortality. To reduce mortality due to congenital anomalies and birth defects, the Birth Defects Monitoring Network performs surveillance.

These direct care, enabling, population-based, and infrastructure building interventions address the known contributing causes of infant mortality. The research on infant mortality continues to leave unanswered many of the contributing causes of preterm births and infant mortality. Nationally and in Louisiana, the disparities in preterm births are extreme among the African American and White populations. In Louisiana, 39 percent of the births are to African Americans compared to 15 percent in the U.S. Other factors beyond the control of MCH are the social determinants of health, such as Louisiana's high poverty rate. MCH funds the Nurse Family Partnership Program statewide that is proven to address social issues such as increasing workforce participation and decreasing maternal arrest rates. However, Louisiana's excellent ranking in prenatal care adequacy does not translate to good outcomes such as infant mortality and preterm births.

**New Activities:**



Infants born between 34 and 36 weeks gestation, referred to as “late preterm,” have a higher incidence of morbidity and mortality when compared with term infants (37-42 weeks). Among preterm births (<37 completed weeks), late preterm infants are both the largest proportion and the fastest growing subgroup. Much of these higher rates are due to complications necessitating early delivery, including some birth defects, rather than due to early delivery itself. Late preterm infants incur greater costs and longer lengths of stay in neonatal intensive care units and experience higher rates of re-hospitalization after neonatal discharge.

Louisiana plans to begin a late preterm birth initiative to decrease the numbers of infants electively born at this gestation which will include the review of non-medically indicated interventions to deliver early. Elective induction should follow ACOG guidelines which call for confirmation of 39 weeks gestation for singleton births under most circumstances. Medicaid and insurance payment reform will be proposed such that a consultation with a perinatologist is required for late preterm cesarean sections or labor induction before 39 weeks gestation.

Priority Need 2: Decrease intentional and unintentional injuries in the maternal, child, adolescent, and children with special health care needs populations.

Related Performance Measures (PM):

National Performance Measures:

NPM 10- The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children

NPM 16- The rate (per 100,000) of suicide deaths among youths 15-19

State Performance Measures:

SPM 3– The rate of children (per 1,000) under 18 who have been abused or neglected

SPM 6 – Percent of women giving birth who undergo screening for substance abuse, depression and domestic violence using SBIRT-HBI approved methods

SPM 8- Percent of African American women who most often lay their baby on their back to sleep.

Outcome Measure:

OM 1- The infant mortality rate per 1,000 live births

OM 6 – The child death rate per 100,000 children aged 1-14

#### Existing Activities:

MCH funds a comprehensive child safety/injury prevention program to address injury-related mortality through case reviews, data analysis, technical assistance, and state/community-based injury prevention educational outreach via health fairs, special safety and media events, and presentations. The Child Death Review Panel, which is managed by the MCH Program, reviews all unexpected deaths in children under the age of 15, including SIDS, and makes prevention intervention recommendations. MCH funds the full-time Child Death Review Panel Coordinator position along with complete infant death scene investigations and autopsies which meet AAP/National Center for Child Death Review standards. MCH funds a network of Regional MCH Child Safety Coordinators who also serve as the local Child Death Review Panel Coordinators and who work to decrease unintentional injuries in children in each of the 9 Office of Public Health regions. Prevention interventions address motor vehicle/child passenger safety; fire and safety; home, child care center, and playground safety; bicycle and pedestrian safety; accidental suffocation and infant safe sleep environments. The MCH Child Care Health

Consultant Program provides training on out-of-home child care health and safety standards to health and safety professionals who then provide health and safety trainings to child care centers.

The Best Start program addresses primary prevention of family violence. Children's Bureau-Project Last provides crisis intervention services, funded by MCH, to children and families who have experienced violence and provides community education about violence prevention. MCH funds the Nurse Family Partnership, a psycho-social intervention for first time mothers of low socioeconomic status proven to reduce child maltreatment. MCH collaborates with the Office of Mental Health (OMH) to provide mental health support and services to the Program. MCH and CSHS collaborate with the OMH Early Childhood Supports and Services (ECSS) program that provides mental health services to children from birth to age 5. MCH distributes a parenting newsletter to interested Louisiana parents. The series emphasizes developing healthy infant caregiver relationships, healthy social and emotional development, parent and parenting issues, and mental health concerns. Public health nurses assist child protection workers in investigating suspected cases of medical neglect, malnutrition and failure to thrive, through an interagency agreement with Office of Community Services. A 30-hour Infant Mental Health (IMH) Educational Series is provided to professionals who work with young children.

#### New Activities:

MCH will develop an injury prevention strategic plan to address the top safety priority areas identified by the MCH Needs Assessment. The data book of unintentional injury-related fatalities of children ages 0-14 years from 2002-2007, which was developed for the MCH Child Safety Needs Assessment, will be disseminated electronically to MCH partners and posted on the MCH website. Media outreach will include the implementation of the infant Safe Sleep campaign and the development of an injury prevention media plan for child passenger safety and falls prevention. Also, an Injury Prevention web page will be added to the MCH Program's website to display such information as injury-related data and reports, safety resources, fact sheets, educational materials, contact information for the MCH Child Safety/Child Death Review Staff, MCH Child Safety Coordinators, and Child Care Health Consultants.

For unintentional injuries of children, prevention activities related to unintentional firearm injury-related fatalities, other causes of accidental suffocation, and falls will be addressed at the state and community levels. Evidence-based Teen Driver Safety Programs will be assessed for promotion by the Louisiana Child Death Review, MCH Child Safety Initiative, the Injury Research and Prevention Program, and the Adolescent School Health Initiative for implementation at the community levels. For intentional injuries, bullying and teen dating/partner violence prevention activities will be addressed through an integrative partnership with the Injury Research and Prevention Program. Case reviews of children ages 10-18 years who died by suicide will be supported by Louisiana Child Death Review. Child maltreatment/Child safety has been added as a priority area of the BrightStart Advisory Council and integrative, inter-agency infrastructure-building activities will be selected for implementation by a BrightStart child maltreatment/child safety work group.

Priority Need 3: Improve preconception and interconception health among Louisiana women  
Related Performance Measures:

National Performance Measures:

NPM 15- Percent of women who smoke in the last three months of pregnancy

State Performance Measures:

SPM 7 Percent of women who use alcohol during pregnancy

SPM 9- Percent of women who visited a healthcare worker to be checked or treated for high blood pressure during the 12 months before pregnancy

Existing Activities:

The NFP program has a strong focus on the inter-conceptional health of its clients, addressing physical health issues including postpartum care and family planning; mental health issues including depression and domestic violence; and social health issues including educational and vocational attainment.

MCH sponsored a conference on pre and interconceptional health with 130 health professionals attending with Michael Lu, M.D., a noted expert, as the featured speaker. MCH provides funding for folic acid to be distributed to OPH Family Planning patients.

The Stork Reality was initiated in the Fall 2009 as a sub-campaign of the MCH Partners for Healthy Babies project in order to address pre and interconception health utilizing health communication strategies. Traditional multi-media (TV/Radio/Print/Website) tactics are employed along with social media (Facebook, Twitter) components. In addition street teams and a 7 ft Stork visit restaurants, bars, football games, and fairs and events statewide to engage target audiences and distribute messages about interconceptional health.

New Activities:

MCH plans to collaborate with Louisiana Department of Health and Hospital's new Birth Outcomes initiative by implementing a program that begins with women who are already Medicaid eligible for health care services past the postpartum period. These include women receiving Temporary Assistance for Needy Families and Supplemental Security Income benefits. The goal is to provide primary health care, chronic disease management and social support for these women. The project will be accomplished through care coordination for enrollees by definition of an individualized interpregnancy care plan based on assessments of medical and social risks for subsequent poor pregnancy outcomes; provision of primary health care in accordance with the individualized interpregnancy care plan for 24 months; and assist in achieving a woman's desire for subsequent pregnancies and her need for optimum child spacing (ideally 18-20 months); and provision of appropriate social services and community outreach in each woman's community. High risk women will be the target of this project and will be defined by women who have preterm or low birth weight delivery, diabetes, hypertension, and other chronic diseases.

MCH provides funding to the Family Planning Program and collaborate on pre and interconception health activities. The Family Planning Program (FPP) will work with communities to improve the percentage of family planning clients receiving multivitamins which include folic acid. FPP will refer smokers to the *FAX to Quit* Program which provides follow up to women interested in stopping smoking. FPP will develop a protocol for postpartum women coming to parish health units for FP or WIC services to be sure they have an appointment for Family Planning services and to follow up with women who had a preterm birth at future visits.

Priority Need 4: Reduce unintended pregnancies and reduce births spaced less than 24 months apart

Related Performance Measures:

State Performance Measures

SPM 2 – Percent of unintended pregnancies among women who had a live birth

SPM 10 - Percent of women delivering a live birth in less than 24 months of a previous live birth

Existing Activities:

MCH provides funding for the operation of the Family Planning program and provided leadership and technical assistance for the development of the Louisiana Family Planning Medicaid Waiver. MCH is conducting the evaluation for the Family Planning Medicaid Waiver program.

New Activities:

Family Planning Program will implement a pre and interconception health component to their services by making sure women with previous preterm, previous infant death, and pregnancy within past 15 months receive follow up and are given appointment as one of the highest priority patients in places where access is a problem.

Health Communication materials and messages are designed and distributed statewide to increase the target audience's awareness of unintended pregnancy, and to promote the cluster of behaviors related to women's health (folic acid, nutrition, sexually transmitted infections, family planning, exercise, and stress) that also lead to future improved birth outcomes. The Stork Reality Campaign has implemented a lead message that increases the target audience's awareness that 50 % of pregnancies are not planned.

Priority Need 5: Increase care coordination for CHSCN and their families

Related Performance Measures:

State Performance Measure:

SPM4 - The difference in the percent of publicly insured and percent of privately insured CYSHCN in Louisiana who need more care coordination services

National Performance Measures:

NPM 2- The percent of children with special health care needs age 0 to 18 whose families partner in decision-making at all levels and are satisfied with the services they receive.

NPM 3- The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home

NPM 5- The percent of children with special health care needs age 0 to 5 whose families report the community-based service system are organized so that they can use them easily.

Existing Activities:

CSHS central office staff include the director who is a board certified developmental pediatrician, a nurse consultant with over 30 years experience with CYSHCN, a social worker specializing in CYSHCN, a nurse certified case manager, a nutritionist, an audiologist who directs the hearing, speech, and vision program (HSV), and parent consultants for both the CSHS and HSV programs, and a strong epidemiology section. The Newborn Hearing Screening Program and the Louisiana Birth Defects Monitoring

Network are programs within CSHS, permitting early identification of infants born with hearing loss and infants with birth defects for provision of care coordination. Parent liaisons contracted from Families Helping Families in all CSHS clinics meet with families to identify need for community resources. Collaboration with F2FHICs provides additional support for parent liaisons and families with CYSHCN requiring access to care coordination resources. CSHS provides financial incentives for MH's to designate a care coordinator, and provides technical assistance to practices through its nurse certified case manager and social worker. CSHS trains all pediatric residents from both medical schools in the role of MH in care coordination and in public health and community resources. CSHS has formed a new stakeholder advisory group with representatives from all public health programs from both Department of Health and Hospitals (DHH) and the Department of Social Services (DSS) that provide services for CYSHCN and their families, permitting improved coordination between programs. CSHS participates in a DSS-DHH data integration project to make public health services easier to access for families by providing single point of entry into multiple programs.

New Activities:

CSHS will expand care coordination in CSHS clinics to 2 additional regions.

CSHS will expand care coordination to 4 additional private physician practices through incentive contracts.

CSHS will improve medical home capacity by addressing training needs of private providers identified by CSHS Needs Assessment and disseminating region-specific information to pediatric and family practice clinics on community-based resources, family support organizations and public health resources.

CSHS will disseminate self-advocacy skills information in CSHS clinics and during health fairs and community outreach events via CSHS Parent Liaisons.

CSHS will increase knowledge of and referral to programs that serve CYSHCN among front-line staff by sponsoring multi-program community resource information workshops.

CSHS will work with DHH administration and the AAP to ensure that the needs of CYSHCN are considered in LA's health care reform and ensuring that CC is reimbursed adequately.

Priority Need 6: Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding

Related Performance Measures:

National Performance Measures:

NPM 11- Percentage of mothers who breastfeed their infants at 6 months of age

NPM 14- Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile

Existing Activities

Parish health units provide all pregnant women with extensive counseling and education on healthy nutrition, breastfeeding and proper weight gain. Families of children receiving WIC services receive counseling and educational materials. MCH has initiated a breastfeeding promotion program entitled The Gift. This intervention targets delivery hospitals and seeks to

certify the hospitals as a "breastfeeding-friendly" once a list of requirements are met. Breastfeeding coordinators in each parish health unit and peer educators promote breastfeeding among the WIC population.

#### New Activities

To address the increasing concern of childhood obesity in our state, Louisiana MCH is planning a childhood obesity prevention program in childcare programs across the state. The childcare program will include a Registered Dietitian working with childcare settings to implement the NAP SACC (Nutrition and Physical Activity Self- Assessment for Child Care) program, an evidence-based program designed to enhance policies, practices, and environments in child care by improving the nutritional quality of food served, the amount and quality of physical activity, staff-child interactions, and the facility nutrition and physical activity policies and practices and related environmental characteristics. Louisiana MCH will also collaborate with Louisiana Department of Social Services to ensure Louisiana childcare licensure regulations include strong nutrition and physical activity policies.”

Priority Need 7: Assure that strategies and methods in MCH programs are culturally competent to reduce racial disparities

#### Related Performance Measures:

##### State Performance Measure

SPM 8- Percent of African American women who most often lay their baby on their back to sleep.

##### Outcome Measure:

OM 2- The ratio of the Black infant mortality rate to the White infant mortality rate

#### Existing Activities

The MCH program provides ongoing educational and training opportunities to enhance cultural competence among staff with the goal of increasing sensitivity to interpersonal attitudes and behaviors. These initiatives address sensitivity to the variety of cultural needs and issues encountered in MCH settings and populations. Staff of MCH programs including Nurse Family Partnership and child care health consultants receive cultural competency guidance focusing on racial, economic and linguistic issues.

MCH’s social marketing efforts, such as its health and safety campaigns, the Partners for Healthy Babies website, targeted public service announcements, flyers and the *Happy and Healthy Kids* newsletter are crafted with the primary goal of reaching the diverse MCH population. As a result, health education strategies include formative and evaluative research which is conducted with consumers to receive feedback on specific messages.

MCH’s Safe Sleep efforts encompass several programmatic components to ensure safe sleeping environments for infants. The Safe Sleep social marketing campaign targets African American women in an effort to provide education on the importance of placing an infant on his or her back to sleep. In addition, MCH engages in ongoing market research to develop strategies to effectively target hard to reach African American women. The initiative also provides ongoing technical assistance for development of policy and regulatory standards related to the safe sleep environment in licensed childcare facilities and collaborates with existing community-based

agencies and organizations in promotion of safe sleep environment messages and provision of trainings.

MCH also provides educational materials in other languages as part of its effort to enhance cultural competency. Many of the health education materials, including SIDS risk reduction and perinatal depression materials, are developed, produced and printed to reach Spanish-speaking audiences. Also, language translation services are available in the Louisiana Department of Health and Hospitals. The Office of Public Health (OPH) contracts with the ATT Language Line Service to provide translation in the appropriate language for non-English speaking clients in the public health units. The Louisiana Medicaid online and paper enrollment process and educational information are available in Spanish and Vietnamese.

#### New Activities

The maternity program will develop and evaluate approaches that ensure access to pre and interconception health resources such as diabetic educational information. Staff will examine the impact of race, ethnicity and other cultural influences on access and will develop culturally appropriate methods to increase access to health services and resources for women of reproductive age. These methods will complement MCH's existing activities to ensure cultural competence throughout its programming.

In the coming year, MCH will strengthen its partnership with the state's Tobacco Control Program and Tobacco Free Living Program in an effort to target cessation efforts on pregnant women. MCH will provide resources to staff a full time position that will work with tobacco control staff. Staff will develop and evaluate approaches that ensure tobacco referrals and interventions are provided in a culturally competent manner to ultimately reduce disparities in access to Quitline services.

Priority Need 8: Improve oral health of MCH and CSHCN population by increasing access to preventive measures and access to oral health

Related Performance Measures:

National Performance Measure:

NPM 9 – Percent of third grade children who have received protective sealants on at least one permanent molar tooth

#### Existing Activities

The Oral Health Program (OHP), in conjunction with the Fluoridation Advisory Board of Louisiana and the Health Smiles Coalition works with non-fluoridated communities to initiate fluoridation. In addition, the OHP provides funding and technical assistance for community water fluoridation projects to both update existing systems to bring the system into compliance with the rules of operation and with new systems to initiate fluoridation. Through direct service and partnership with community resources, school-based sealant initiatives are being implemented in 12 parishes. The OHP implemented a surveillance plan to collect and analyze data to define the burden of oral disease in Louisiana. In addition the OPH promoted dental services for Medicaid eligible children, supporting legislative efforts to increase the reimbursement through the analysis and reporting of usage data. The OPH also promoted dental services for pregnant women with periodontal disease to pregnant women, prenatal providers, and dentists.

CSHS funds a Dental Clinic for CYSHCN in the New Orleans area. Services are provided by LSU School of Dentistry and are designed to be readily accessible to this population, known to have barriers to accessing regular dental care. This project also enhances training for dental students in providing care to CYSHCN. CSHS provides assistance for non-Medicaid eligible children to receive routine dental services through the private sector.

Oral Health Screening Survey was conducted to determine the oral health status of school-aged children. School nurses and OHP staff screened 3<sup>rd</sup> grade students statewide. Seventy-five schools were randomly selected to be included in a representative sample of the 3<sup>rd</sup> grade student population. The survey included an assessment of the children's oral health status and determination of the presence of dental sealants on permanent 1<sup>st</sup> molars.

To better address the oral health needs of the state, the program is providing and guidance and expertise in the organization and development of a state-wide Oral Health Coalition. In this organizational year, the Coalition members have created a draft of an Oral Health State Plan to address the many issues affecting oral health in Louisiana. The program and the Coalition are also developing a Policy Action Plan designed to identify and address policy issues that affect prevention, assess and work force issues.

#### New Activities:

In the coming year, the Oral Health Program (OHP), has identified one new community to initiate fluoridation and two communities that need financial assistance to upgrade equipment to meet newly revised operational standards. The program in partnership the Fluoridation Advisory Board, the Health Smiles Coalition, local chapters of the Dental and Dental Hygiene Associations, and the DHH Regional staff will launch a grass-roots community education campaign in two targeted areas. Eventually the program will expand this campaign, reaching all regions of the state. Through direct service and partnership with community resources, school-based sealant initiatives are planning to serve 15 parishes. The OHP will use the resources and newly formed Oral Health Coalition to promote the Medicaid covered dental services for pregnant women with periodontal disease to pregnant women, prenatal providers, and dentists. The OHP will work with our program stakeholder to promote stability for the continuation of the Oral Health Coalition and implementation of the Oral Health State Plan. The OHP will continue our efforts to implement Medicaid reimbursement for the application of dental sealants under the direction of the OHP. The OHP and the Policy group of the Oral Health Coalition will work to bring about policy and/or systems changes that will result in increased access to dental services for the MCH population.

Priority Need 9: Improve the behavioral health of the MCH and CHSCN population through prevention, early intervention, screening, referral, and treatment, where appropriate

Related Performance Measures:

National Performance Measure:

NPM 15- Percentage of women who smoke in the three months of pregnancy

State Performance Measures:

SPM 7-Percent of women who use alcohol during pregnancy

SPM 6- Percent of Louisiana resident women giving birth who undergo screening for substance use, depression and domestic violence using the SBIRT-HBI approved methods

#### Existing Activities

MCH co-funds the SBIRT-Screening, Brief Intervention, Referral, and Treatment program with the state Office of Behavioral Health which addresses maternal substance use, depression, and



domestic violence. Referrals are made to local substance abuse treatment facilities, mental health resources and battered women shelters. Contracts with the state Office of Addictive Disorders provides pregnancy testing for women in treatment for substance abuse. MCH targets smoking cessation services for perinatal populations. All Louisiana School-Based Health Centers (SBHCs) must employ a minimum of one full-time, qualified behavioral health professional to provide direct behavioral health care. Behavioral health services include psychosocial assessments, treatment plans, individual and group counseling, progress/follow-up notes, and any activity related to the psychosocial/emotional well-being of the child. There are a few SBHCs that were given prior authorization to have a part-time behavioral health provider.

Specially trained licensed mental health clinicians provide direct and consultative services to 7 of the 16 Nurse Family Partnership (NFP) teams. These clinicians support NFP nurses in the identification of women in need of mental health services, guide nurses in providing support as appropriate, provide direct in-home services as needed, and assist with referral to more intensive services when indicated. In addition, there are clinical services for perinatal depression to participants of Nurse Family Partnership and Healthy Start in Orleans Parish and in Region 5 (Lake Charles area).

The Children's Bureau Project LAST is contracted by the MCH program to provide grief and trauma intervention services to families who have lost an infant to sudden infant death syndrome, or SIDS, and to children from infancy through 17 years of age who have experienced trauma/loss, violence, or disaster. Children's Bureau of New Orleans is a private, non-profit United Way partner which offers a variety of counseling services to children and families in New Orleans.

Existing Activities:

CSHS clinic staff assess the behavioral health needs of patients and provide needed referrals to community-based services.

CSHS PLs statewide inform families of CYSHCN of available resources to address behavioral health needs during health fairs and community outreach events.

Priority Need 10: Increase preventive services for adolescents and transition services for youth with special health care needs (YSHCN)

Related Performance Measures:

National Performance Measure

NPM 6- The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence (CYSHCN Survey)

State Performance Measure:

SPM 1- Percent of all children and adolescents enrolled in public schools in Louisiana that have access to school-based health center services

Existing Activities:

CSHS staff complete transition screenings in direct clinical settings in all 9 regions and provide service coordination for identified needs for YSHCN. Two regions provide more intensive care coordination for youth in transition.

Transition screening is provided in 2 academic primary pediatric practices through incentive contracts for care coordination to CYSHCN in private physician practices.

CSHS central office staff disseminate region-specific information on transition services to CSHS regional clinics and private physician practices.

Regional CSHS Parent Liaisons (PLs) provide transition information and guidance at local health fairs and in conjunction with other local parent training and community events.

CSHS works closely with a liaison from the Medicaid Office to facilitate applications for YSHCN to other appropriate Medicaid programs especially for youth over age 19 that become ineligible for LaCHIP.

#### **New Activities:**

CSHS will expand care coordination focusing on youth in transition in CSHS clinics to 2 additional regions and continue screening and providing service coordination for adolescents over age 14 for transition needs in the other 5 regions.

CSHS will expand care coordination in 4 additional private primary care practices, all of which will include transition screening and services. CSHS will also disseminate region-specific information on transition services to each office.

CSHS will educate and support families/YSHCN on transition through participation in health fairs and trainings in all nine regions by CSHS Parent Liaisons.

CSHS will disseminate region-specific information on transition services to Federally Qualified Health Centers, school based health clinics, adult and pediatric orthopedic and neurology subspecialists.

CSHS will participate in multi-agency collaborations targeted at comprehensive, coordinated transition services for YSHCN.

CSHS will submit transition articles to the state AAP and LAFP newsletters to inform physicians about needs of YSHCN in transition and about newly available and/or expanded transition services.

CSHS will create a transition section on the CSHS website to provide links to transition service information.

CSHS will develop an informational brochure on transition for dissemination to various public and private clinics serving YSHCN.

#### **New Activities**

Statewide implementation of a hypertension screening, diagnosis, monitoring, and referral protocol based on the results of a 2009-2010 hypertension pilot to evaluate and update current screening tools and practice within SBHCs, based on CDC and AAP best practices recommendations.

### **C. MCH Needs Assessment Summary**

The Louisiana MCH Program engaged in a thorough process to establish priority needs for MCH and CSHCN populations for the period 2010-2015. Through extensive quantitative and

qualitative analyses, , MCH leaders identified the leading priorities needs for women, infants, children, and CYSHCN while also assessing local, regional, and state capacity to address these priorities. The 2010 needs assessment process reminded leaders that several MCH problems identified in 2005 remain today. Infant mortality, child injuries, care coordination for the CSHCN population and oral health remain leading priorities for Louisiana MCH population. Yet, the 2010 assessment underscored the need for greater emphasis on obesity prevention and interconceptional health care. Access to prenatal care and insurance coverage for women, children and YSHCN continues to improve since the 2005 Needs Assessment.

**Priority Need 1. Decrease infant mortality through the reduction of preterm births in the African-American population.** The 2005 priority “decrease infant mortality and morbidity in collaboration with regional coalitions comprised of public and private health and social service providers” was replaced with this new focus on the primary contributing cause of infant mortality, preterm birth. The regional Infant Mortality Reduction Initiative (IMRI) has created strong infrastructure in each of the 9 regions of Louisiana, consisting of a public-private collaboration of health providers and community leaders. IMRI coordinators will continue to be funded by MCH and will lead new interventions aimed at reducing infant mortality and preterm births. The large racial disparity in preterm births between African Americans and Whites coupled with the large proportion of Louisiana births to African Americans (40%) justified this focus. The social marketing campaigns funded by MCH to address contributing causes of infant mortality will have a greater focus on the African American population in order to address these disparities.

**Priority Need 2. Decrease intentional and unintentional injuries in the maternal, child, adolescent, and children with special health care needs populations.** This priority was continued since injury remains as the leading cause of death among maternal, child, and adolescent populations. In 2005 the regional Injury Prevention Coordinators who administered the injury prevention measures across the state were moved from the Injury Research & Prevention Program to the MCH Program. In this new capacity these coordinators had the added responsibility of facilitating local child death review panels in each region. MCH will focus the Child Safety Initiative in strategically addressing the leading causes of unintentional injury mortality for children under 15years of age.

**Priority Need 3. Improve preconception and interconception health among Louisiana women.** The 2005 priority “Promote pre-conceptional and inter-conceptional health care including family planning and folic acid education” was replaced to broaden Louisiana’s MCH Program’s focus to add interconception management of chronic diseases. MCH will continue funding Louisiana’s Family Planning Program (FPP) contraceptive services and distribution of folic acid to FPP patients. In addition, FPP will refer smokers to the *FAX to Quit* Program which provides follow up to women interested in stopping smoking. FPP provides referral and follow-up with a provider for management of a patient’s chronic conditions. MCH will initiate a pre-interconception care coordination program for high risk postpartum women in conjunction with the Department of Health and Hospital’s new Birth Outcomes Project.

**Priority Need 4. Reduce # of unintended pregnancies and reduce pregnancies spaced at less than 24 months.** The 2005 priority “Promote pre-conceptional and inter-conceptional health care including family planning and folic acid education” was replaced due to the findings from a Louisiana study that showed 3 times the odds of subsequent preterm births if pregnancy spacing was less than 12 months. Additionally, since 2005 a Family Planning Medicaid Waiver was approved for Louisiana increasing the Medicaid eligibility from 13 percent of the Federal Poverty Level to 200 percent. Family Planning Program will address the spacing priority by

making sure women with previous preterm, previous infant death, and pregnancy within past 15 months are given appointment as one of the highest priority patients in places where access is a problem.

**Priority Need 5. Increase care coordination statewide for CSHCN and their families.** Data indicate twice the unmet need for care coordination among Medicaid eligible CSHCN than those with private insurance (22.4% vs. 11.0%). CSHCN have almost 5 times the prevalence rate for not receiving comprehensive care coordination than children generally (7.9% vs. 34.4%) and have more difficulty getting referrals (34.9% vs. 7.9%). CSHS is expanding care coordination capacity in medical homes and in CSHS subspecialty clinics through its care coordination initiatives. CSHS is improving coordination of public health services through its new stakeholder group as well as through the DHH-DSS data integration project to establish a master patient database for DHH and DSS. Finally, CSHS is active in health care reform initiatives to ensure that care coordination services are reimbursed by Medicaid in the medical home.

**Priority Need 6. Improve the nutritional health of the maternal and child population with a focus on obesity prevention and breastfeeding.** The 2005 priority “Improve the health behaviors of the maternal, child, adolescent, and children with special health care needs populations, addressing healthy nutrition, proper prenatal weight gain, breastfeeding, and physical activity” was changed to address Louisiana’s low rate of breastfeeding and to provide a new emphasis on the high rate of childhood obesity and the need for effective interventions. A collaboration with Louisiana State University School of Public Health experts in obesity prevention will result in an MCH funded obesity prevention initiative in child care centers.

**Priority Need 7. Assure that strategies and methods in MCH programming are culturally competent to reduce racial disparities.** The 2005 priority “Obtain and utilize reliable evidence to: a) identify preventable causes of maternal, child and adolescent mortality and morbidity, b) develop preventive public health campaigns targeting high risk populations, and c) perform process and outcome evaluation” was replaced in order to highlight the wide racial disparities in health outcomes among the two main racial groups in the state, African Americans and Whites, and to target MCH resources to close this gap.

**Priority Need 8. Improve oral health of MCH population by increasing access to preventive measures and access to oral health care.** The 2005 priority need “Address the oral health needs of the maternal, child, adolescent, and children with special health care needs populations” was changed to focus on preventive interventions to address the low rate of dental sealants among 3<sup>rd</sup> grade children in Louisiana (33.2%) and the low rate of Louisiana citizens receiving the benefits of optimally fluoridated water (41%).

**Priority Need 9. Improve the behavioral health of the MCH population through prevention, early intervention, screening, referral, and treatment where appropriate.** The two 2005 priorities to address the mental health needs and the substance abuse needs of the maternal, child, adolescent, and children with special health care needs populations, through prevention and early intervention, screening, referral, and where appropriate, treatment were combined to be consistent with Louisiana’s merger of the state Office of Mental Health and Office of Addictive Disorders into one Office of Behavioral Health. Since 2005, the Nurse Family Partnership Program participating clients have almost doubled and the new Health Care Reform grants should allow further expansion of this psychosocial health intervention.

**Priority Need 10. Increase preventive services for adolescents and transition services for adolescents with special health care needs.** The 2005 priority need “Promote comprehensive

systems of care and seamless transition to adult services for the Children with Special Health Care Needs population by providing care coordination” was expanded to include preventive services for all adolescents. According to NS-CSHCN, Louisiana is slightly below the national average for the NPM addressing transition for YSHCN. CSHS will expand its two transition pilots in CSHS clinics in regions 1 and 6 to additional regions. CSHS will also incorporate more focus on transition into care coordination for medical homes.

### **C. CSHS Needs Assessment Summary**

The 2010 CSHS Needs Assessment began with an in depth review of existing data on CYSHCN in Louisiana including the 2005/06 NS-CSHCN, the 2007 NSCH, the FHF database of services provided, and the DOE Special Education Data Profile. When findings from these sources were discussed in light of the six NPM’s for CYSHCN, two themes emerged for further exploration: the Medical Home and the burden placed on families to navigate the complex systems of care. The 2010 CSHS Needs Assessment was therefore designed to capture the medical home capacity in the state and the existing and potential coordination of enabling services provided by CYSHCN stakeholder agencies. With the help of PRG consultants, three stakeholder groups were engaged and surveys were developed. The three groups were families of CYSHCN, pediatricians and family practitioners, and public health and community programs serving CYSHCN.

This methodology differed from that used for the 2005 Needs Assessment, which included review of 2001NS-CSHCN data, an in depth survey of 96% of physicians serving children, and family focus groups. The 2005 Priority Needs included “Assure access to quality health care for the maternal, child, adolescent, and CYSHCN populations, addressing barriers including Medicaid provider availability and lack of transportation” and “Promote comprehensive systems of care and seamless transition to adult services for CYSHCN by providing care coordination.” All of these priorities are continuing concerns for Louisiana CYSHCN. However, the methodology of the 2010 Needs Assessment permitted a more in depth analysis of Medical Home capacity and care coordination need on many levels. The resulting priorities and new SPM reflect the results of this more comprehensive analysis as well as shifting strengths and needs as described below.

#### **Changes in CYSHCN strengths and needs:**

NS-CSHCN analyses showed improvement in four out of six NPM’s for CYSHCN between 2001 and 2005/06, from below to above the national average. There was improvement in percent with a Medical Home, percent with adequate insurance, percent with family-centered care, and percent that find services easy to use. Only receipt of transition services and receipt of early and continuous screening lag behind the national average. Geographic disparities exist, with families living in urban areas and major cities less likely to meet all NPMs. Urban and Non-Hispanic Black families with CYSHCN were also less likely to say their health insurance was adequate, and were more likely to go to the emergency room when sick and to report no usual source of care. Families with CYSHCN whose household income was higher and those with private insurance were more likely to have a usual source of care and a Medical Home.

#### **Changes in Insurance Coverage:**

Probably the most significant change since the 2005 Needs Assessment was insurance coverage for CYSHCN, which improved dramatically as a result of changes in Medicaid policies and a focus on outreach. In Louisiana, a much higher percentage of CYSHCN are covered by public insurance than the national average (45% vs. 28.6%), and a higher percentage have health insurance that adequately meets their needs (71.8% vs. 66.9%). Because of this, many families

with CYSHCN have been able to access care in the private sector. Several CSHS clinics have been able to close due to lack of demand, including several clinics in New Orleans and Hammond. Patient volume in CSHS clinics has decreased annually over the past several years. Despite this trend, lack of Medicaid providers was still ranked highest among priority needs by families, with one fifth saying this was a barrier to subspecialty medical care access. More than half of pediatric providers expressed difficulty obtaining psychiatry, developmental/behavioral pediatrician, neurology, orthopedic, and dermatology consults. Therefore CSHS will continue to provide these direct safety-net services, while working to improve access to care through other levels of the pyramid. Since adequacy of insurance is addressed in a NPM and need for CSHS subspecialty clinics is clearly slowly decreasing over time, need for Medicaid providers was not included as a separate 2010 priority need.

### **Need for Care Coordination:**

CYSHCN in Louisiana have almost five times the prevalence for not receiving needed care coordination than non-CYSHCN. Compared to the national average, Louisiana families spend significantly more time coordinating their child's care, especially for children from 0-5 years. Having a Medical Home did not significantly improve receipt of care coordination. Data indicate that families with public insurance receive more care coordination help than those with private insurance, while still spending significantly more hours per week coordinating their child's care. Families with public insurance were twice as likely to stop working to care for their CYSHCN, and twice as likely to say services were difficult to use.

CSHS Needs Assessment Survey results provide a comprehensive analysis of care coordination gaps in services. Physician Surveys indicated physicians do not refer to many key public health and community resources for CYSHCN, and less than half meet Medical Home criteria. Agency Surveys indicated that public health programs do not collaborate with or refer to each other to meet family needs. Family Surveys indicated that families believe lack of physician knowledge about resources is a barrier to access.

### **Need for Transition Services:**

Louisiana is slightly below the national average in CYSHCN who receive transition services. Only 27% of families with YSHCN reported that their physician discussed health insurance. Non-Hispanic Black youth, lower income households, those with public insurance, and youth with a functional impairment all had a greater unmet need for transition services. Having a Medical Home was associated with a 30% increase in receipt of transition services. Family Survey results indicated that less than half of YSHCN received any transition service, and similarly, Physician Surveys indicated that only 16.9% discuss independent living skills, less than 25% discuss community resources, and only 45.4% discuss educational/vocational choices. Agency Surveys revealed that many programs providing transition services to YSHCN do not collaborate with other programs.

### **Changes in the CSHS Program and System Capacity:**

CSHS system capacity has improved on many levels. In recent years, CSHS has developed and is now expanding its program to provide technical assistance and care coordination to Medical Homes. A CSHS Social Worker Consultant and a Statewide Care Coordinator Supervisor have been added to central office staff. Second, as a result of the 2010 Needs Assessment, a new stakeholder group was formed with representatives of public health programs and key community organizations that serve CYSHCN, many of which offer specific resources for YSHCN in

transition. The stakeholder group has already begun to improve collaboration between public health programs. Finally, CSHS is involved in DHH healthcare reform initiatives such as the Healthcare Quality Forum Medical Home Committee and the DSS-DHH Data Integration Project. Greater involvement in these infrastructure building committees will provide improved capacity to advocate for CYSCHN as the administration implements budget streamlining measures and health care reform initiatives.

As a result of these changes in need and capacity, the 2010 Priority Needs #5 and #10 were added to reflect these tremendous gaps in care coordination and transition services for CYSCHN.

# APPENDIX A

## TABLES      TITLE

FIGURE 1----- Racial Distribution, 2007

FIGURE 2----- Hispanic Origin Distribution, 2007

FIGURE 3----- Louisiana Live Births by Race 2003- 2007

FIGURE 4----- Louisiana Infant Mortality Rates by Race 2002-  
2007

FIGURE 5----- Louisiana Low Birthweight by Race 2002- 2007

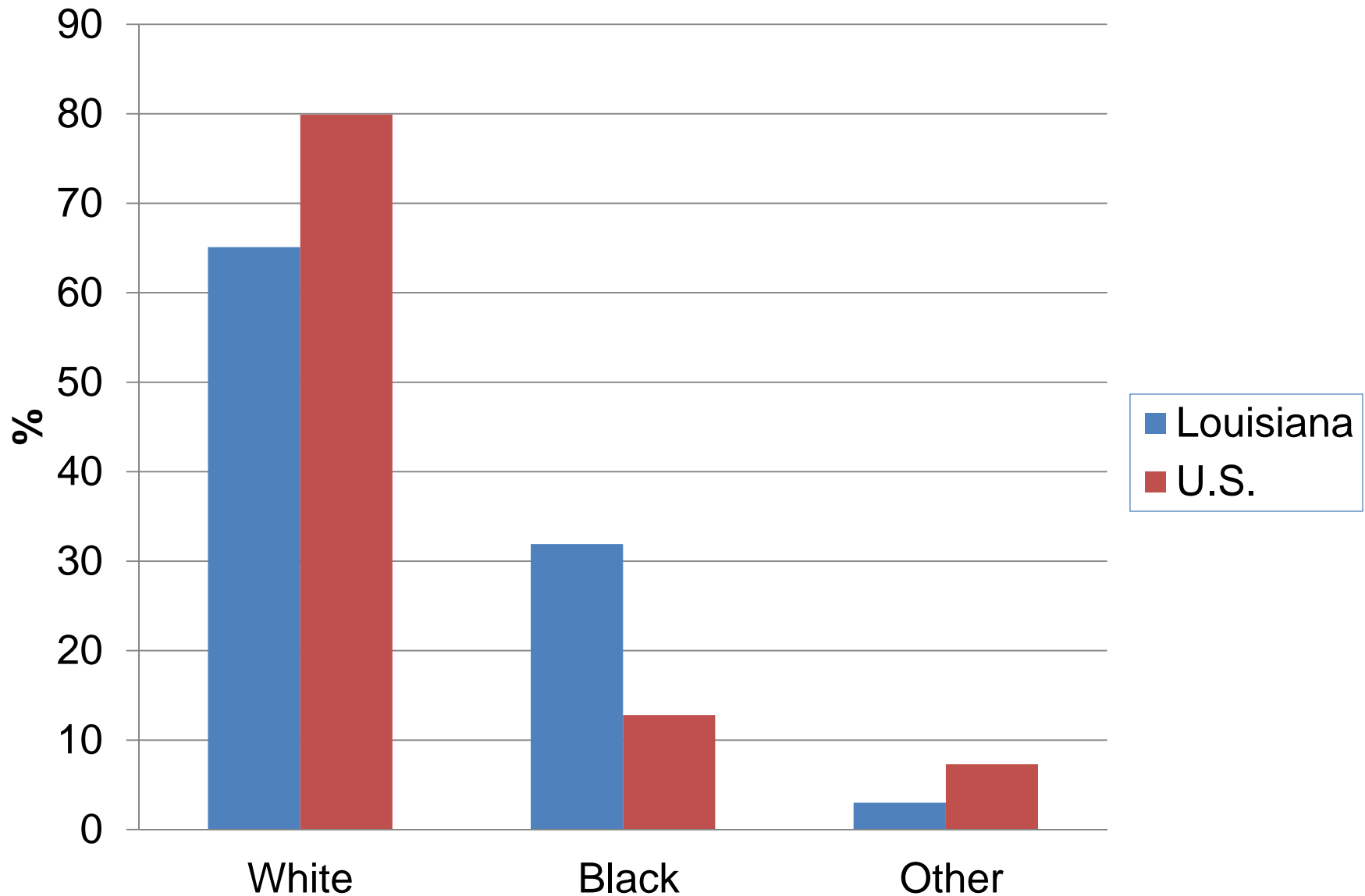
FIGURE 6----- Medicaid Paid Deliveries 2007

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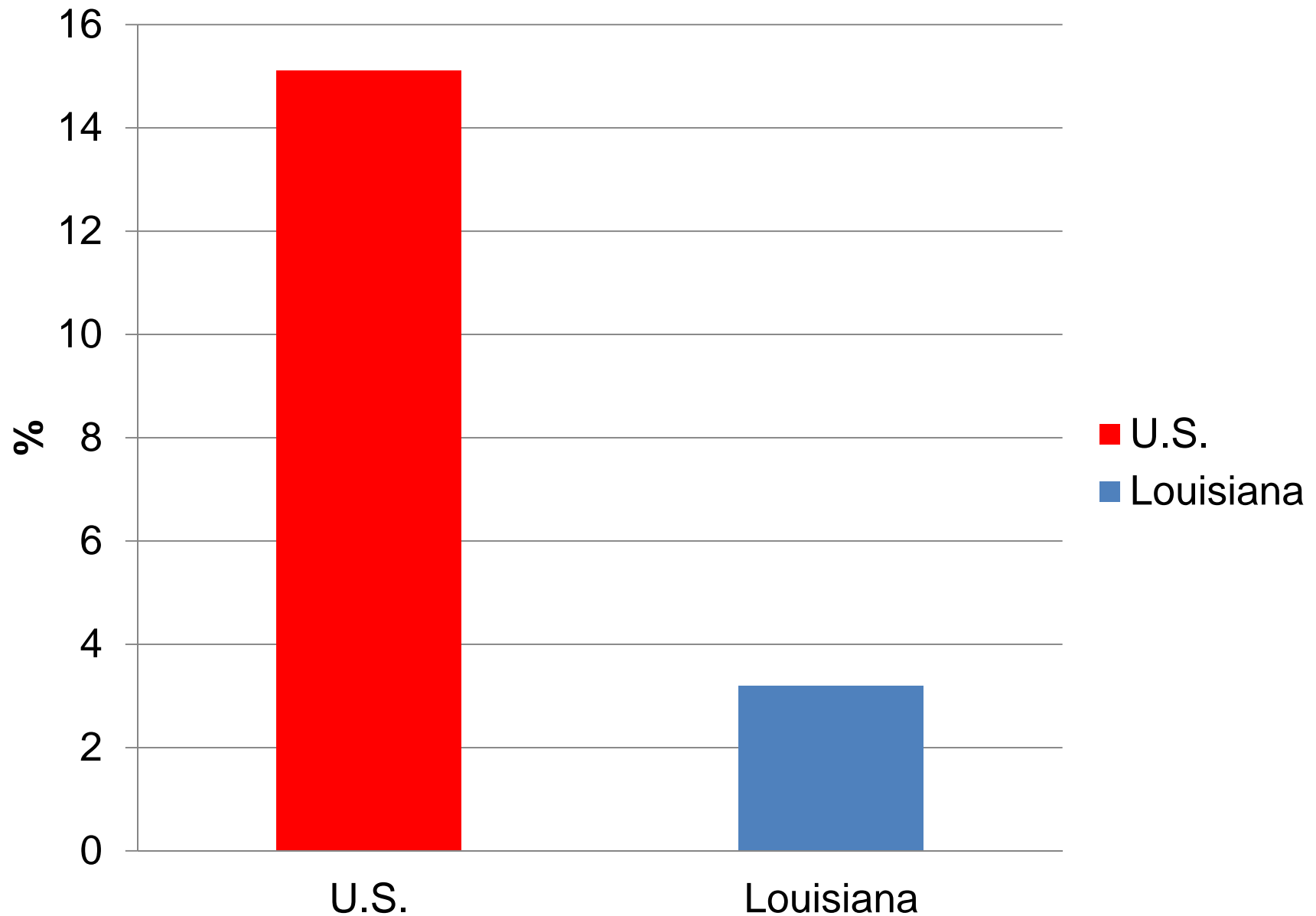
# Racial Distribution

## Louisiana and National

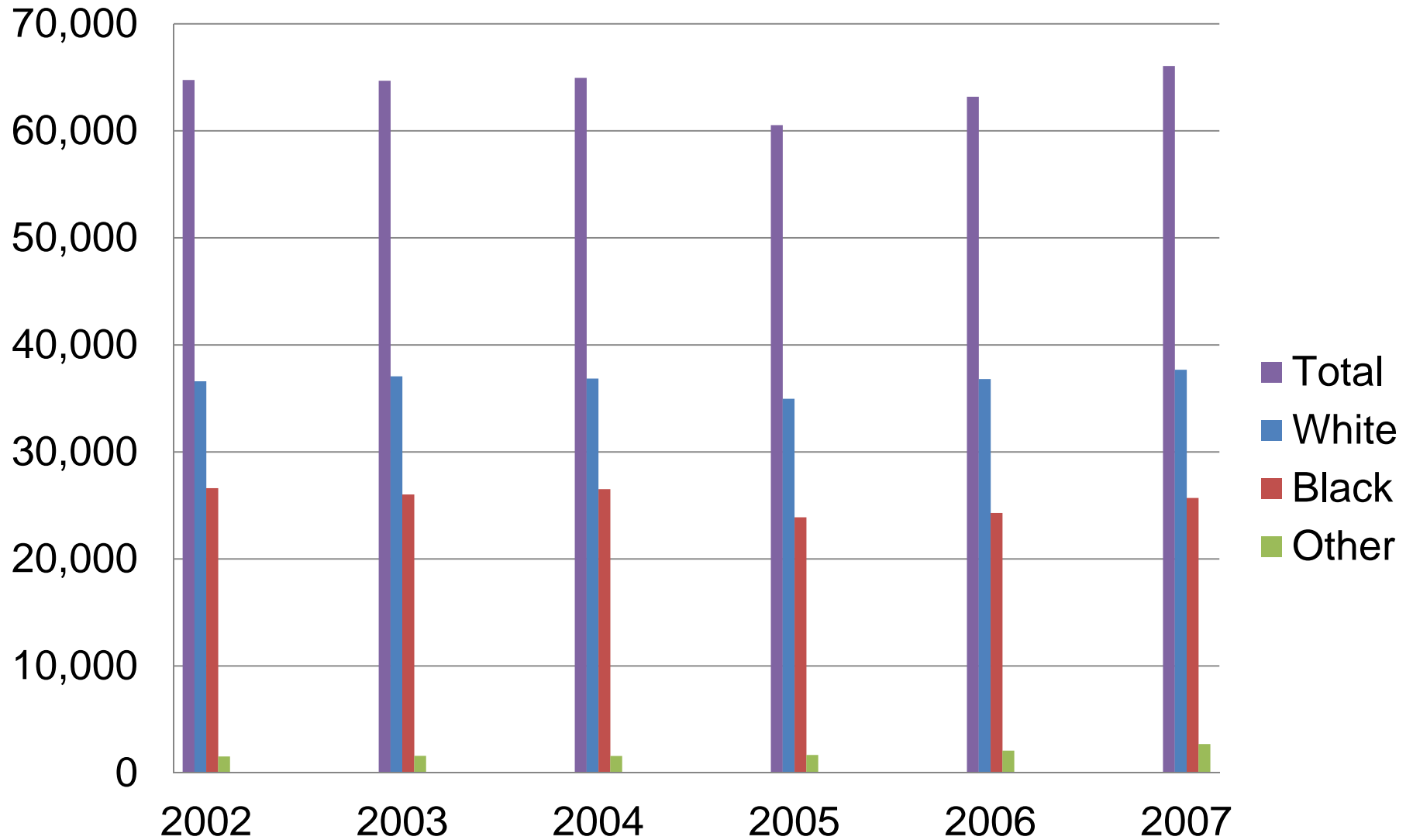


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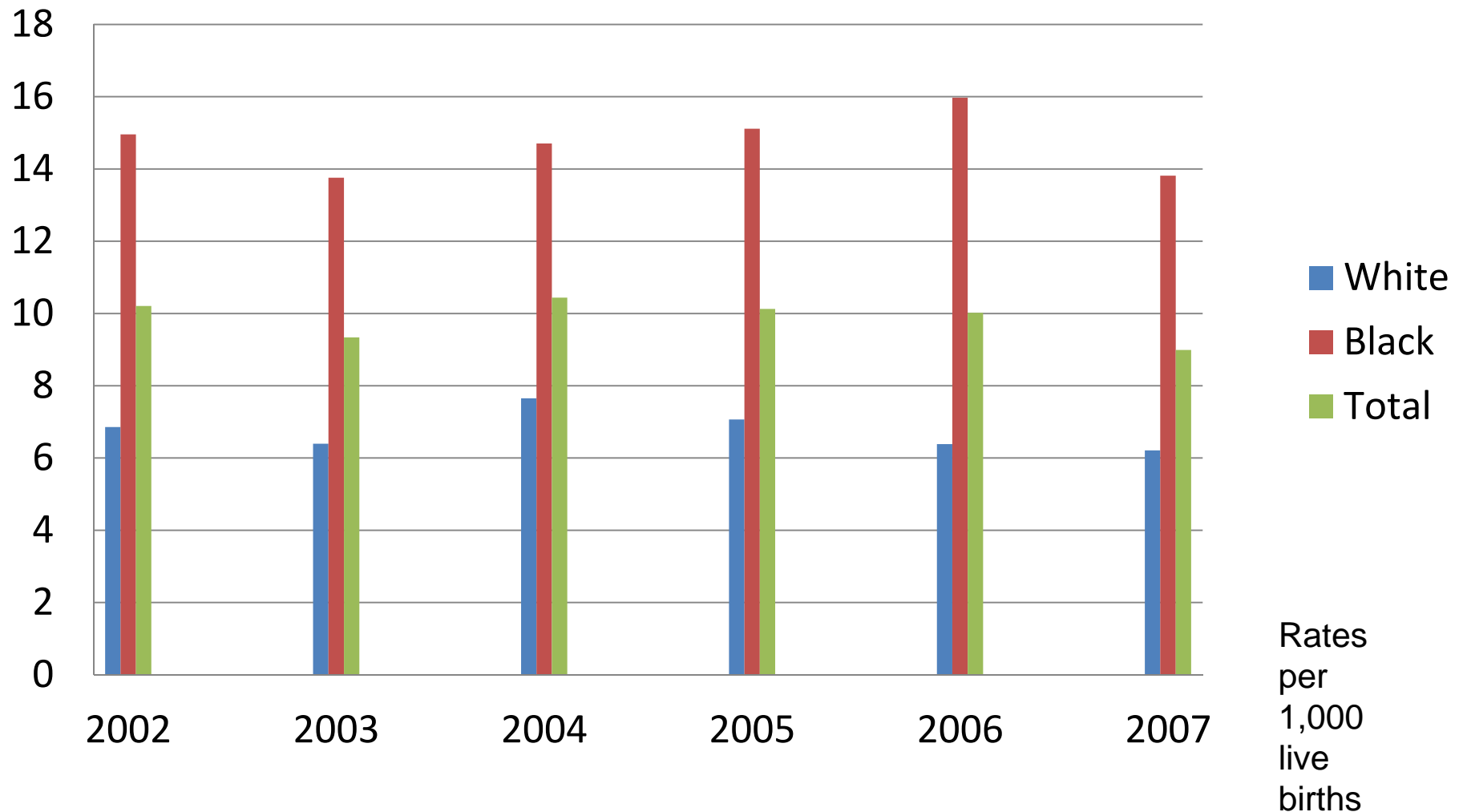
## Louisiana and National



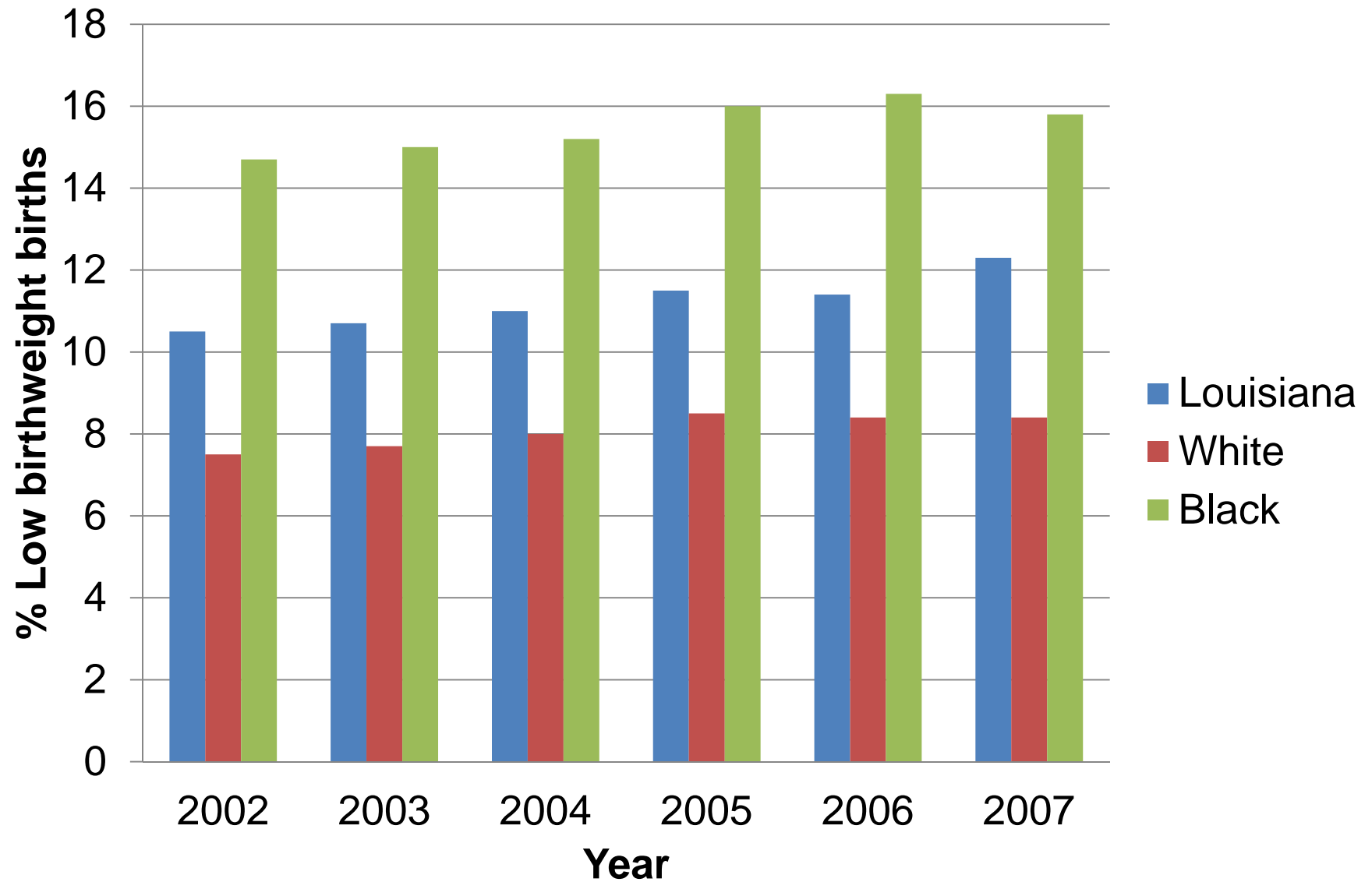
# Louisiana Live Births by Race, 2002-2007



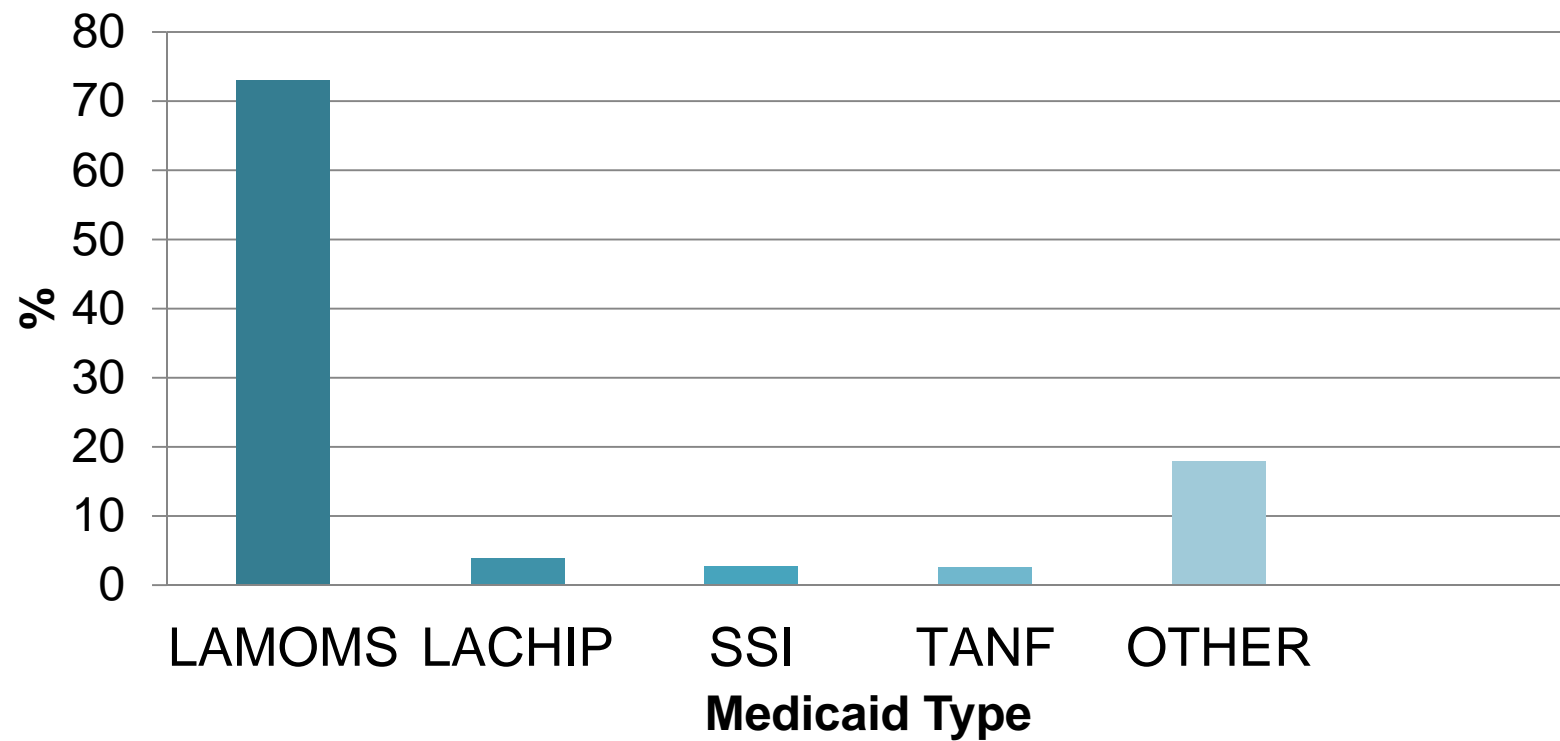
# Louisiana Infant Mortality Rates by Race, 2002-2007



# Louisiana Low Birthweight by Race, 2002-2007



# Medicaid Paid Deliveries by Medicaid Type



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# APPENDIX B

## TABLES      TITLE

FIGURE 1----- State Population Estimates, 2007

FIGURE 2----- Number (Rate) of Child Deaths by Age and Cause  
of Death, 2002-2007

FIGURE 3----- Number of Primary Care Provider by Parish, 2007

## 2002-2007 Louisiana State Population Estimates

	2007	2006	2005	2004	2003	2002
White alone	2,756,277	2,760,233	2,795,263	2,799,224	2,792,194	2,768,556
Black	1,357,893	1,356,981	1,425,685	1,422,273	1,401,061	1,405,012
Other	179,034	170,554	168,799	159,389	168,016	174,074
Total	4,293,204	4,287,768	4,389,747	4,380,886	4,361,271	4,347,642



## Causes (Percentage) of Child Deaths by Age group 2002-2007

Cause	Infant (<1yr)	1-14yr	15-19yr
External causes of mortality	6.3	51.1	79.7
Conditions originating in the perinatal period	47.0	NA	NA
Sudden infant death syndrome	11.1	NA	NA
Neoplasm	NA	9.0	3.6
Diseases of nervous system	NA	8.6	2.8
Congenital malformations, deformations and chromosomal abnormalities	18.0	7.2	NA
Disease of respiratory system	NA	6.0	NA
Disease of the circulatory system	NA	5.5	3.7
Other	17.6	12.6	10.2

**Physician workforce 2005 to 2008**

	Mailing address (a)						Census (b)					Phys/ 100K pop ( c )					
	7/20/05	10/1/06	9/6/07	8/28/08	dif	%	7/1/05	7/1/06	7/1/07	dif	%	7/20/05	10/1/06	9/6/07	8/28/08	dif	%
ORLEANS	2,518	1,663	1,629	1,793	(725)	-29%	453,726	210,198	239,124	(214,602)	-47%	555	791	681	750	195	35%
SAINT BERNARD	50	8	6	6	(44)	-88%	64,683	13,875	19,826	(44,857)	-69%	77	58	30	30	(47)	-61%
SABINE	12	13	11	7	(5)	-42%	23,430	23,600	23,683	253	1%	51	55	46	30	(22)	-42%
WEST CARROLL	7	6	5	4	(3)	-43%	11,801	11,698	11,553	(248)	-2%	59	51	43	35	(22)	-42%
UNION	10	9	9	7	(3)	-30%	22,741	22,846	22,773	32	0%	44	39	40	31	(13)	-30%
EVANGELINE	43	43	43	40	(3)	-7%	35,227	35,675	35,905	678	2%	122	121	120	111	(11)	-9%
RICHLAND	26	29	27	24	(2)	-8%	20,318	20,473	20,469	151	1%	128	142	132	117	(11)	-8%
ASSUMPTION	7	6	5	5	(2)	-29%	22,859	23,065	22,991	132	1%	31	26	22	22	(9)	-29%
TENSAS	1				(1)	-100%	5,958	6,038	5,865	(93)	-2%	17	-	-	-	(17)	-100%
EAST CARROLL	4	3	3	3	(1)	-25%	8,467	8,319	8,302	(165)	-2%	47	36	36	36	(11)	-24%
LA SALLE	7	6	5	6	(1)	-14%	13,904	14,046	14,041	137	1%	50	43	36	43	(8)	-15%
BIENVILLE	1				(1)	-100%	15,002	14,896	14,907	(95)	-1%	7	-	-	-	(7)	-100%
CAMERON	3	2	1	2	(1)	-33%	9,571	7,705	7,414	(2,157)	-23%	31	26	13	27	(4)	-14%
BEAUREGARD	26	28	28	25	(1)	-4%	34,264	34,720	34,776	512	1%	76	81	81	72	(4)	-5%
WEBSTER	45	45	43	44	(1)	-2%	40,876	40,989	40,924	48	0%	110	110	105	108	(3)	-2%
SAINT HELENA	2	3	3	2	-	0%	10,183	10,700	10,620	437	4%	20	28	28	19	(1)	-4%
GRANT	4	5	4	4	-	0%	19,296	19,713	19,758	462	2%	21	25	20	20	(0)	-2%
CLAIBORNE	9	10	10	9	-	0%	16,313	16,441	16,283	(30)	0%	55	61	61	55	0	0%
FRANKLIN	9	10	11	9	-	0%	20,170	20,091	20,060	(110)	-1%	45	50	55	45	0	1%
CALDWELL	7	7	5	7	-	0%	10,398	10,359	10,307	(91)	-1%	67	68	49	68	1	1%
WINN	11	12	12	11	-	0%	15,736	15,684	15,521	(215)	-1%	70	77	77	71	1	1%
DE SOTO	10	12	11	11	1	10%	25,977	26,061	26,269	292	1%	38	46	42	42	3	9%
CONCORDIA	17	21	19	18	1	6%	18,949	19,225	19,058	109	1%	90	109	100	94	5	5%
JACKSON	2	1	2	3	1	50%	15,068	15,265	15,139	71	0%	13	7	13	20	7	49%
MADISON	7	8	7	8	1	14%	12,105	11,964	11,858	(247)	-2%	58	67	59	67	10	17%
SAINT JOHN THE BAPTIST	39	42	41	41	2	5%	45,602	47,693	47,684	2,082	5%	86	88	86	86	0	1%
MOREHOUSE	26	27	26	28	2	8%	29,440	29,274	28,783	(657)	-2%	88	92	90	97	9	10%
RED RIVER	1	2	3	3	2	200%	9,217	9,213	9,195	(22)	0%	11	22	33	33	22	201%
SAINT MARTIN	14	17	20	17	3	21%	50,033	51,221	51,651	1,618	3%	28	33	39	33	5	18%
SAINT LANDRY	144	147	149	148	4	3%	88,690	90,764	91,362	2,672	3%	162	162	163	162	(0)	0%
IBERIA	112	121	119	116	4	4%	73,654	74,690	74,965	1,311	2%	152	162	159	155	3	2%
SAINT MARY	52	56	57	56	4	8%	50,887	51,649	51,311	424	1%	102	108	111	109	7	7%
JEFFERSON DAVIS	22	23	23	26	4	18%	30,930	31,257	31,177	247	1%	71	74	74	83	12	17%
ALLEN	18	16	18	22	4	22%	24,890	25,567	25,524	634	3%	72	63	71	86	14	19%
WEST BATON ROUGE	4	7	6	8	4	100%	21,534	22,220	22,625	1,091	5%	19	32	27	35	17	90%
EAST FELICIANA	18	18	19	22	4	22%	20,557	21,017	20,833	276	1%	88	86	91	106	18	21%
BOSSIER	154	149	160	159	5	3%	105,341	107,653	108,705	3,364	3%	146	138	147	146	0	0%
WASHINGTON	34	35	38	40	6	18%	43,951	44,061	44,920	969	2%	77	79	85	89	12	15%
IBERVILLE	27	31	30	33	6	22%	32,229	32,847	32,501	272	1%	84	94	92	102	18	21%
CATAHOULA	4	4	4	11	7	175%	10,270	10,396	10,452	182	2%	39	38	38	105	66	170%
SAINT CHARLES	37	49	47	45	8	22%	50,164	51,969	52,044	1,880	4%	74	94	90	86	13	17%
AVOYELLES	22	27	28	30	8	36%	41,344	42,332	42,169	825	2%	53	64	66	71	18	34%
POINTE COUPEE	11	18	16	19	8	73%	21,828	22,415	22,392	564	3%	50	80	71	85	34	68%
LIVINGSTON	23	28	26	33	10	43%	107,480	113,275	116,580	9,100	8%	21	25	22	28	7	32%
VERMILION	33	39	37	43	10	30%	54,938	55,425	55,691	753	1%	60	70	66	77	17	29%
NATCHITOCHES	41	43	47	52	11	27%	38,803	39,412	39,485	682	2%	106	109	119	132	26	25%
SAINT JAMES	17	19	20	28	11	65%	20,982	21,459	21,578	596	3%	81	89	93	130	49	60%
LINCOLN	68	72	77	80	12	18%	42,715	42,580	42,562	(153)	0%	159	169	181	188	29	18%
VERNON	33	37	41	45	12	36%	50,296	48,493	47,380	(2,916)	-6%	66	76	87	95	29	45%

PLAQUEMINES	12	11	10	27	15	125%	28,588	21,625	21,540	(7,048)	-25%	42	51	46	125	83	199%
WEST FELICIANA	8	13	15	23	15	188%	15,053	15,287	15,113	60	0%	53	85	99	152	99	186%
ACADIA	38	45	42	54	16	42%	58,804	59,745	59,958	1,154	2%	65	75	70	90	25	39%
OUACHITA	392	402	385	414	22	6%	148,289	149,733	149,502	1,213	1%	264	268	258	277	13	5%
ASCENSION	60	80	85	87	27	45%	89,056	95,449	99,056	10,000	11%	67	84	86	88	20	30%
RAPIDES	371	395	392	402	31	8%	127,367	129,994	130,079	2,712	2%	291	304	301	309	18	6%
TERREBONNE	190	213	211	221	31	16%	106,255	108,157	108,424	2,169	2%	179	197	195	204	25	14%
CALCASIEU	365	381	380	400	35	10%	184,549	183,426	184,512	(37)	0%	198	208	206	217	19	10%
TANGIPAHOA	120	143	144	161	41	34%	106,253	113,144	115,398	9,145	9%	113	126	125	140	27	24%
LAFOURCHE	128	136	134	170	42	33%	91,433	92,878	92,713	1,280	1%	140	146	145	183	43	31%
JEFFERSON	1,829	1,800	1,798	1,888	59	3%	449,640	420,891	423,520	(26,120)	-6%	407	428	425	446	39	10%
SAINT TAMMANY	697	763	767	797	100	14%	217,551	224,227	226,625	9,074	4%	320	340	338	352	31	10%
CADDO	1,144	1,226	1,215	1,265	121	11%	250,411	253,469	252,609	2,198	1%	457	484	481	501	44	10%
LAFAYETTE	609	675	680	735	126	21%	197,428	203,457	204,843	7,415	4%	308	332	332	359	50	16%
EAST BATON ROUGE	1,269	1,418	1,417	1,783	514	41%	412,196	431,278	430,317	18,121	4%	308	329	329	414	106	35%

Address in LA	11,024	10,678	10,626	11,580	556	5%
Address not in LA	5,159	4,839	4,991	4,051	(1,108)	-21%
Address not listed	24	35	30	39	15	
Total licensed	16,207	15,552	15,647	15,670	(537)	-3%

LA	10,678						4,495,670	4,243,288	4,293,204			245	252	248	270
US	921,904	(d)						299,398,484	(e)				308		

a	Louisiana State Board of Medical Examiners 8 28 08	
b	<a href="http://quickfacts.census.gov/qfd/states/22000lk.html">http://quickfacts.census.gov/qfd/states/22000lk.html</a>	downloaded 9/18/08
c	2008 physicians per 100K population based on 2007 census	
d	<a href="http://www.ama-assn.org/ama/pub/category/12912.html">http://www.ama-assn.org/ama/pub/category/12912.html</a>	downloaded 9/18/08
e	<a href="http://quickfacts.census.gov/qfd/states/00000.html">http://quickfacts.census.gov/qfd/states/00000.html</a>	downloaded 9/18/08

# APPENDIX C

## Maps

## Title

MAP 1-----

Louisiana Public Health Regions

MAP 2-----

Louisiana Fluoridated Water Distribution

MAP 3-----

Louisiana Health Professional Shortage  
Area (HPSA) Designations

MAP 4-----

Number of Private OB/GYN Services  
Accepting Medicaid

MAP 5-----

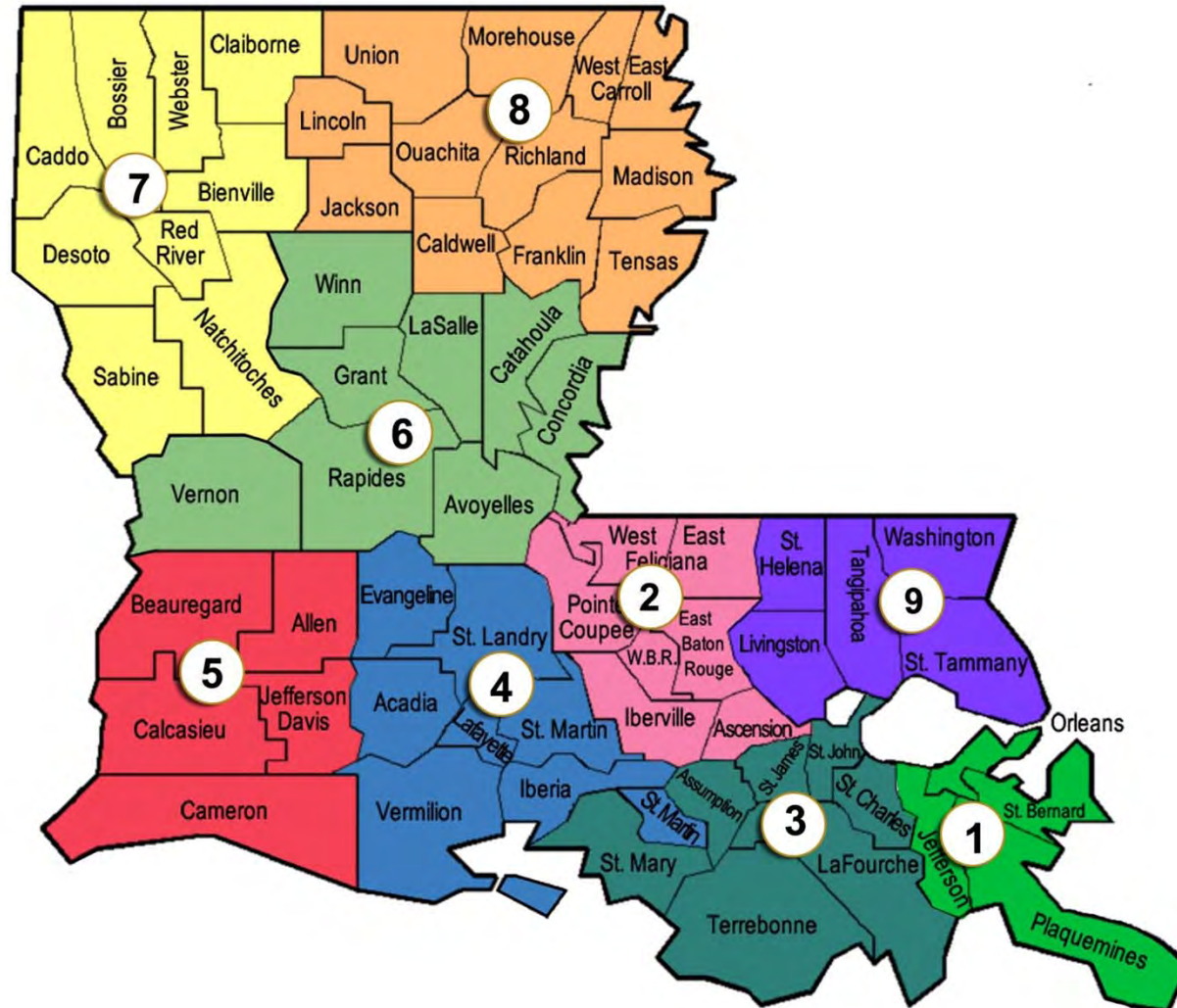
Federally Qualified Centers

Map 6-----

Louisiana Adolescent Health Initiative

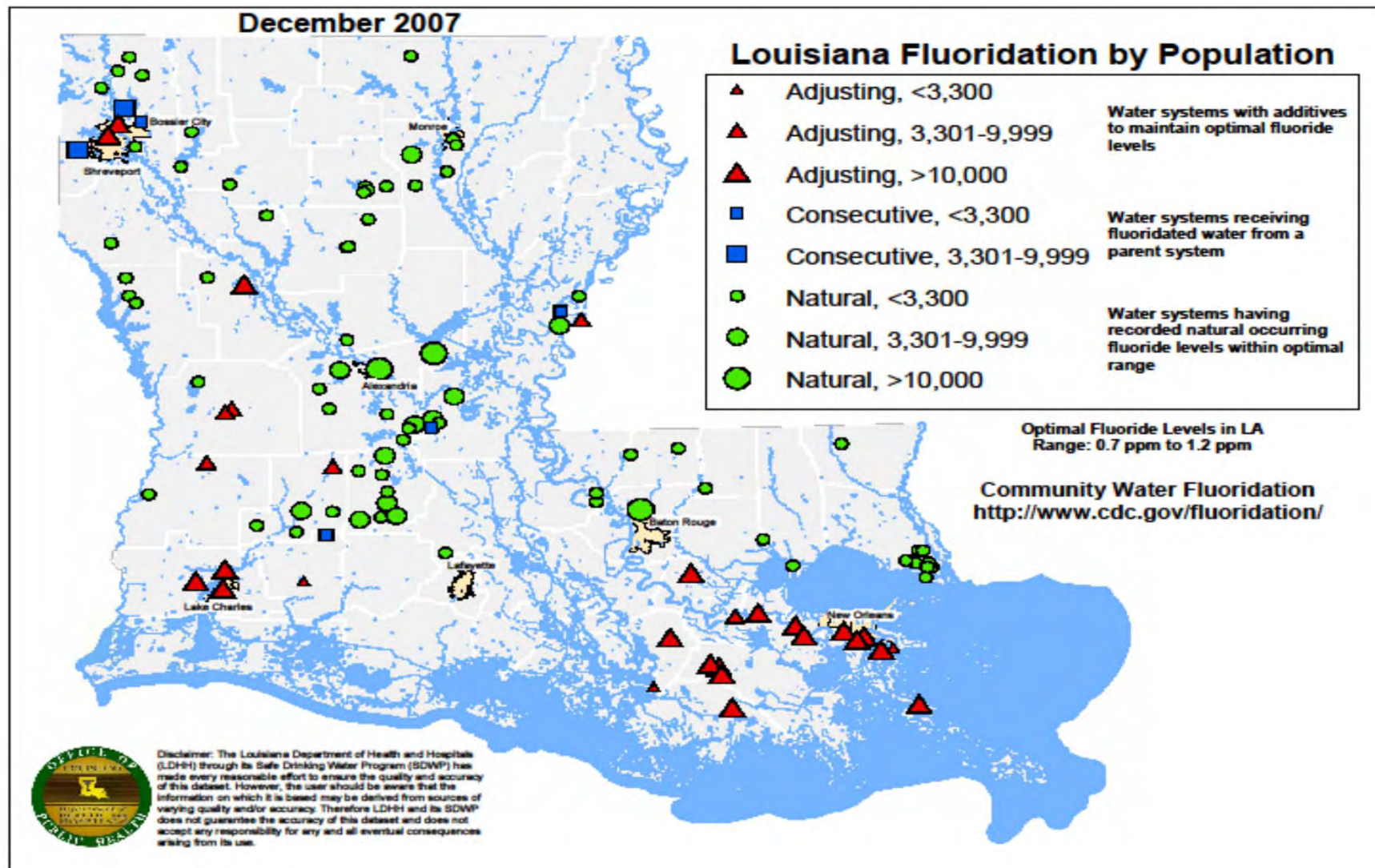
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# Louisiana Public Health Regions

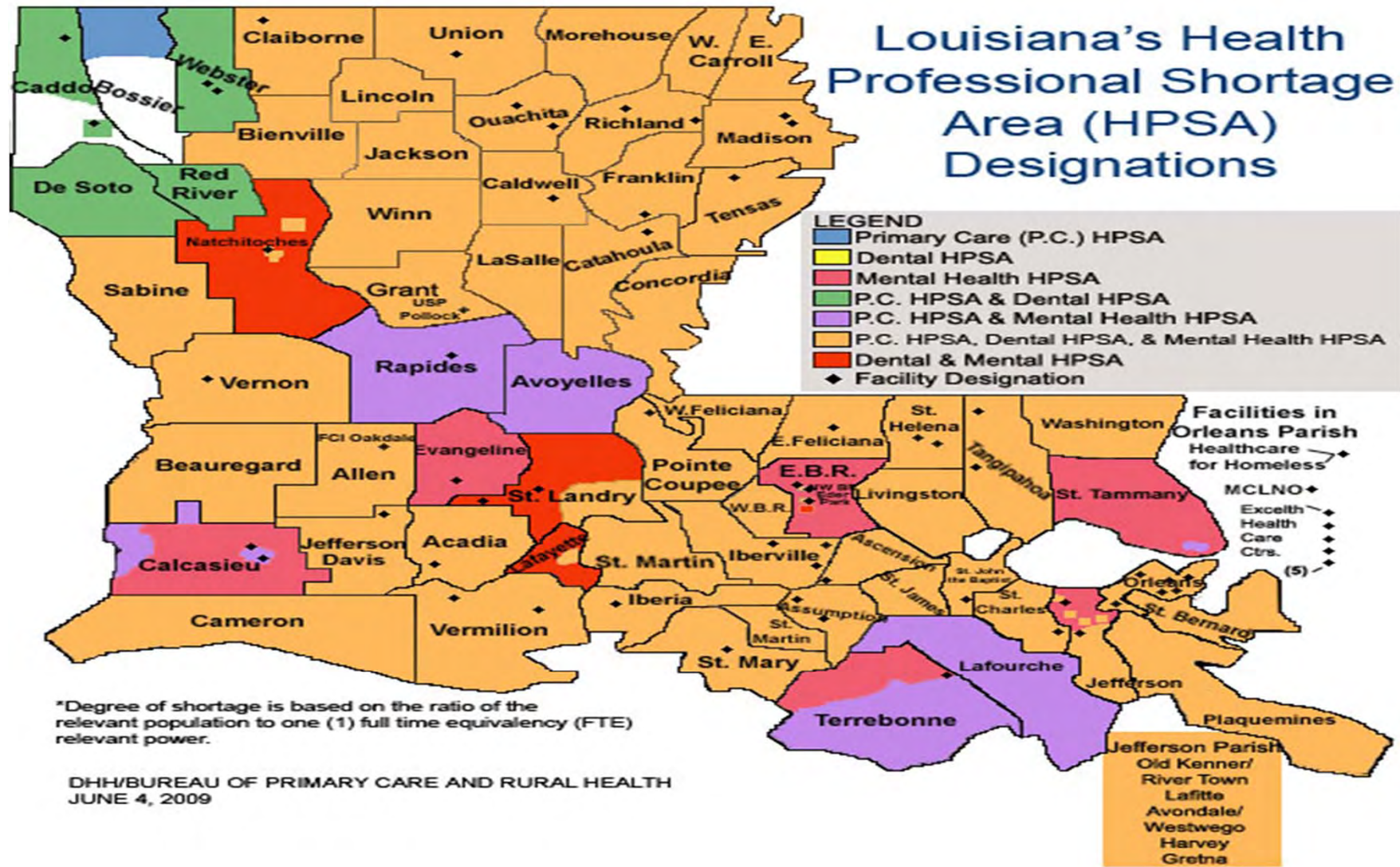




# Louisiana Fluoridated Water Distribution

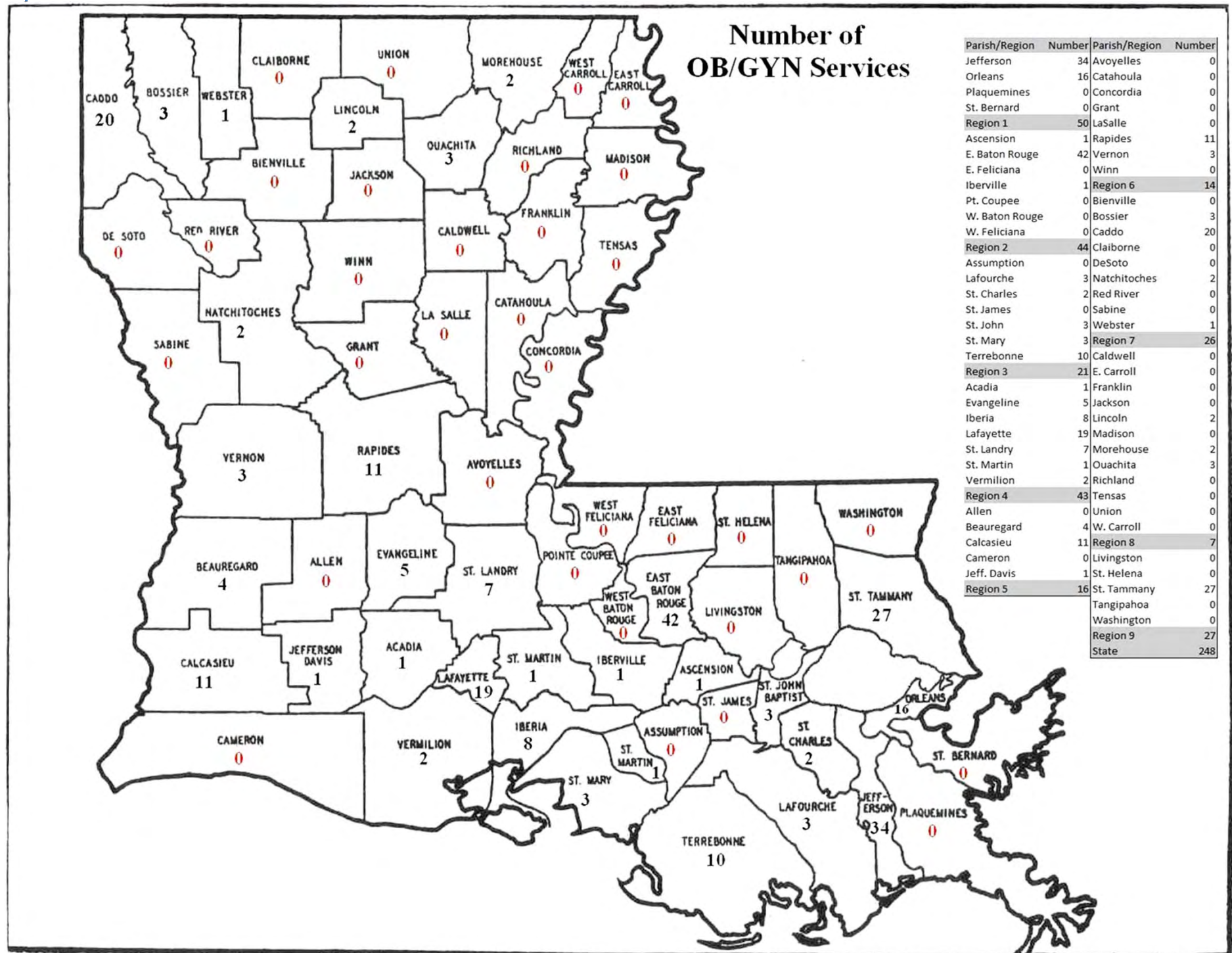


# Louisiana's Health Professional Shortage Area (HPSA) Designations



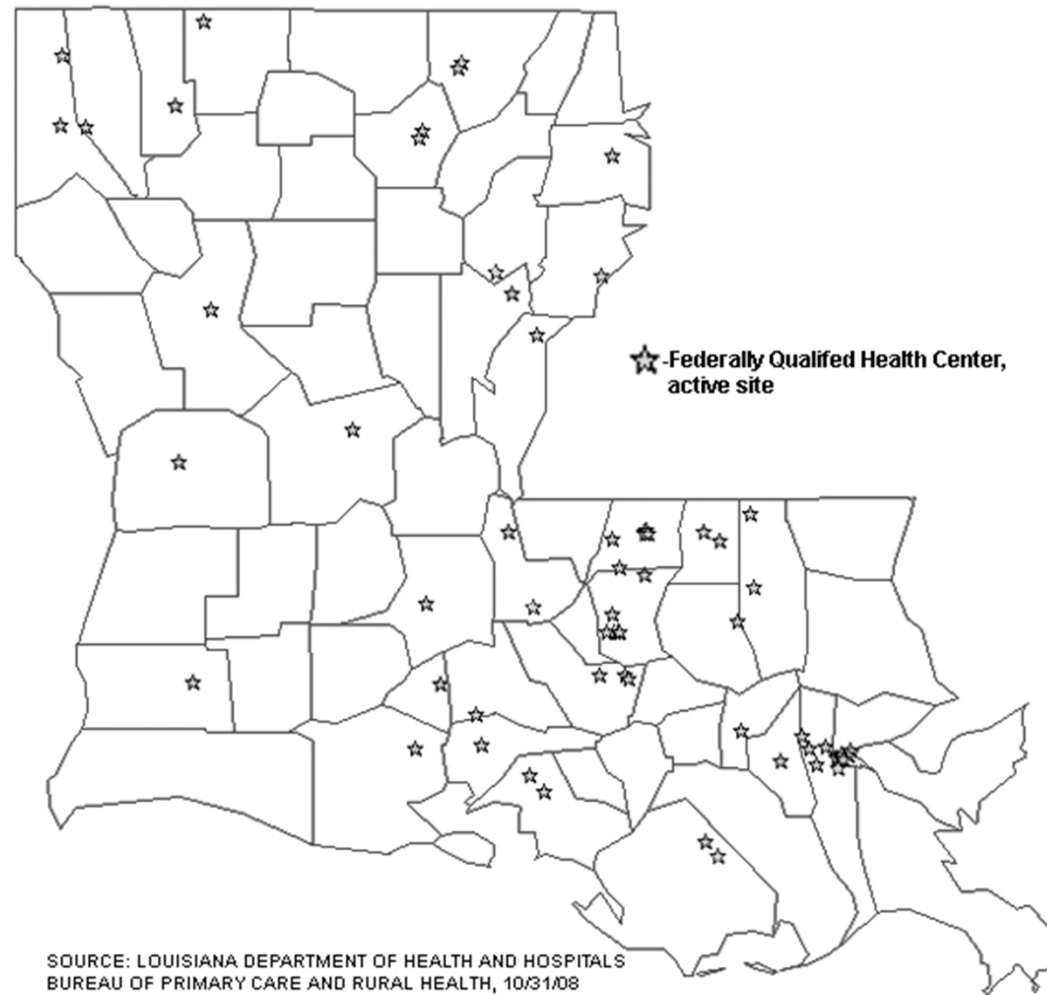


# Number of Private OB / GYN Services Accepting Medicaid

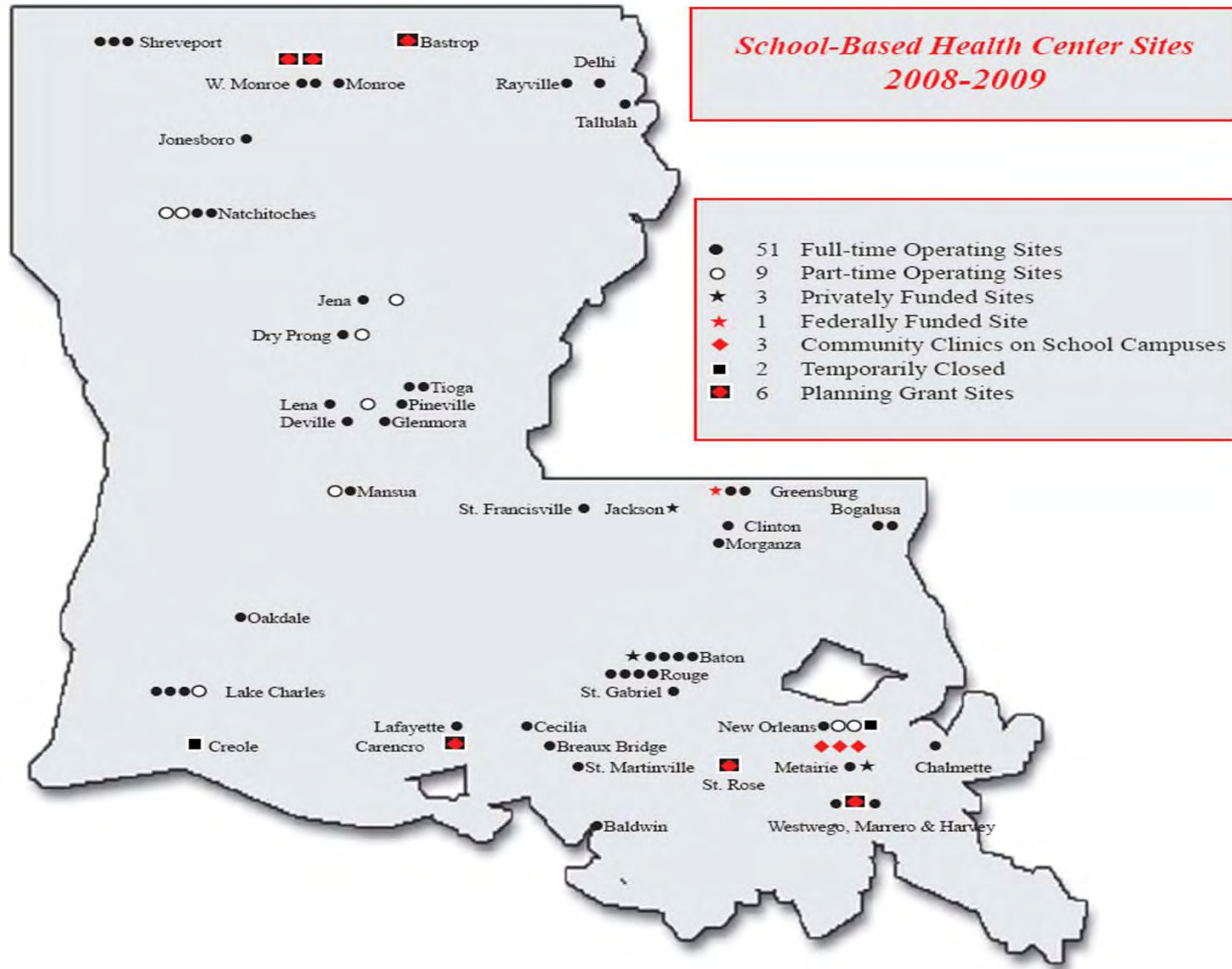




# Federally Qualified Health Centers



# Louisiana Adolescent Health Initiative



# MCH APPENDIX D

- I. Maternal Health Need Assessment Regional Workbook
  - II. Maternal Health Needs Assessment Regional Results
  - III. Child Health and Safety Survey
  - IV. Child Health and Safety Needs Assessment Statewide Results
  - V. MCH Priority Needs Presentations
  - VI. Initial Evaluation of Louisiana Needs
  - VII. Adolescent Health Priority Needs Presentation
  - VIII. Oral Health Priority Needs Presentation
  - IX. Community Partners
  - X. DHH Inter-agency Data Sharing Agreement
  - XI. SBHC Sponsors
  - XII. Consumer Based Survey
-

# 2010 Maternal and Child Health Needs Assessment

Maternal Health Regional Presentations

Prioritization, Gaps and Strategies Workbook

Region \_\_\_\_



NAME \_\_\_\_\_

## **Regional Preliminary Perinatal Needs**

Please list the top perinatal needs in your region based on the data presented today.

List up to ten (10) needs. During subsequent meetings, you will have an opportunity to prioritize these needs based on a number of factors including extent, severity of consequences, and resource availability.

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

---

## **Prioritizing Perinatal Needs Worksheet**

### **MCHB Prioritization Method (*Modified*)**

This method of setting priority needs incorporates a framework that considers various criteria (the extent of the health problem, whether the trend is increasing, the severity of consequences, resource availability, and acceptability). The Prioritization Method is used as a way of organizing a discussion to achieve consensus among different people and groups for ultimately setting priority perinatal health needs within the region.

#### **Instructions:**

1. Using the list of needs facing your region identified on the “Perinatal Need Identified Worksheet,” enter these Perinatal Needs into the column labeled “Perinatal Needs/Problems.”
  2. Fill out table using the scoring method provided.
  3. Once the extent of the health problem, whether the trend is increasing, the severity of consequences, resource availability, and acceptability have been scored for each Perinatal Need/Problem, calculate a total score for the Perinatal Need/Problem.
  4. Record the five highest scoring Perinatal Needs/Problems (These are your **Top 5** Perinatal Needs).
  5. Before making final decisions about the priority needs, the process and the results should be reviewed and agreed upon by all participants.
-

## Example:

### Scoring Method

#### Extent

- 1 = low incidence or prevalence
- 2 = moderate incidence or prevalence in some subgroups
- 3 = moderate incidence or prevalence in all groups
- 4 = high incidence or prevalence in some subgroups
- 5 = high incidence or prevalence in all subgroups

#### Trends Increasing

- 1 = rapid decrease in past 5 years
- 2 = moderate/slow decrease in past 5 years
- 3 = no change in past 5 years
- 4 = moderate/slow increase in past 5 years
- 5 = rapid increase in past 5 years

#### Severity of Consequences

- 1 = not life threatening
- 2 = slightly debilitating to individuals or society

3 = moderately debilitating to individuals or society

**4 = life threatening or debilitating to individuals or society**

5 = life threatening and debilitating to individuals and society

#### Resources Available

- 1 = no resources available
- 2 = resources moderately available
- 3 = resources highly available

#### Acceptability

- 1 = not perceived as a health problem; any effort to address it would be opposed
- 2 = not perceived as a health problem; efforts to address it would not be opposed
- 3 = recognized as a health problem; any effort to address it would be opposed
- 4 = recognized as a health problem; efforts to address it would not be opposed
- 5 = recognized as a health problem; efforts to address it would be welcomed

## Example:

MCH Issues/ Problems Facing Region	Extent (High incidence/ prevalence)	Trends Increasing	Severe Consequences	Resources Available	Acceptability to citizens	Total
Low Birthweight	4	4	4	3	5	20
Infant Mortality	4	2	5	3	5	19
Vision Impairments	2	3	3	1	4	13
Adolescent Pregnancy	4	4	4	2	4	18

## Regional Needs: Scoring Method

### Extent

- 1 = low incidence or prevalence
- 2 = moderate incidence or prevalence in some subgroups
- 3 = moderate incidence or prevalence in all groups
- 4 = high incidence or prevalence in some subgroups
- 5 = high incidence or prevalence in all subgroups

### Trends Increasing

- 1 = rapid decrease in past 5 years
- 2 = moderate/slow decrease in past 5 years
- 3 = no change in past 5 years
- 4 = moderate/slow increase in past 5 years
- 5 = rapid increase in past 5 years

### Severity of Consequences

- 1 = not life threatening
- 2 = slightly debilitating to individuals or society
- 3 = moderately debilitating to individuals or society
- 4 = life threatening or debilitating to individuals or society
- 5 = life threatening and debilitating to individuals and society

### Resources Available

- 1 = no resources available
- 2 = resources moderately available
- 3 = resources highly available

### Acceptability

- 1 = not perceived as a health problem; any effort to address it would be opposed
- 2 = not perceived as a health problem; efforts to address it would not be opposed
- 3 = recognized as a health problem; any effort to address it would be opposed
- 4 = recognized as a health problem; efforts to address it would not be opposed
- 5 = recognized as a health problem; efforts to address it would be welcomed

Perinatal Needs/ Problems Facing Region	Extent (High incidence/ prevalence)	Trends Increasing	Severe Consequence s	Resources Available	Acceptability to citizens	Total
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						



## **Resource/Service Availability and Accessibility**

For Services and Resources in the region where you live/work, please “√” all that apply and provide comments, where appropriate.

Availability & Accessibility of Resources/Services							
Resources/Services	Present in All Parishes within Region? (Yes or No)	Present in Region?				Not Present	Comments
		Available to All	Available, but to special groups	Limited Availability to All	Availability unknown		
Pregnancy Testing							
Prenatal Care							
Home Visiting/NFP							
Adequate high risk prenatal care & delivery services							
Health Education/ Counseling							
Substance Use/ Mental Health Assessment							
Substance Use Treatment & Intervention/ Mental Health Services (referrals)							
HIV Counseling & Testing							
Sleep Position & Sleep Environment Education							
Family Planning							
Breast Feeding Promotion							

### **Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region.

Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1.</b>	1.
	2.
	3.
<b>2.</b>	1.
	2.
	3.
<b>3.</b>	1.
	2.
	3.

4.	1.
	2.
	3.
5.	1.
	2.
	3.

*Thank you for your participation in the assessment and prioritization of perinatal needs in your region.  
Your feedback is critical to improving the health and wellbeing of Louisiana's women and infants.*  
**Please return your workbook to your FIMR Coordinator.**

## **Region I Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

\*Repeat Preterm Deliveries and Pre & Inter Conception Care were combined by group consensus.

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Violence</b>	1. Make screening for violence a priority during prenatal care. Reimbursement for doctors should be examined as part of this effort.
	2. Develop social marketing campaign to address stigma of domestic violence in society.
	3. Work with law enforcement to develop strategies. Advocate for increased penalties for violence committed against pregnant women.
<b>2. STD Intervention</b>	1. Implement campaign to raise public awareness.
	2. Advocate for policy changes to allow STD screening and treatment in school based health centers. (Strategy targets teen population which has high rates of STDs.)
	3. Review current Take Charge policies to determine if women are screened for STDs.
<b>3. Repeat Preterm &amp; Pre &amp; Inter Conception Care*</b>	1. Work with Medicaid to cover females with preexisting condition before pregnancy.
	2. Promote linkage of females to pre and inter conception care post pregnancy. Develop tools/modules for providers to use during post partum period. Ensures a longitudinal plan for better patient care.
	3.
<b>4. Substance Use</b>	1. Dedicate funding for adequate intervention resources. There are more women who want help than there are resources available.
	2.
	3.
<b>5. Maternal Depression</b>	1. Increase screening during prenatal period.
	2. Partner with state agencies to develop tools to address MCH population specifically.
	3.

## **Region II Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Infant Health</b>	1. Increase health promotion/ health education efforts throughout region. Increase peer to peer opportunities.
	2. Identify populations for targeted interventions (contact Medicaid to identify late preterm deliveries). Once identified, develop targeted education for this group. For example, establish a referral system for identified late preterm births to specific programs/interventions, i.e. Healthy Start. This strategy involves the use of data to influence interventions.
	3. Channel MCH funds to expand Healthy Start to reach non-eligible "NFP like" patients.
<b>2. Preconception Health/Family Planning</b>	1. Improve access to appointments for family planning services. Decrease delays in waiting times for appointments.
	2. Augment existing health education/preconception resources (i.e. college health programs, Baton Rouge Community College health programs, health care centers in schools) in order to reach a larger population. Increase health promotion resources/efforts to 20-30 year old age group. Target efforts to those individuals who have completed their GED education.
	3. Develop advocacy initiative to address needed policy changes regarding preconception education in schools.
<b>3. Domestic Violence</b>	1. Increase preventive education efforts with an emphasis on culture. Consider partnering with 100 Black Men of Baton Rouge, Fatherhood program and others to engage the population. Increase education in schools to prevent early incidents of domestic violence. Create a curriculum that can be used in schools to address domestic violence. Focus on female to female violence in area schools.
	2. Implement social marketing campaign that utilizes area musicians and sports figures.
	3. Explore current domestic and abuse resources such as the Sunshine Foundation's booklet on child abuse. Available to every kindergarten class in state free of charge.
<b>4. STDs</b>	1. Facilitate a series of special guest speakers to travel to schools and churches.
	2. Institute texting and Facebook campaign to target youth.
	3. Increase early screening of pregnant women for all STDs at the onset of prenatal care.
<b>5. Mental Health</b>	1. Expand scope of public and private services for depressed moms and non-chronically ill women (i.e. stress, anxiety).
	2. Improve reimbursement for private mental health doctors. Improve access to free medications for patients.
	3. Expand peer to peer support groups (NAMI) to pregnant women.

## **Region III Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Behavioral Health</b>	1. Implement SBIRT in the Region
	2. Identify referral resources for both out-patient and in-patient behavioral health
	3. Address stigma related to behavioral health in other populations
<b>2. Transportation</b>	1. Increase Medicaid funded transportation resources. Explore certification process to become a Medicaid transporter
	2. Identify resources for mobile clinics especially for prenatal care, tooth bus, etc.
	3. Partner with area hospitals to bring physicians health units to practice part-time
<b>3. Access and Coordination of Care</b>	1. Develop a media campaign about what the Public Health Unit can provide in terms of services
	2. Explore programs related to health navigators (peers)
	3. Expansion of healthcare coverage and continuation of coverage between pregnancies
	4. Link health units with public hospital system for better referrals to specialty care- health information technology
<b>4. Comprehensive Education (sexual health and adolescent health)</b>	1. Improve relationships between nursing supervisors and local school nurses
	2. Advocate at the Department of Education level for more comprehensive education in schools related to sexual and adolescent health
	3. Explore Life Skills and Cross roads educational curriculumns
<b>5. Breast feeding, Prenatal Care, Injury Prevention</b>	1. GIFT certification at hospitals (some pros and cons to this)
	2. Provide breastfeeding classes for free through WIC
	3. Provider education on the importance of breast feeding, prenatal care and injury prevention
	4. Look for strategies to address difficulties in obtaining breast pumps.

## **Region IV Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Behavioral Health and Substance Abuse</b>	1. Increased education and need for referral and treatment resources
	2. Identify expanded audiences to discuss behavioral health and substance abuse that are inclusive of the family
<b>2. Teen Pregnancy</b>	1. State mandated program for health education that is more comprehensive – includes info on the maturing teenager
	2. Increase the use of school nurses and school health clinics
	3. Mobile health centers e.g. SWALAHEC
	4. Build and implement mentoring program for teens: a) life goals b) life course c) future planning
<b>3. Transportation</b>	1. Increase resources for mobile units that could offer prenatal care for low risk pregnancies
	2. Increase Medicaid covered transportation and use of transportation vouchers
<b>4. Pre and Interconception care</b>	1. Increase use of mobile clinics partnering with Healthy Start offering preconception care
	2. Expand Nurse- Family Partnership and engage in community education so it becomes a priority
	3. GIFT certification for all regional hospitals as well as provider education so providers understand what info to give on prenatal care, breastfeeding etc.
<b>5. Pre-term birth</b>	1. Build and implement mentoring program for women who have had a pre-term birth
	2. Advocate for expanding coverage of women who have had pre-term births
	3. Provider and community education on what services are available as well as education on spacing

## **Region V Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Breastfeeding</b>	1. GIFT certification for all regional hospitals
	2. Promote breastfeeding through a social marketing campaign
	3. Address stigma around breastfeeding, promote more workplace stations for breastfeeding
<b>2. Safe sleep practices</b>	1. Promote safe sleeping policies in hospitals- providers speaks to parents <i>before</i> the baby is born about where the baby will sleep
<b>3. Access to Care</b>	1. Increase transportation programs (vouchers)
	2. Increase staffing and capabilities of March of Dimes mobile unit. Schedule van to go to rural areas on a regular basis. Partner with FQHCs to make this happen.
	3. Advocacy around the expansion of coverage for interconception care
	4. Promote medical home concept- one stop shopping
<b>4. Behavioral health</b>	1. Provider education on substance abuse (alcohol, tobacco, etc.)
	2. Increase pre-natal care screenings through questionnaires, SBIRT, etc.
<b>5. Health Education</b>	1. Provider education on violence
	2. Comprehensive health education in schools- opt-out vs. opt-in that include abstinence, be faithful and condoms
	3. Promote an initiative around fatherhood through faith based groups



## **Region VI Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Substance Abuse</b>	1. Promotion of existing resources to address substance abuse during pregnancy
	2. Enhance existing substance abuse programs
	3. Health navigators/mentoring- particularly for those who want to quit smoking
<b>2. Nutrition/Breastfeeding</b>	1. Provider education and mentoring possibly through Office of Minority Health (nursing and college students volunteering for credit)
	2. Focus efforts on school based clinics and schools in general- start early
<b>3. Interconceptional</b>	1. Media campaign to get facts out on teen pregnancy and general maternal and child health statistics in Region 6
<b>4. Safe sleeping practices</b>	1. Back to sleep programs
	2. Increase work with older generations who may be taking care of children (conduct focus groups with grandparents and parents)
	3. Promote safe sleeping practices through child care centers
<b>5. Family Planning</b>	1. Health education at a young age in schools- focus on self-esteem
	2. Build curriculums that address dating, violence, etc.
	3. Develop school health education program- "so you want to be a mommy someday" or "baby think it over"

## **Region VII Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Preconceptual Care and Access to care</b>	1. Advocacy with local school board on comprehensive health education and acceptance of coordinated school health
	2. Social marketing strategies targeted at youth
	3. Working formally and informally with community leaders (elected officials) with a set of structured messages about the importance of access to care
	4. Increase transportation vouchers to get people to care
<b>2. Addictive disorders</b>	1. Provider education on the importance of screening
	2. Public education and improvement of linkages with CPS
	3. Increase out-patient referral resources, increased use of OAD satellite clinics
	4. Increase alcohol abuse education particularly during pregnancy
<b>3. Mental health</b>	1. Strengthen referral system for mental health (not just screenings)
	2. Increase resources for mental health referrals for both minor and major mental health problems
	3. Collaborate with other sectors for mental health support (faith based communities)
<b>4. Breastfeeding and SUID</b>	1. Social marketing campaign on the dangers of co-sleeping
	2. Increase resources to promote breastfeeding
	3. Breastfeeding promotion through WIC- incentives for breastfeeding instead of formula
	4. Programs that focus on grandmothers and other caretakers of children besides mothers
	5. Expansion of peer counselor programs and provider education
<b>5. STDs/HIV</b>	1. Advocacy with local policy makers- issues related to STDs and HIV; recruit local advocates to talk about HIV/STD issues
	2. Address stigma and trust issues related to HIV/STDs in the community

## VIII Strategies to Improve Regional Health Status

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region. Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

Top 5 Priorities	Specify Strategies for Your Region (List All)
<b>1. Infant mortality</b>	1. Reduce pre-term birth and repeat pre-term birth
	2. Improve preconceptual care
	3. Many strategies across priority areas below relate to reduction of infant mortality
<b>2. Access to Care</b>	1. Medical home where a person can receive many services in one place or virtual home through robust referral relationships <ul style="list-style-type: none"> <li>- More locally available providers in rural areas</li> <li>- Family planning</li> <li>- STD</li> <li>- School health</li> <li>- Screening and treatment for substance abuse, expansion of treatment</li> <li>- Preconception health</li> <li>- Mental Health</li> </ul>
	2. Health education and personal health <ul style="list-style-type: none"> <li>-Parenting education</li> <li>- Sex education in schools</li> <li>-Research based curriculums in schools</li> <li>- Extend access to Nurse Family Partnership</li> <li>- Physical education activities in schools</li> <li>-Nutritional health</li> </ul>
	3. Transportation <ul style="list-style-type: none"> <li>-Making sure Medicaid system for transportation works</li> </ul>
	4. Coverage <ul style="list-style-type: none"> <li>- Expand Medicaid eligibility for prior pre-term birth and chronic medical disease</li> </ul>
<b>3. Child safety and physical abuse</b>	1. Health education- back to sleep campaigns
	2. Expansion of nurse family partnership
	3. Parenting education
	4. Mental health
	5. Public education campaigns- seat belts, fire safety, etc.
<b>4. Teen Pregnancy</b>	1. Back to sleep programs
	2. Increase work with older generations who may be taking care of children (conduct focus groups with grandparents and parents)
	3. Promote safe sleeping practices through child care centers
<b>5. Health Disparities/Cultural Competency</b>	1. Health education at a young age in schools- focus on self-esteem
	2. Build curriculums that address dating, violence, etc.
	3. Develop school health education program- "so you want to be a mommy someday" or "baby think it over"

## **IX Strategies to Improve Regional Health Status**

Based on your **top 5 priorities** from page 5, please list strategies that will improve the overall health status in your region.

Examples: Policy Changes, Direct Health Services, Screening/Treatment/Counseling, Patient Education (one on one), Home Visitation, Health Promotion (via health communication/social marketing, mass media).

<b>Top 5 Priorities</b>	<b>Specify Strategies for Your Region (List All)</b>
<b>1. Infant mortality</b>	1. Reduce pre-term birth and repeat pre-term birth
	2. Improve preconceptional care
	3. Many strategies across priority areas below relate to reduction of infant mortality
<b>2. Access to Care</b>	1. Medical home where a person can receive many services in one place or virtual home through robust referral relationships <ul style="list-style-type: none"> <li>- More locally available providers in rural areas</li> <li>- Family planning</li> <li>- STD</li> <li>- School health</li> <li>- Screening and treatment for substance abuse, expansion of treatment</li> <li>- Preconception health</li> <li>- Mental Health</li> </ul>
	2. Health education and personal health <ul style="list-style-type: none"> <li>-Parenting education</li> <li>- Sex education in schools</li> <li>-Research based curriculums in schools</li> <li>- Extend access to Nurse Family Partnership</li> <li>- Physical education activities in schools</li> <li>-Nutritional health</li> </ul>
	3. Transportation <ul style="list-style-type: none"> <li>-Making sure Medicaid system for transportation works</li> </ul>
	4. Coverage <ul style="list-style-type: none"> <li>- Expand Medicaid eligibility for prior pre-term birth and chronic medical disease</li> </ul>
<b>3. Child safety and physical abuse</b>	1. Health education- back to sleep campaigns
	2. Expansion of nurse family partnership
	3. Parenting education
	4. Mental health
	5. Public education campaigns- seat belts, fire safety, etc.
<b>4. Teen Pregnancy</b>	1. Back to sleep programs
	2. Increase work with older generations who may be taking care of children (conduct focus groups with grandparents and parents)
	3. Promote safe sleeping practices through child care centers
<b>5. Health Disparities/Cultural Competency</b>	1. Health education at a young age in schools- focus on self-esteem
	2. Build curriculums that address dating, violence, etc.
	3. Develop school health education program- "so you want to be a mommy someday" or "baby think it over"

2009

**LOUISIANA OFFICE OF PUBLIC HEALTH  
MATERNAL AND CHILD HEALTH PROGRAM**



**1010 Common St., Suite 2710  
New Orleans, LA. 70112**

The Title V Maternal and Child Health (MCH) Block Grant is a federal grant which provides over \$13 million to fund services throughout Louisiana for women of childbearing years, infants, children (including children with special healthcare needs), and adolescents. Funding is managed through the Office of Public Health's MCH Program. Every five (5) years, state Title V agencies are required to conduct a comprehensive needs assessment to identify state MCH priority needs, develop programmatic activities and policies to address these needs, and evaluate/monitor efforts.

MCH will be conducting its first ever needs assessment for child safety and injury prevention separate from the child health needs assessment. For the past five years, Priority needs for child safety that have been addressed by MCH over the past five years include decreasing infant deaths due to SIDS, decreasing unintentional injuries in children, and decreasing child abuse and neglect. The MCH activities that currently address these needs include a statewide SIDS Risk Reduction and Safe Sleep Environment public awareness media campaign, intensive nurse home visiting program for first-time mothers (NFP), infant mental health trainings, State and community-level death reviews of children 0-14 years of age, community-level child safety/injury prevention activities by the regional MCH Child Safety Coordinators, Safe Kids Louisiana, the Child Care Health Consultant Program, and the distribution of the Happy and Healthy Kids newsletter.

The MCH Child Health Program would like your input regarding the safety of Louisiana's children 0-14 years of age that can be addressed by the Louisiana Maternal and Child Health Program over the next 5 years. Please take a brief moment to complete this survey, and return your completed survey to the MCH Program by **email** to [Gina.Lagarde@LA.GOV](mailto:Gina.Lagarde@LA.GOV) or by **fax** to **(504) 568-3503**. I can be reached at (504) 568-3504 if you have any questions regarding the survey or the MCH Title V Block Grant.

Thank you for your time!

Sincerely,

Gina Payton Lagarde, M.D., MBA

Child Health Medical Director

Department of Health and Hospitals

Office of Public Health

Maternal and Child Health Program

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Section A:

- 1. From the following list of topics, which do you feel are the most important issues affecting the physical safety of **children 0-5 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING of your 10 choices (1 <sup>st</sup> - 10 <sup>th</sup> )
Acute injury care (incl. emergency medical services)		
Accidental Suffocation and Strangulation		
Home environment safety (incl. infant sleeping environment, child-proofing)		
Child Care/School safety		
Playground safety		
Sports Injuries		
Motor vehicle injuries		
Other land transport injuries (incl. ATV, bicycle, train)		
Child passenger safety		
Pedestrian safety		
Drowning		
Falls		
Firearm and weapon		
Fires/burns		
Poisoning		
Unaccompanied children in cars (or children in cars alone)		
Rural and Farm injuries		
Child abuse and maltreatment		
Teen Driving		
School violence/bullying		
Dating/partner violence		
Suicide		
Homicide		
Substance abuse (incl. alcohol, illegal drugs, prescription drugs)		
Cyberspace /texting misuse (incl. cyber bullying, sexting)		
Other:		

- 2. From the following list of topics, which do you feel are the most important issues affecting the physical safety of **children 6-14 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING your 10 choices 10 <sup>th</sup> ) of (1 <sup>st</sup> -
Acute injury care (incl. emergency medical services)		
Accidental Suffocation and Strangulation		
Home environment safety (incl. infant sleeping environment, child-proofing)		
Child Care/School safety		
Playground safety		
Sports Injuries		
Motor vehicle injuries		
Other land transport injuries (incl. ATV, bicycle, train)		
Child passenger safety		
Pedestrian safety		
Drowning		
Falls		
Firearm and weapon		
Fires/burns		
Poisoning		
Unaccompanied children in cars (or children in cars alone)		
Rural and Farm injuries		
Child abuse and maltreatment		
Teen Driving		
School violence/bullying		
Dating/partner violence		
Suicide		
Homicide		
Substance abuse (incl. alcohol, illegal drugs, prescription drugs)		
Cyberspace /texting misuse (incl. cyber bullying, sexting)		
Other:		



- 3. From the following list of topics, which do you feel are the most important issues affecting the physical safety of **ALL children 0-14 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING of your 10 choices (1 <sup>st</sup> -10 <sup>th</sup> )
Acute injury care (incl. emergency medical services)		
Accidental Suffocation and Strangulation		
Home environment safety (incl. infant sleeping environment, child-proofing)		
Child Care/School safety		
Playground safety		
Sports Injuries		
Motor vehicle injuries		
Other land transport injuries (incl. ATV, bicycle, train)		
Child passenger safety		
Pedestrian safety		
Drowning		
Falls		
Firearm and weapon		
Fires/burns		
Poisoning		
Unaccompanied children in cars (or children in cars alone)		
Rural and Farm injuries		
Child abuse and maltreatment		
Teen Driving		
School violence/bullying		
Dating/partner violence		
Suicide		
Homicide		
Substance abuse (incl. alcohol, illegal drugs, prescription drugs)		
Cyberspace /texting misuse (incl. cyber bullying, sexting)		
Other:		

- 4. From the following list of topics, which do you feel are the most important issues affecting **children 15-19 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING of your 10 choices (1 <sup>st</sup> -10 <sup>th</sup> )
Acute injury care (incl. emergency medical services)		
Accidental Suffocation and Strangulation		
Home environment safety (incl. infant sleeping environment, child-proofing)		
Child Care/School safety		
Playground safety		
Sports Injuries		
Motor vehicle injuries		
Other land transport injuries (incl. ATV, bicycle, train)		
Child passenger safety		
Pedestrian safety		
Drowning		
Falls		
Firearm and weapon		
Fires/burns		
Poisoning		
Unaccompanied children in cars (or children in cars alone)		
Rural and Farm injuries		
Child abuse and maltreatment		
Teen Driving		
School violence/bullying		
Dating/partner violence		
Suicide		
Homicide		
Substance abuse (incl. alcohol, illegal drugs, prescription drugs)		
Cyberspace /texting misuse (incl. cyber bullying, sexting)		
Other:		

Section B:

1. For Services and Resources in the region where you live/work, please “√” all that apply.

Resources/Services	Present within Region				Not Present	Don't Know
	Available to All	Available, but to special groups	Limited availability to All	Availability unknown		
MCH Child Safety Coordinators						
Safe Kids Louisiana Coalition/Chapter						
Child Care Health Consultants (CCHC's)/Safety trainings for Child Care Centers						
Emergency medical service for children						
Early Childhood Supports and Services (ECSS)						
SIDS/Safe Sleep Education (incl. childbirth classes, birthing hospitals, child care centers)						
Child Passenger Safety Technicians						
Child Safety Seat/Restraints Inspection services						
Teen Driving Monitoring Programs (incl. Street Watch and SAV-TEEN)						
Fire safety and home fire escape education (incl. Risk Watch)						
Operation Lifesavers						
Swim/Water Safety Classes for children and parents/caregivers of young children						
ATV Safety Classes						
Crib/Baby Bed distribution with education						
Child Restraints (car seat/booster seat) Distribution with education						
Bicycle Helmet Distribution with education						
Smoke alarm distribution with education						
Gun Lock Distribution with education						
Youth Suicide Prevention Program (incl. school gatekeeper training)						
School violence/bullying prevention services						

Resources/Services	Present within Region				Not Present	Don't Know
	Available to All	Available , but to special groups	Limited availability to All	Availability unknown		
Dating/Partner violence prevention services						
Smoking cessation education and support						
Parenting Education/Family Support Services						
Nurse Family Partnership						
Happy and Healthy Kids Newsletter						
Bereavement/Grief Support services for families/caregivers who experience a loss						
Stress debriefing for responders to death scenes						
Safe Havens						
*						
*						
*						
*						
*						
* Please fill in any additional resources/services available in your region that is not on the list.						

<b>Reviews</b>	<b>Present within Region</b>	<b>Not Present</b>	<b>Don't Know</b>
<b>Child Death Reviews</b>			
<b>Feto-Infant Mortality Reviews (FIMR)</b>			
<b>Domestic Violence Death Reviews</b>			
<b>Child Maltreatment Death Reviews</b>			
*			
*			
*			

2. Based on your **top 5 priorities for children 0-14yrs old** from **page 5**, please select the services that you feel are needed to improve/address the safety needs in the region where you live/work. Please “√” all that apply. **If possible, please provide specific detail where possible (ex. Service: Budget Allocation: √CPS Grant through CDC)**

Please <u>write in</u> your TOP 5 Priority Areas from page 5	Early Identification/ Screening and Referral	Preventive / Direct Services	Public Education/ Social Marketing	Mobilize community Partnerships	Policy Develop ment/ Legislati on/ Advocac y	Education/ Trainings to professional s	Data/ Research/ Quality Assurance	Enforcement
1.								
2.								
3.								
4.								
5.								
Please add in any services that you feel may be needed in your region that are not included in the above chart								
1.					3.			
2.					4.			

3. Based on your **top 5 priorities for children 15-19yrs old** from **page 6**, please select the services that you feel are needed to improve/address the safety needs in the region where you live/work. Please “√” all that apply. **If possible, please provide specific detail where possible (ex. Service: Budget Allocation: √CPS Grant through CDC)**

Please <u>write in</u> your TOP 5 Priority Areas from page 5	Early Identification/ Screening and Referral	Preventive / Direct Services	Public Education / Social Marketing	Mobilize community Partnerships	Policy Development/ Legislation/ Advocacy	Education/ Trainings to professionals	Data/ Research/ Quality Assurance	Enforcement
1.								
2.								
3.								
4.								
5.								
Please add in any services that you feel may be needed in your region that are not included in the above chart								
1.				3.				
2.				4.				

## Section C:

**What best describes your profession? (✓ all that apply)**

- ☐ **Public Health**
- ☐ **Law Enforcement**
- ☐ **Firefighter**
- ☐ **Child Protective Services**
- ☐ **Medical Examiner/Coroner**
- ☐ **Emergency Medical Services**
- ☐ **Prosecutor/District Attorney**
- ☐ **Medical Provider (specify type) \_\_\_\_\_**
- ☐ **Education (specify type) \_\_\_\_\_**
- ☐ **Injury Prevention Partner (specify type) \_\_\_\_\_**
- ☐ **Other (specify type) \_\_\_\_\_**

**I am a:**

- ☐ **Male**
- ☐ **Female**

**What is the zip code of your residence/practice? \_\_\_\_\_**

**THANK YOU!!!!**



## Section D: – Glossary of Terms:

- MCH Child Safety Coordinators:** The LA Office of Public Health's community action arm of the Child Death Review process, charged with the role of coordinating local case reviews and injury prevention recommendations and strategies.
  - Safe Kids Louisiana Coalition/Chapter:** A national child injury prevention service that coordinates and implements child injury prevention strategies.
  - Child Care Health Consultants (CCHC's)/Safety trainings for Child Care Centers:** a training service to licensed child care facilities to assist in maintained the 3-clock hours of child health and safety training required of each provider to maintain licensure. Trainings are provided by certified Child Care Health Consultants who are typically RNs, Social Workers, or Child Injury Specialists.
  - Emergency medical service for children:** a service providing immediate service to acute injuries, provided by a medical doctor.
  - Early Childhood Supports and Services (ECSS):** Provides a coordinated system of screening, evaluation and referral services and treatment for children ages 0 through 5-years and their families.
  - SIDS/Safe Sleep Education (incl. childbirth classes, birthing hospitals, child care centers):** a resource that provides awareness and education specifically regarding Sudden Infant Death Syndrome (SIDS), strategies and recommendations to reduce risk and the importance of establishing safe sleep environments for infants.
  - Child Passenger Safety Technicians:** individuals certified by the LA Highway Safety Commission who are equipped to provide caregivers with awareness, education, and training on proper child passenger safety, including proper car seat/booster seat installation.
  - Child Safety Seat/Restraints Inspection services:** locations where caregivers can go to have certified child passenger safety technicians evaluate and correct, if necessary, the installation of a car seat/booster seat. These sites are typically located at police stations.
  - Teen Driving Monitoring Programs (incl. Street Watch and SAV-TEEN):** programs wherein vehicles driven by teens are marked to allow any observing poor habits to report them to law enforcement; law enforcement then either visits that teen's home to report the incident to that teen's parent(s) or the owner of the vehicle.
  - Fire safety and home fire escape education (incl. Risk Watch):** programs in schools, preschools, and/or child care settings that provide education and training on fire safety and home fire escape.
  - Operation Lifesavers:** a program offering awareness, education, and/or training on railroad safety, to children, families, and/or communities.
  - Swim/Water Safety Classes for children and parents/caregivers of young children:** a program offering awareness, education, and/or training on water safety, to children, families, and/or communities.
  - ATV Safety Classes:** a program offering awareness, education, and/or training on proper use and safety precautions regarding All Terrain Vehicles (ATVs).
  - Crib/Baby Bed distribution with education:** a service that provides an approved crib or baby bed to families in need, free-of-charge, along with education and training on proper use as well as recommended safe sleep environment strategies.
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## Section D: – Glossary of Terms:

- Child Restraints (car seat/booster seat) Distribution with education:** a service that provides car seats/booster seats to families in need, free-of-charge, along with education and training on proper use as well as recommended child passenger safety strategies.
  - Bicycle Helmet Distribution with education:** a service that provides bicycle helmets to children & families in need, free-of-charge, along with education and training on proper use, as well as recommending bicycle safety strategies.
  - Smoke alarm distribution with education:** a service that provides smoke detectors to families in need, free-of-charge, along with education and training on proper use, as well as recommended fire safety strategies.
  - Gun Lock Distribution with education:** a service that provides gun locks to families in need, free-of-charge, along with education and training on proper use, as well as recommended gun safety strategies.
  - Youth Suicide Prevention Program (incl. school gatekeeper training):** A program of the LA Department of Health and Hospitals that seeks to prevent youth suicide and suicidal behavior statewide through evidence-based interventions and recommended best practices.
  - School violence/bullying prevention services:** a resource or service specifically messaging that bullying will not be accepted in school. Well designed and implemented programs can create an improved climate by educating staff and students to recognize and respond to instances of bullying.
  - Dating/Partner violence prevention services:** resources and/or services in the community addressing preventive strategies to dating and/or partner violence.
  - Smoking cessation education and support:** training, education, and/or support services or resources to encourage individuals to stop smoking.
  - Parenting Education/Family Support Services:** program and/or resource that provides education, training, resources, and/or social-emotional support to families in need.
  - Nurse Family Partnership:** a program of the MCH program that provides training and support services to first-time mothers in communities, leading to improved outcomes for both mothers and children.
  - Happy and Healthy Kids Newsletter:** resource offered by the Office of Public Health's Maternal & Child Health (MCH) Program that provides information regarding the health & well-being of women of childbearing age and children in Louisiana.
  - Bereavement/Grief Support services for families/caregivers who experience a loss:** program and/or resource that provide direct social-emotional support or referrals to such services, to individuals or families who have experienced the death of an infant or child.
  - Stress debriefing for responders to death scenes:** a service offering social-emotional support to individuals and/or teams whose duty is to participate in death scene investigations and the like.
  - Safe Havens:** providers obligated to accept and offer safety to infants, 30-days or younger, whose biological parent(s) chose to relinquish custody of, without fear of prosecution for child abandonment. Typically these providers are child advocacy centers, hospitals, police, etc.
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2009

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MATERNAL AND CHILD HEALTH PROGRAM**



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Thank you for your time!

Sincerely,

Gina Payton Lagarde, M.D., MBA

Child Health Medical Director

Department of Health and Hospitals

Office of Public Health

Maternal and Child Health Program

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## Section A

1. From the following list of health and quality of life topics, which do you feel include the most important issues affecting **children 0-5 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING your 10 choices 10 <sup>th</sup> ) of (1 <sup>st</sup> -
Cultural competency		
Poverty/Financial Impact on the Family		
Health Insurance (incl. access, adequacy)		
Access to Care (incl. services, providers, quality, specialists)		
Medical Home (incl. care coordination, primary care doctor)		
Preventive Health (incl. screenings, immunizations, well-checks)		
Environmental Health (incl. lead poisoning)		
School-Based Health		
Oral Health Care/Dental Home		
Mental Health/Emotional-Behavioral Health		
Reproductive Health (incl. birth control, annual pelvic exams)		
Breastfeeding		
Sudden Infant Death Syndrome/Unsafe Infant Sleep Practices		
Safe Communities/Neighborhoods		
Child Safety/Unintentional Injury (incl. motor vehicle, fire, drowning, suffocation, firearm, poisoning)		
Violence/Intentional Injury (incl. child abuse and neglect, suicide, homicide, bullying)		
Teen Pregnancy		
Sexually Transmitted Diseases (incl. GC, Chlamydia, HIV)		
Obesity		
Physical Activity		
Nutrition/Healthy Eating		
Chronic Disease Management (incl. asthma, diabetes, hypertension)		
Tobacco exposure in the home (second hand)		
Tobacco use (smoking, chewing)		
Alcohol use/abuse		
Illegal drug use/prescription drug abuse		
Family/Parent Support Services		
School Readiness (incl. quality child care and early education)		

2. From the following list of health and quality of life topics, which do you feel include the most important issues affecting **children 6-10 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING of your 10 choices (1 <sup>st</sup> - 10 <sup>th</sup> )
Cultural competency		
Poverty/Financial Impact on the Family		
Health Insurance (incl. access, adequacy)		
Access to Care (incl. services, providers, quality, specialists)		
Medical Home (incl. care coordination, primary care doctor)		
Preventive Health (incl. screenings, immunizations, well-checks)		
Environmental Health (incl. lead poisoning)		
School-Based Health		
Oral Health Care/Dental Home		
Mental Health/Emotional-Behavioral Health		
Reproductive Health (incl. birth control, annual pelvic exams)		
Breastfeeding		
Sudden Infant Death Syndrome/Unsafe Infant Sleep Practices		
Safe Communities/Neighborhoods		
Child Safety/Unintentional Injury (incl. motor vehicle, fire, drowning, suffocation, firearm, poisoning)		
Violence/Intentional Injury (incl. child abuse and neglect, suicide, homicide, bullying)		
Teen Pregnancy		
Sexually Transmitted Diseases (incl. GC, Chlamydia, HIV)		
Obesity		
Physical Activity		
Nutrition/Healthy Eating		
Chronic Disease Management (incl. asthma, diabetes, hypertension)		
Tobacco exposure in the home (second hand)		
Tobacco use (smoking, chewing)		
Alcohol use/abuse		
Illegal drug use/prescription drug abuse		
Family/Parent Support Services		
School Readiness (incl. quality child care and early education)		

3. From the following list of health and quality of life topics, which do you feel include the most important issues affecting **children 11-14 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING of your 10 choices (1 <sup>st</sup> - 10 <sup>th</sup> )
Cultural competency		
Poverty/Financial Impact on the Family		
Health Insurance (incl. access, adequacy)		
Access to Care (incl. services, providers, quality, specialists)		
Medical Home (incl. care coordination, primary care doctor)		
Preventive Health (incl. screenings, immunizations, well-checks)		
Environmental Health (incl. lead poisoning)		
School-Based Health		
Oral Health Care/Dental Home		
Mental Health/Emotional-Behavioral Health		
Reproductive Health (incl. birth control, annual pelvic exams)		
Breastfeeding		
Sudden Infant Death Syndrome/Unsafe Infant Sleep Practices		
Safe Communities/Neighborhoods		
Child Safety/Unintentional Injury (incl. motor vehicle, fire, drowning, suffocation, firearm, poisoning)		
Violence/Intentional Injury (incl. child abuse and neglect, suicide, homicide, bullying)		
Teen Pregnancy		
Sexually Transmitted Diseases (incl. GC, Chlamydia, HIV)		
Obesity		
Physical Activity		
Nutrition/Healthy Eating		
Chronic Disease Management (incl. asthma, diabetes, hypertension)		
Tobacco exposure in the home (second hand)		
Tobacco use (smoking, chewing)		
Alcohol use/abuse		
Illegal drug use/prescription drug abuse		
Family/Parent Support Services		
School Readiness (incl. quality child care and early education)		



4. From the following list of health and quality of life topics, which do you feel include the most important issues affecting **children 15-19 years of age** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING your 10 choices -10 <sup>th</sup> ) of (1 <sup>st</sup>
Cultural competency		
Poverty/Financial Impact on the Family		
Health Insurance (incl. access, adequacy)		
Access to Care (incl. services, providers, quality, specialists)		
Medical Home (incl. care coordination, primary care doctor)		
Preventive Health (incl. screenings, immunizations, well-checks)		
Environmental Health (incl. lead poisoning)		
School-Based Health		
Oral Health Care/Dental Home		
Mental Health/Emotional-Behavioral Health		
Reproductive Health (incl. birth control, annual pelvic exams)		
Breastfeeding		
Sudden Infant Death Syndrome/Unsafe Infant Sleep Practices		
Safe Communities/Neighborhoods		
Child Safety/Unintentional Injury (incl. motor vehicle, fire, drowning, suffocation, firearm, poisoning)		
Violence/Intentional Injury (incl. child abuse and neglect, suicide, homicide, bullying)		
Teen Pregnancy		
Sexually Transmitted Diseases (incl. GC, Chlamydia, HIV)		
Obesity		
Physical Activity		
Nutrition/Healthy Eating		
Chronic Disease Management (incl. asthma, diabetes, hypertension)		
Tobacco exposure in the home (second hand)		
Tobacco use (smoking, chewing)		
Alcohol use/abuse		
Illegal drug use/prescription drug abuse		
Family/Parent Support Services		
School Readiness (incl. quality child care and early education)		



5. From the following list of health and quality of life topics, which do you feel include the most important issues affecting **ALL CHILDREN (0-19 years of age)** in the community where you live and/or work? Select only ten (10) topics, and priority rank your 10 choices only by numbering them from 1-10 (with #1 being most important).

TOPICS	Check Ten (10) choices only	PRIORITY RANKING of your 10 choices (1 <sup>st</sup> - 10 <sup>th</sup> )
Cultural competency		
Poverty/Financial Impact on the Family		
Health Insurance (incl. access, adequacy)		
Access to Care (incl. services, providers, quality, specialists)		
Medical Home (incl. care coordination, primary care doctor)		
Preventive Health (incl. screenings, immunizations, well-checks)		
Environmental Health (incl. lead poisoning)		
School-Based Health		
Oral Health Care/Dental Home		
Mental Health/Emotional-Behavioral Health		
Reproductive Health (incl. birth control, annual pelvic exams)		
Breastfeeding		
Sudden Infant Death Syndrome/Unsafe Infant Sleep Practices		
Safe Communities/Neighborhoods		
Child Safety/Unintentional Injury (incl. motor vehicle, fire, drowning, suffocation, firearm, poisoning)		
Violence/Intentional Injury (incl. child abuse and neglect, suicide, homicide, bullying)		
Teen Pregnancy		
Sexually Transmitted Diseases (incl. GC, Chlamydia, HIV)		
Obesity		
Physical Activity		
Nutrition/Healthy Eating		
Chronic Disease Management (incl. asthma, diabetes, hypertension)		
Tobacco exposure in the home (second hand)		
Tobacco use (smoking, chewing)		
Alcohol use/abuse		
Illegal drug use/prescription drug abuse		
Family/Parent Support Services		
School Readiness (incl. quality child care and early education)		

## Section B

1. For Services and Resources in the region where you live/work, please “√” all that apply.

Resources/Services	Present within Region				Not Present	Don't Know
	Available to All	Available, but to special groups	Limited availability to All	Availability unknown		
Medical Specialty Providers						
Dental Sealant Programs						
Injury Prevention Services						
Suicide Prevention Program						
Mental Health Services						
Substance Use Services						
School-Based Health Centers						
Nutrition Education/Counseling						
Violence Prevention Programs						
Breastfeeding Promotion						
Information on Health Care Coverage options /Enrollment (incl. Medicaid, LaCHIP)						
SIDS & Safe Sleep Education						
Home Visitation/NFP Services						
Immunization Services						
Training for Child Care Centers in health & safety						
Early Steps						
Fluoridated Water						
Parenting Education/Family Support Services						
Child Death Reviews						
STD/HIV Counseling & Testing						
Happy and Healthy Kids Newsletter						

Resources/Services	Present within Region				Not Present	Don't Know
	Available to All	Available, but to special groups	Limited availability to All	Availability unknown		
Head Start/ Pre-K						
Emergency Medical Services for Children						
Family Planning Services						
Smoking Cessation Services						
*						
*						
*						
*						
*						
*						
*						
* Please fill in additional resources/services available in your region that are not on the list.						

2. Based on your **top 5 priorities** from page 7, please select the MCH services that you feel are needed to improve/address the health and well-being needs in the region where you live/work. Please “√” all that apply.

Please <u>write in</u> your TOP 5 Priority Areas from page 7	MCH Services						
	Early Identification/ Screening and Referral	Preventive / Direct Services	Public Education/S ocial Marketing	Mobilize community Partnership s	Policy Developme nt/ Legislation/ Advocacy	Education/ Trainings to professional s	Data/ Research/ Quality Assurance
1.							
2.							
3.							
4.							
5.							

Please add in any services that you feel may be needed in your region that are not included in this chart	1.
	2.
	3.

# Section C

**I am a:**

- ☐ **Physician**
- ☐ **Nurse**
- ☐ **Mid-level Healthcare Provider (specify)**  
\_\_\_\_\_
- ☐ **Program Administrator**
- ☐ **Other (specify)** \_\_\_\_\_

**I am a:**

- Male**
- Female**

**My professional area of expertise is (✓ all that apply):**

- ☐ **Neonatal Health**
- ☐ **Infant/Child Health**
- ☐ **Adolescent Health**
- ☐ **Oral Health**
- ☐ **Women's Health**
- ☐ **Public Health**
- ☐ **Other (please specify)** \_\_\_\_\_

**What is the zip code of your residence/practice?** \_\_\_\_\_

**What best describes your place of practice? (✓ all that apply)**

- ☐ **Hospital-Based**
- ☐ **Private Clinic**
- ☐ **School-Based**
- ☐ **Public Health Unit**
- ☐ **State Department/Agency (please specify)** \_\_\_\_\_
- ☐ **Non-profit organization (please specify)**
- ☐ **Other (please specify)** \_\_\_\_\_

## Child Health Priority Needs/ Final Results (0-14y)

TOPICS	PRIORITY AREAS	EXCLUDED FROM FINAL RANKING  (based on: resource analysis, data trends, feasibility)	FINAL TOP 5
Poverty/Financial Impact on the Family	1	Not feasible	-
Health Insurance (incl. access, adequacy) Access to Care (incl. services, providers, quality, specialists) Medical Home (incl. care coordination, primary care doctor) Preventive Health (incl. screenings, immunizations, well-checks)	5	Positive trends and Adequate resources	-
Oral Health Care/Dental Home	6	Separate OPH program to address this area	-
Mental Health/Emotional-Behavioral Health	3		4 Behavioral Health
Safe Communities/Neighborhoods Child Safety/Unintentional Injury (incl. motor vehicle, fire, drowning, suffocation, firearm, poisoning) Violence/Intentional Injury (incl. child abuse and neglect, suicide, homicide, bullying)	4		2 Intentional & Unintentional Injuries
Teen Pregnancy Sexually Transmitted Diseases (incl. GC, Chlamydia, HIV)	9 and 10		5 Teen Pregnancy
		Adequate resources	-
Obesity Nutrition/Healthy Eating	2		1 Obesity/Healthy Eating
Tobacco exposure in the home (second hand) Tobacco use (smoking, chewing)	9 and 10	Adequate resources	-
Family/Parent Support Services School Readiness (incl. quality child care and early education)	7 and 8		3 Parenting Education/Family Support
		Adequate resources	-

# Survey of Safety and Injury Prevention Needs For Infants and Children

## Section A: Children 0-14 yrs of age

<b>TOPICS</b>	<b>ALL (tallied)</b>	<b>REORGANIZED</b>	<b>Consumer</b>	<b>LA Data (Vital Records, Hospital Discharge)</b>	<b>FINAL PRIORITY SETTING</b>
<i>Acute injury care (incl. emergency medical services)</i>	10				
<i>Accidental Suffocation and Strangulation</i>	10	6		2 <sup>nd</sup> Leading cause of death No Change in rate	✓
<i>Home environment safety (incl. infant sleeping environment, child-proofing)</i>	2				
<i>Fires/burns</i>			X	Rate decreasing but higher than the national average	
<i>Child Care/School safety</i>	7	3			
<i>Playground safety</i>		34			
<i>Sports Injuries</i>					
<i>Motor vehicle injuries</i>	3	4	X	Leading Cause of death Rate decreasing but higher than the national average	✓
<i>Child passenger safety</i>	5				
<i>Unaccompanied children in cars (or children in cars alone)</i>	3				
<i>Other land transport injuries (incl. ATV, bicycle, train)</i>					
<i>Pedestrian safety</i>					
<i>Drowning</i>		5	X	Rate decreasing but higher than the national average	✓
<i>Falls</i>		23			
<i>Firearm and weapon</i>	6	2		(check data from ppt)	✓
<i>Poisoning</i>		56	X	5 <sup>th</sup> leading cause of death of LA children	
<i>Substance abuse (incl. alcohol, illegal drugs, prescription drugs)</i>	4				
<i>Rural and Farm injuries</i>	8				
<i>Child abuse and maltreatment</i>	1	1	X	Rate has increased (0-18yrs of age)	✓
<i>Teen Driving</i>					
<i>School violence/bullying</i>	6		X	Rate increasing and higher than the national average	
<i>Homicide</i>					
<i>Dating/partner violence</i>					
<i>Suicide</i>				Rate increasing and higher than the national average	
<i>Cyberspace /texting misuse (incl. cyber bullying, sexting)</i>	10				
<i>Childhood Asthma</i>			X		
<i>Healthy Eating</i>			X		
<i>Vaccinations</i>			X		
<i>Physical Activity</i>			X		

# Survey of Safety and Injury Prevention Needs For Infants and Children

## Children 15-19 years of age

TOPICS	ALL STAKEH	COLLAP SED	Consum er	LA Data			FINAL PRIORIT
Acute injury care (incl. emergency medical services)	49						
Accidental Suffocation and Strangulation	10						
Home environment safety (incl. infant sleeping environment, child-proofing)	5						
Child Care/School safety	8						
Playground safety	3						
Sports Injuries	73 (9)						
Motor vehicle injuries	105 (4)	146		Leading cause of death (maintained 02-07)			
Teen Driving	110 (2)						
Other land transport injuries (incl. ATV, bicycle, train)	76 (8)						
Child passenger safety	13						
Pedestrian safety	12						
Drowning	33			3 <sup>rd</sup> Leading cause of death (02-07)			
Falls	5						
Fires/burns	15			5 <sup>th</sup> leading cause of death			
Unaccompanied children in cars (or children in cars alone)	1						
Rural and Farm injuries	10						
Child abuse and maltreatment	38			Rate has increased (0- 18yrs of age)			
Firearm and weapon	90 (5)	90		4 <sup>th</sup> Leading cause of death; Rate has increased			
Suicide	107 (3)	107		Rate has decreased			
Homicide	62 (10)	82		Rate has increased			
Substance abuse (incl. alcohol, illegal drugs, prescription drugs)	114 (1)	63		2 <sup>nd</sup> Leading cause of death; Rate has increased			
Poisoning	11						
Cyberspace /texting misuse (incl. cyber bullying, sexting)	89 (6)	132		DATA??			
School violence/bullying	86 (7)						
Dating/partner violence	86 (7)						
Vaccination, Healthy Eating, Physical Activity, Health Education, Teen Pregnancy, Grief Support, Asthma, Obesity, STDs,							

NOTE:



NOTE:

**ALL STAKEHOLDERS** – refer to the survey respondents who participated in the Child Safety Regional Surveys, conducted through the Local Child Death Review Teams. The number in the corresponding box refers the number of individual participants who identified that category.(N=126)

**COLLAPSED** – refers to responses to the Stakeholder Survey, wherein topic areas that were similar where collapsed to form one single new category. The number in the corresponding box refers to the average of the original categories

**CONSUMER SURVEY** – refers to the priority areas identified for this age group in the Consumer Survey, with in “X”

**LA DATA** – refers to Vital Records, Hospital Discharge, and Nat’l Data gathered on the corresponding topic areas.

**FINAL PRIORITY SETTING** – refers to topic areas that were identified by all of the above sources in combination as priority areas to focus

# 2010 Maternal and Child Health Program Needs Assessment Priority Setting Meeting March 30, 2010



# Purpose of MCH Needs Assessment

- Required by Federal Maternal & Child Health Bureau for all states receiving Federal MCH dollars
- Completed every five years (last reported-2005)

# Purpose of MCH Needs Assessment (cont'd)

- To engage all MCH stakeholders in the identification and prioritization of health needs of maternal and child population in Louisiana
- To facilitate optimal planning and delivery of services over the next five years
- Recommend needed changes to current allocation of resources from MCH Block Grant

# Vision of the Louisiana Office of Public Health

- We see a future where all people of Louisiana are born healthy and have the opportunity to grow, develop, and live in an environment that is nurturing, supportive, safe and promotes the physical, mental and social health of individuals, families and communities and the State. We see a future where the Office of Public Health is a key leader and influential partner in creating and sustaining a healthy and prosperous Louisiana.
-

# Goals and Vision of the Needs Assessment

- *Goal*

- To identify leading and emerging health issues impacting women, infants, and children (including those with special health care needs) in Louisiana through the engagement of key Maternal and Child Health (MCH) and Children with Special Health Care Needs (CYSHCN) stakeholders.

- *Vision*

- The Louisiana MCH and CYSHCN Program's vision for the Needs Assessment is to take the results of the qualitative and quantitative information gathered from MCH and CYSHCN stakeholders in each region of the state and among the MCH and CYSHCN population groups, and to synthesize these findings to establish the priority needs of the MCH and CYSHCN population for the period 2010 – 2015.
-

# Format

- Each Program will present their priority needs and supporting data
  - We will try to identify overlap and combine priorities
  - In a group process we will come up with the top 10 priority needs to guide our work in the next 5 years.
-

# Guiding Principles

- Use a 1 to 5 scoring system
  - Is the priority relevant to Maternal and Child Health Program specifically
  - Revisit list of needs
-



# 2010 Needs Assessment

## Maternal Health



# Maternal Health Methods

- 2010 Needs Assessment Methodology
  - Regional Meetings
    - Engage stakeholders (FIMR's, community partners)
    - Identify regional priorities and strategies to address priorities
  - Examine Epidemiological Data
  - Compare Needs Assessment Results (i.e. data from regional meetings) to Epi data.
  - Identify State Priorities
    - 1. Improve Preconception/Interconception care
    - 2. Decrease Preterm Birth
    - 3. Behavioral Health Access, Prevention and Treatment
    - 4. Improve Breastfeeding rates



Regional Priority Needs	Frequency
<b>Access to Care</b>	
<ul style="list-style-type: none"> <li>•Advocacy around the expansion of coverage for interconception care.</li> <li>•Insurance coverage: expanded Medicaid eligibility for prior preterm birth and those with chronic disease</li> </ul>	6
<b>Preconception Care</b>	
<ul style="list-style-type: none"> <li>•Work with Medicaid to cover women with pre-existing conditions before pregnancy.</li> <li>•Expand Nurse-Family Partnership and educate community to make it a priority.</li> </ul>	6
<b>Behavioral Health</b>	
<ul style="list-style-type: none"> <li>•Expand public and private resources for depressed moms and non-chronically ill women.</li> <li>•Implement SBIRT in the region.</li> </ul>	5

Regional Priority Needs	Frequency
<b>STD Intervention</b>	4
<ul style="list-style-type: none"> <li>•Increase early screening of pregnant women for all STDs at the onset of prenatal care.</li> <li>•Implement campaign to raise public awareness.</li> </ul>	
<b>Violence</b>	4
<ul style="list-style-type: none"> <li>•Advocate for increased penalties for violence committed against pregnant women.</li> <li>•Increase bilingual support and resources for Hispanic populations.</li> </ul>	
<b>Breastfeeding</b>	3
<ul style="list-style-type: none"> <li>•Provider education on the importance of breastfeeding, prenatal care, and injury prevention.</li> <li>•Address breastfeeding stigma</li> </ul>	

# Identify State Priorities

- 1) Preconception/Interconception Care
- 2) Prematurity
- 3) Health disparities in birth outcomes
- 4) Behavioral health
- 5) Breastfeeding



# Maternal Health Priority Areas

## Preconception/Interconception Care

Related Performance Measures (PM):

National Performance Measures (NPM): 8

State Performance Measures (SPM): 2

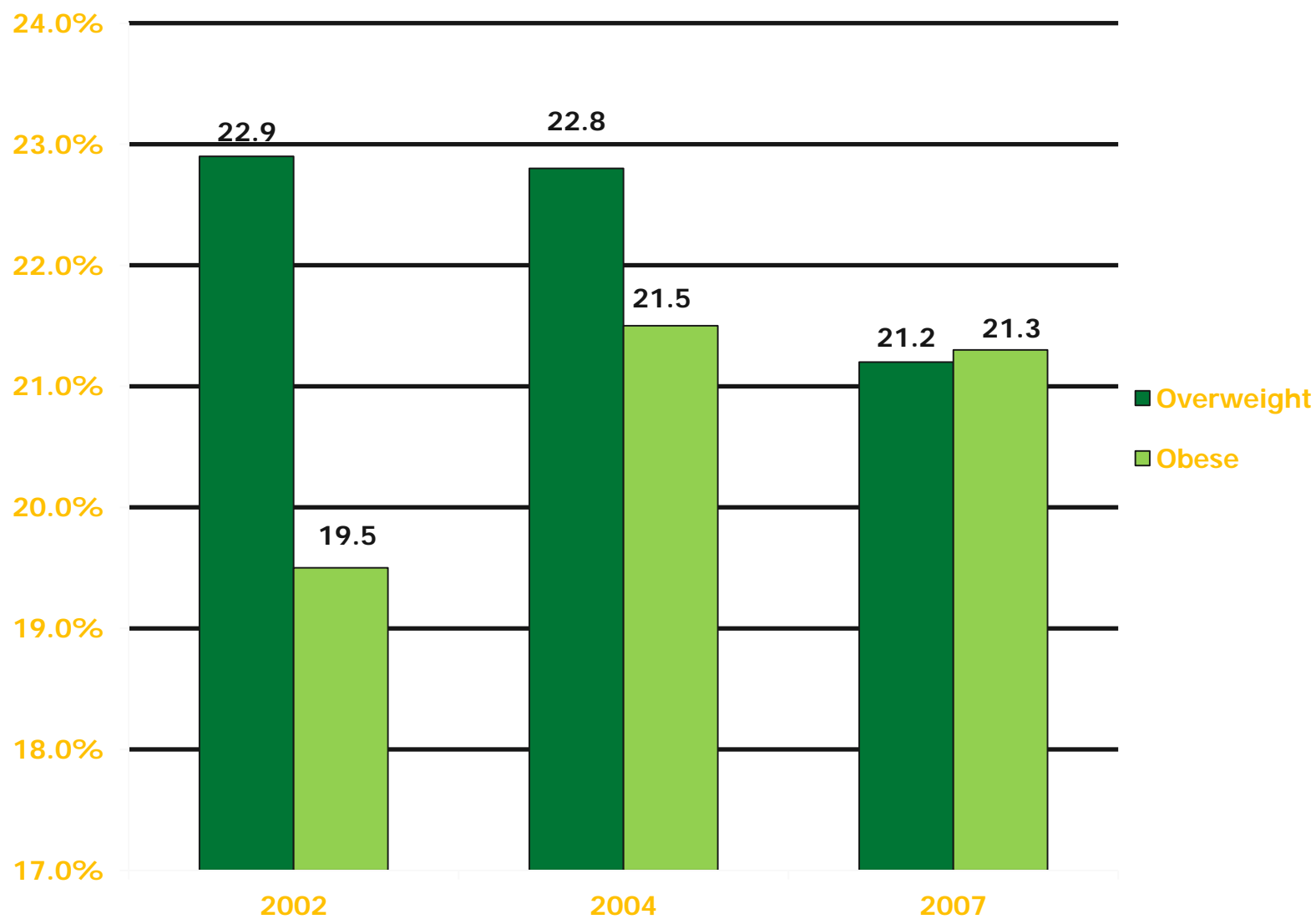


# General Health and Chronic Conditions of Women 18-44

Indicator	2007 18-44	2008 18-44	Caucasian (2008) 18-44	African- American (2008) 18-44
<b>General Health</b>				
Excellent/Good	86.2	87.4	90.4	81.1
Fair/Poor	13.7	12.5	9.5	18.8
<b>Mental Health</b>				
Good	90.2	88.6	90.2	87.3
Fair/Poor	9.7	11.3	9.7	12.6
No Health Plan	25	22.8	18.5	29.7
Could Not Afford Medical	22.7	24.3	21.2	29.3
Inadequate Physical Activity	69	68.8	74.2	61.1
Diabetic	3.4	3.4	3.1	3.3
Gestational Diabetes	<1%	1%		
Smokers	21.4	20	24.2	14
Inadequate Fruits/Veg	79.5	N/A	N/A	N/A
Never had PAP	N/A	17.2	12.7	23.7
Had PAP within 3yrs	N/A	94.5	94.2	96.7
Hypertension	17.7	N/A	15 (2007)	23.2 (2007)



## % of Women Overweight and Obese in LA Prior to Pregnancy



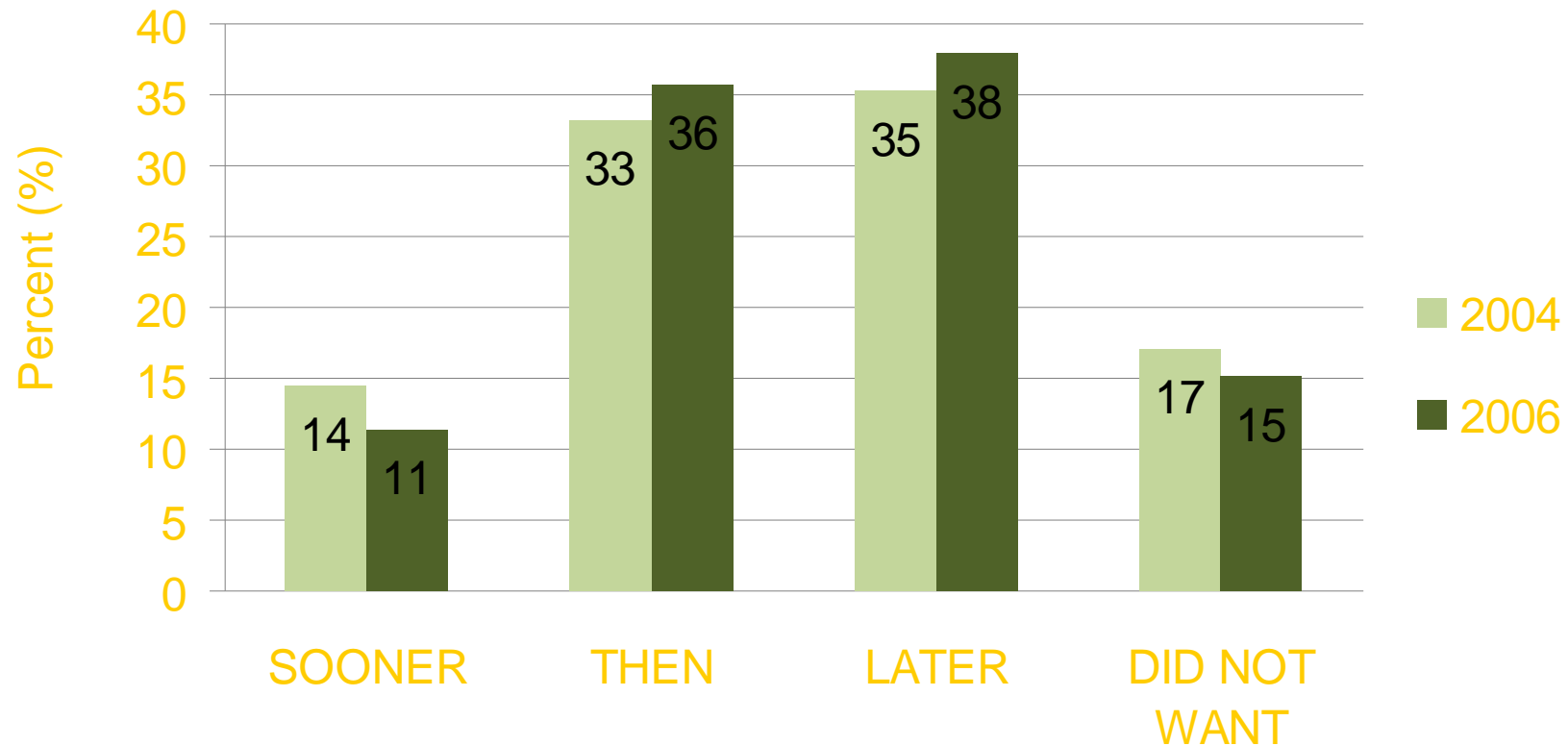
LA PRAMS 2002-2004, 2007





# Pregnancy Intention in Louisiana

Thinking back to *just before* you got pregnant with your *new* baby, how did you feel about becoming pregnant? I wanted to be pregnant:



About 38% of women reported that they were trying to get pregnant



# Pregnancy Spacing

## Louisiana, 2000-2002

- Women whose birth interval was  $< 12$  months were 50% more likely to have a LBW infant, after controlling for other factors
- Factors associated with birth intervals of less than 12 months included:
  - Black (OR=1.4)
  - Less than high school education (OR=1.5)
  - Younger (age $<20$ , OR=2.8; age $<25$ , OR=1.9)
  - Medicaid enrolled (OR=1.4)



# Maternal Health Priority Areas

## Prematurity

Related Performance Measures (PM):

National Performance Measures (NPM) 8, 15, 17, 18

State Performance Measures (SPM) 7, 9



# Preterm Birth

- Definition- Birth prior to the 37<sup>th</sup> week of pregnancy
- Significant problem in the U. S. and Louisiana
  - 2006 Preterm Births (PTB, 20-36 wks)\*
    - U.S. 12.8%
    - Louisiana 13.8%
  - 2006 Very Preterm Births (VPTB, 20-31wks)\*
    - U.S. 2.0%
    - Louisiana 2.4%
- Rates of prematurity remain high and well above HP2010 goal.
- Costs of prematurity
  - Contribution to infant mortality
  - Financial costs (In 2005, U.S. cost \$26 billion, \$51,600 per infant)\*\*



# Leading Causes of Infant Deaths

Louisiana 2004-2006

	<b>All Races</b> Rate (n)	<b>White</b> Rate (n)	<b>Black</b> Rate (n)	<b>B/W</b> <b>Ratio</b>
Preterm / Low Birth Weight	2.0 (377)	0.9 (101)	3.7 (275)	4.0
Congenital malformations	1.9 (356)	1.9 (201)	2.0 (151)	1.1
SIDS	1.1 (201)	0.9 ( 96)	1.4 (104)	1.6

Rates are expressed per 1,000 live births



Louisiana Vital Records, 2004-06

# Maternal Health Priority Areas Disparities in Birth Outcomes

Related Performance Measures (PM):

National Performance Measures (NPM): 8, 11, 18



# Louisiana

## Preterm Birth (< 37 weeks gestation)

	All Races		White		Black		Other Races	
Year	N	%	N	%	N	%	N	%
2007	8571	13.0	4096	<b>10.9</b>	4222	<b>16.5</b>	253	9.4

## Infant Mortality

	Total	Black	White	B/W
HP 2010 goal	<4.5	--	--	--
US 2007	6.7	<b>12.9</b>	<b>5.7</b>	2.4
LA 2007	9.0	<b>13.8</b>	<b>6.2</b>	2.5



# Maternal Health Priority Areas

## Behavioral Health

Related Performance Measures (PM):

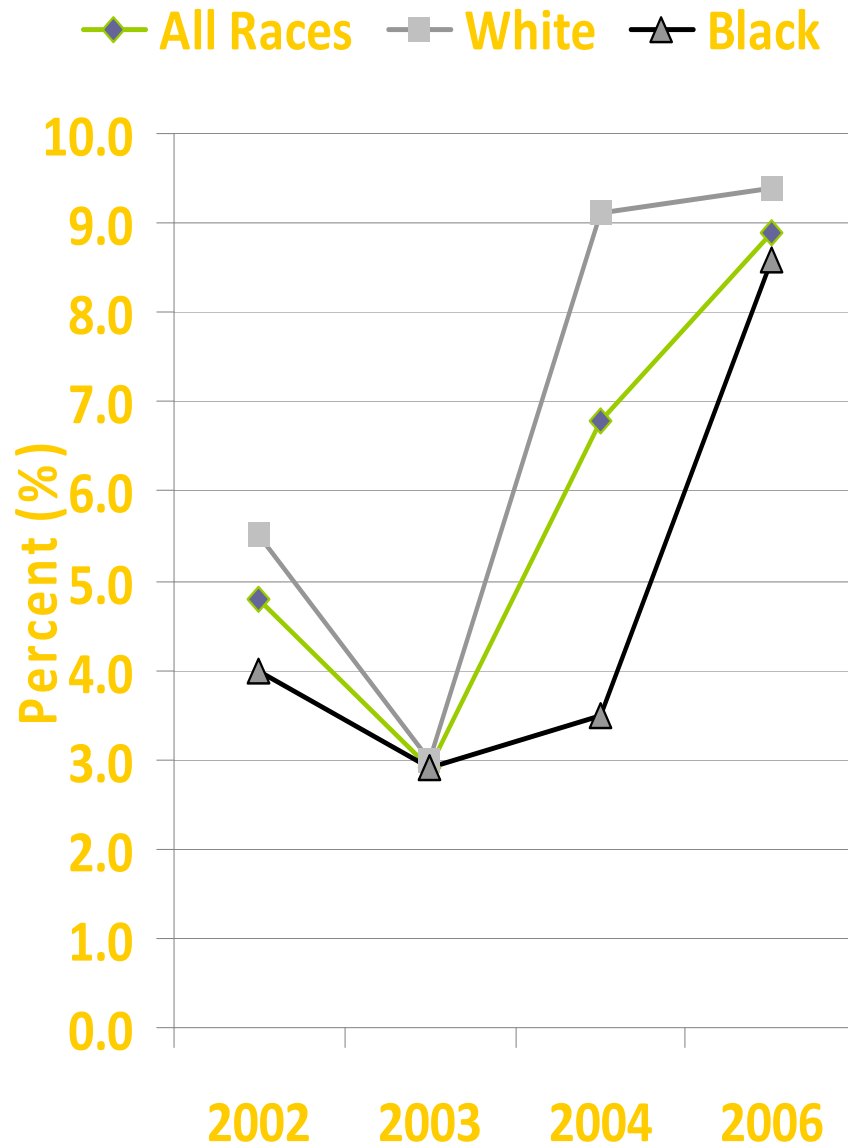
National Performance Measures (NPM): 15

State Performance Measures (SPM): 11

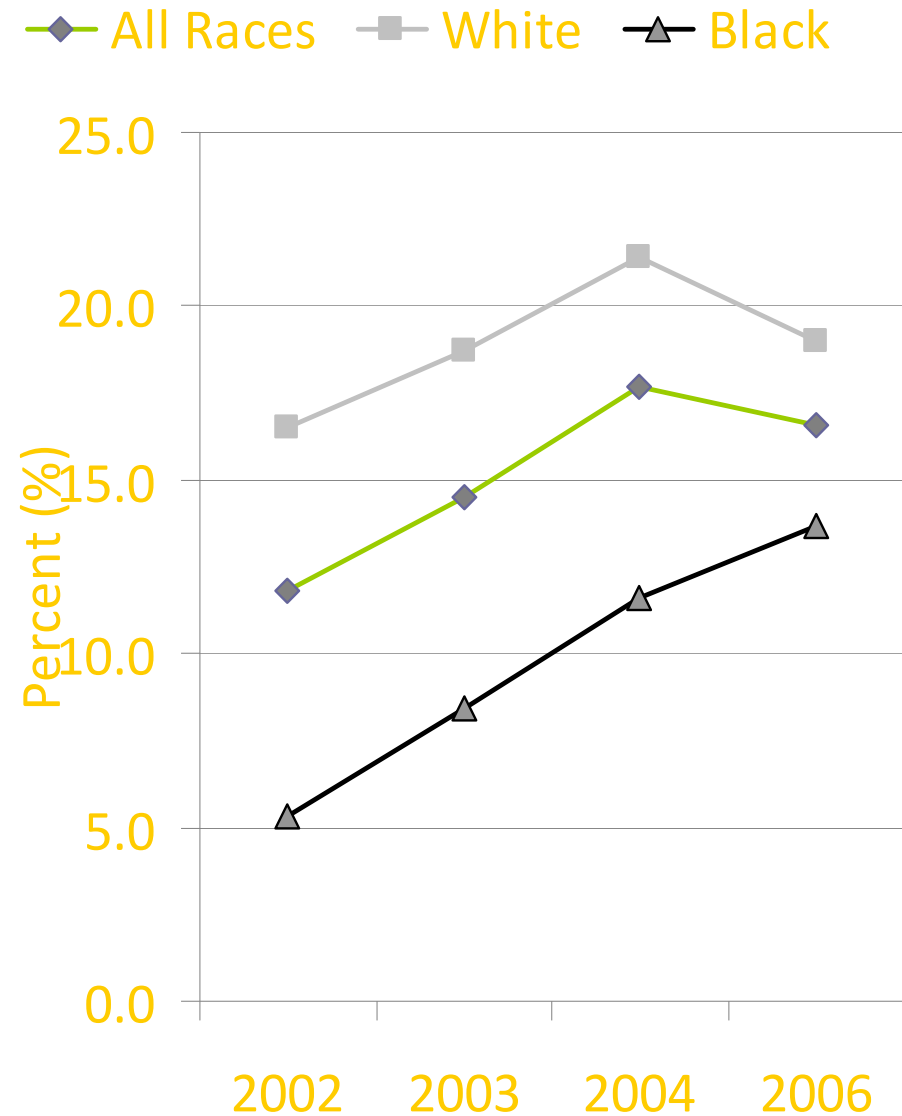




## Alcohol Use During Pregnancy



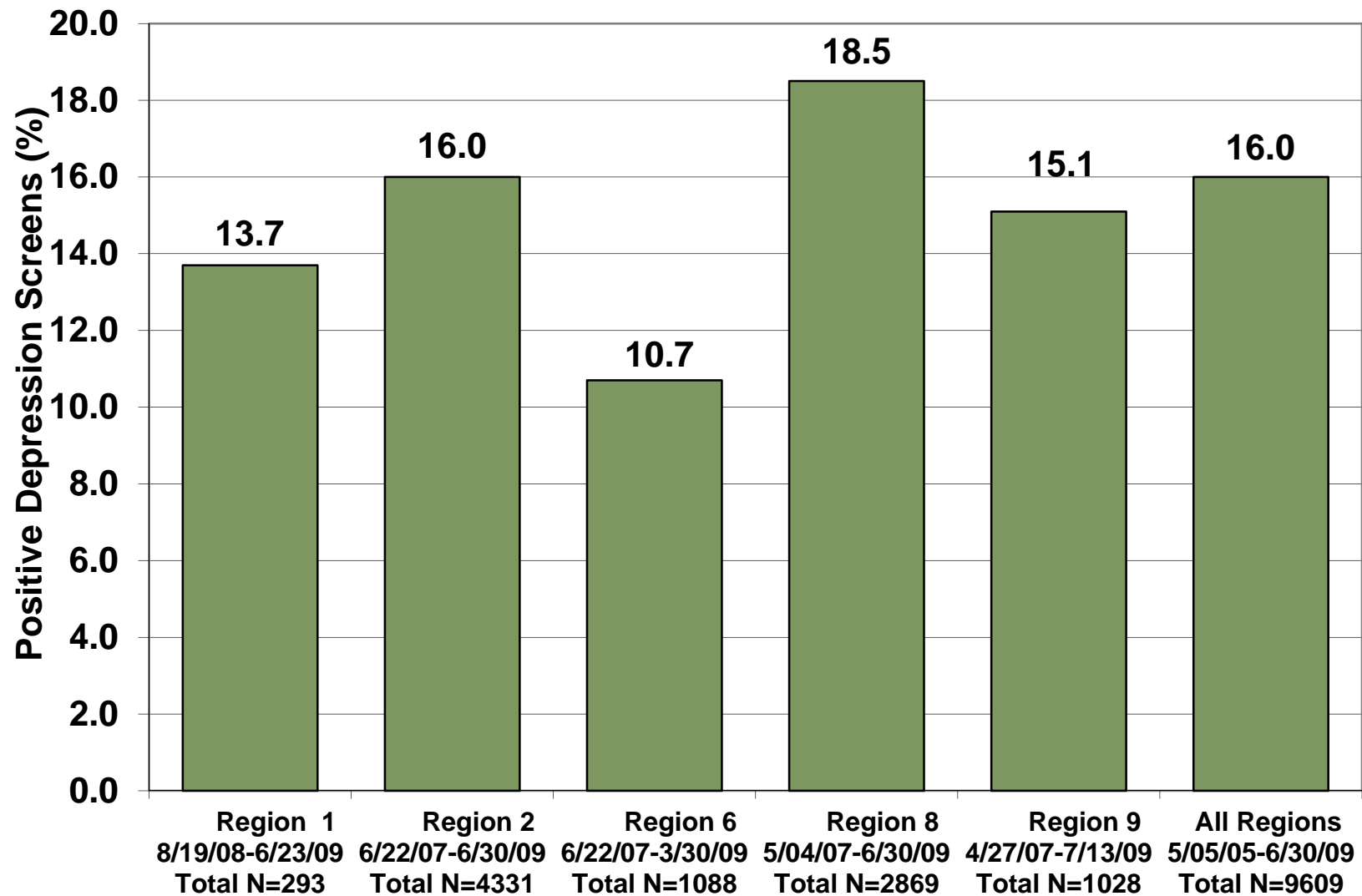
## Smoking During Pregnancy



Louisiana PRAMS data 2002-2006



# Feeling Depressed (SBIRT)



# Maternal Health Priority Areas

## Breastfeeding

Related Performance Measures (PM):  
National Performance Measures (NPM): 11, 14



# Breastfeeding 2004-2008

- White Non-Hispanic

- Initiation 59.8%
- 6 months 24.4%
- 12 months 10.9%

- Black Non-Hispanic

- Initiation 31.8%
- 6 months 13.6%
- 12 months 3.8%



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2010 MCH Needs Assessment  
Priority Setting Meeting

March 30, 2010

**Child Health and Safety**

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# CH & S: Needs Assessment Process

## **CHILD HEALTH**

- Target Audiences:
  - Public-private sector
  - State & community
  - Policy makers (including legislative representatives), program & agency directors (including Assistant Secretaries of State Departments), child & family advocates, resource and medical providers
- Stakeholders:
  - CCAB, BrightStart, SBHC, OPH program and regional staff, AAP
- Materials:
  - Survey (paper/electronic)
    - Priority areas – overall (0-19 yrs) and age subgroups (0-5 yrs, 6-10 yrs, 11-14 yrs, 15-19 yrs)
    - Capacity – availability, accessibility of resources/services
    - MCH public health strategies
  - Databook, presentations

## **CHILD SAFETY**

- Target Audiences:
  - Public-private sector
  - State & Regional
  - Policy makers, investigators of child deaths (coroners, DSI, OCS), safety/injury prevention advocates, resource and medical providers, first responders (EMS, Fire), law enforcement
- Stakeholders:
  - State & Local CDR Panels
  - EMSC Advisory Council
- Materials:
  - Survey (paper)
    - Priority areas – overall (0-14 yrs) and subgroups (0-5 yrs, 6-14 yrs, 15-19 yrs)
    - Capacity – availability, accessibility of resources/services
    - MCH public health strategies
  - Databook, presentations

# CH & S: Prioritization Process

## ■ Key Staff:

- Child Health Subgroup
  - MCH (CH Medical Director, State CDRP/CS Coordinator, Health ED/SIDS & Safe Sleep Program Coordinator, Epidemiologist, Mental Health & Nutrition Consultants); IRPP; Oral Health, LACLPPP, & ASHI
- MCH Regional CDRP/Child Safety Coordinators

## ■ Data Sources:

- National: Vital Statistics Reports, US Kids Count, US Census, National Immunization Survey, CDC Pediatric Nutrition Surveillance, National Survey of Children's Health
- State-based: Louisiana Center for Health Statistics and Vital Records, Louisiana PRAMS, Louisiana Medicaid, Louisiana Hospital Inpatient Discharge

## ■ Indicators:

- U.S. Census, U.S. Kids Count, Healthy People 2010, MCH Title V Block Grant Health Status Indicators and National Outcome Measures, National Survey of Children's Health, National Survey of Children with Special Health Care Needs, Louisiana MCH data profiles, Louisiana Pregnancy Risk Assessment Monitoring System (PRAMS), and Louisiana 2005 Title V MCH Needs Assessment.

## Priority Setting:

MCHB framework - extent, severity or consequences, & acceptability of the top child health and child safety priority areas from:

- Stakeholders/Child Health & Child Safety Survey respondents
- Public/Consumer Survey respondents
- Data related to child health & safety indicators

1. Selection of stakeholders' 10 highest priority health (0-19 yrs) and safety (0-14 yrs) areas by tally method
2. Comparison of top 10 stakeholder priority health and safety areas with consumer survey high ranking health and safety areas for infants, children, and teens
3. Selection of final 5 health and safety priority areas after discussing data (rates, trends), resource availability, and feasibility of impacting a priority area with existing capacity for each of the 10 health and safety priority areas.
4. Recommended priority needs were based on final 5 health and safety priority areas

# CH & S: Priority Areas and Needs

## Priority Areas

- **Obesity/Healthy Eating**
- **Unintentional/intentional Injuries**
  - Motor vehicle related
  - Accidental suffocation
  - Drowning and Fire
  - Firearms
  - Child maltreatment
- **Parenting Education/Family Support**
- **Behavioral Health**
- **Teen Pregnancy**

## Priority Needs

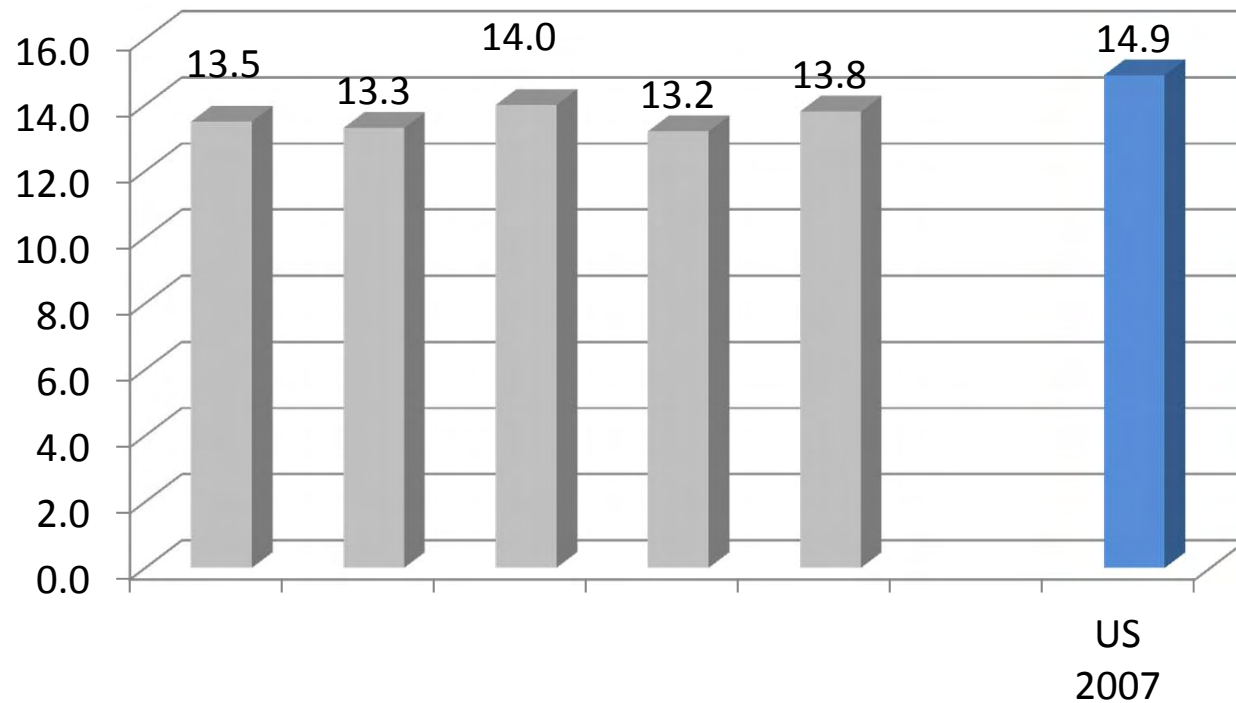
- (1) Ensure access to services and resources which address healthy eating and obesity prevention, especially in the 0-5 years age group
- (2) Decrease child mortality and morbidity due to unintentional and intentional injuries, especially from motor vehicles, child maltreatment, accidental suffocation/strangulation, drowning, and firearms
- (3) Ensure access to quality parenting education/family support services
- (4) Ensure access to quality, comprehensive mental health/behavioral health services;
- (5) Decrease teen pregnancy through collaboration with state agencies and programs such as ASHI, HIV, STD, and Family Planning



# Obesity/Healthy Eating

**2002-2007 PedNSS data shows a static trend in children on WIC  $\geq$  95<sup>th</sup> percentile**

Percent of Children ages 2-5 yrs on WIC Who are Overweight ,  
Louisiana 2002-2007



# Obesity/Healthy Eating

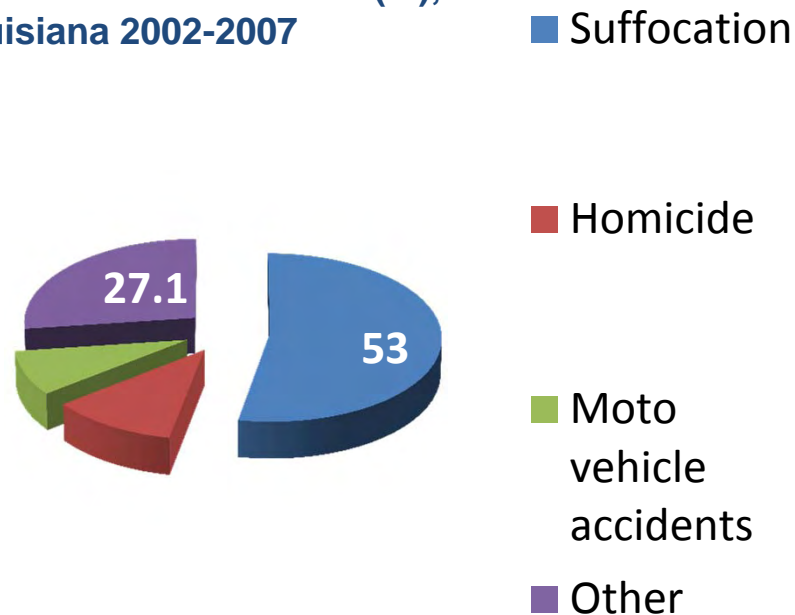
▣ 2007 NSCH data

<b>OVERALL PREVALENCE:</b>	<b>LA</b>	<b>National</b>	<b>Change in LA since 2003</b>
Percentage of children ages 10- 17 yrs who are overweight or obese	35.9%	31.6%	↑
State Rank for overweight or obese children (1 is best)		45	Rank in 2003: 46
<b>RISK FACTORS</b>			
Percentage of children ages 6-17 yrs who participate in 4 or more days of vigorous physical activity per week	68.1%	64.3%	↑
Percentage of children ages 1-5 yrs who engage in 4 or more hours of screen time per weekday (includes TV, videos, etc.)	15.2%	12.8%	***
Percentage of children ages 6-17 yrs who engage in 4 or more hours of screen time per weekday (includes TV, videos, video games, etc.)	18.3%	10.8%	↑
<b>DISPARITIES—ACROSS AND WITHIN STATES</b>			
<b>% Overweight or Obese by Race</b>			
Black, non-Hispanic	42.3%	41.1%	↑
White, non-Hispanic	30.5%	26.8%	↓

## Unintentional/Intentional Injuries

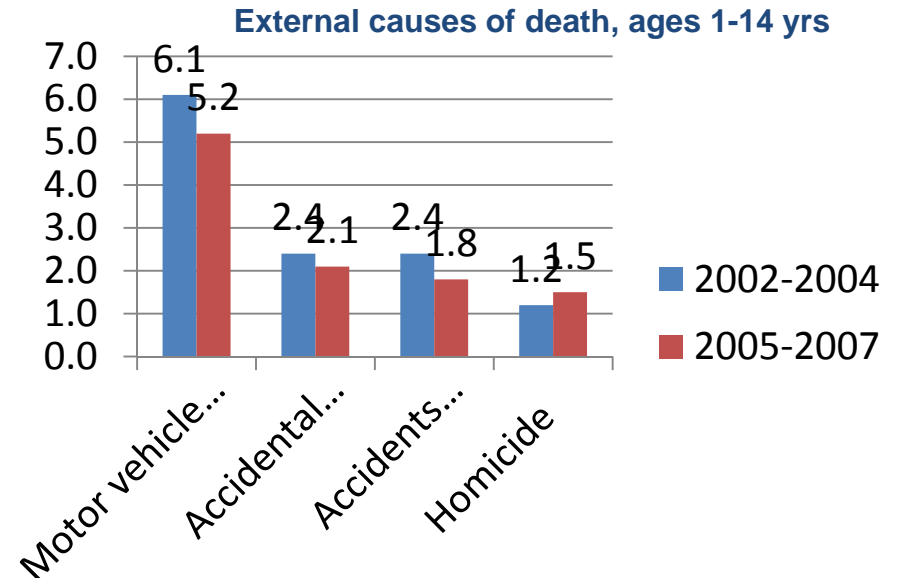
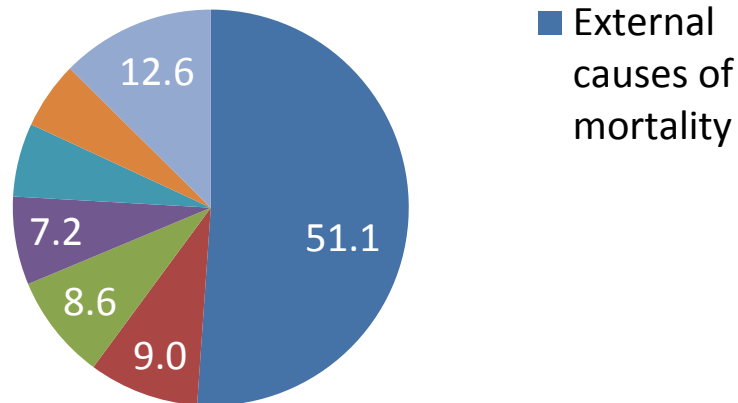
- **Injury continues to be the major killer of children and adolescents.**
- Many children with non-fatal injuries are left with a severe, lifelong disability.
- Injury is a cross-cutting issue that can impact a broad set of priority needs, including substance abuse, infant mortality, child maltreatment, domestic violence, and emergency services for children.

External causes of infant deaths (%),  
Louisiana 2002-2007

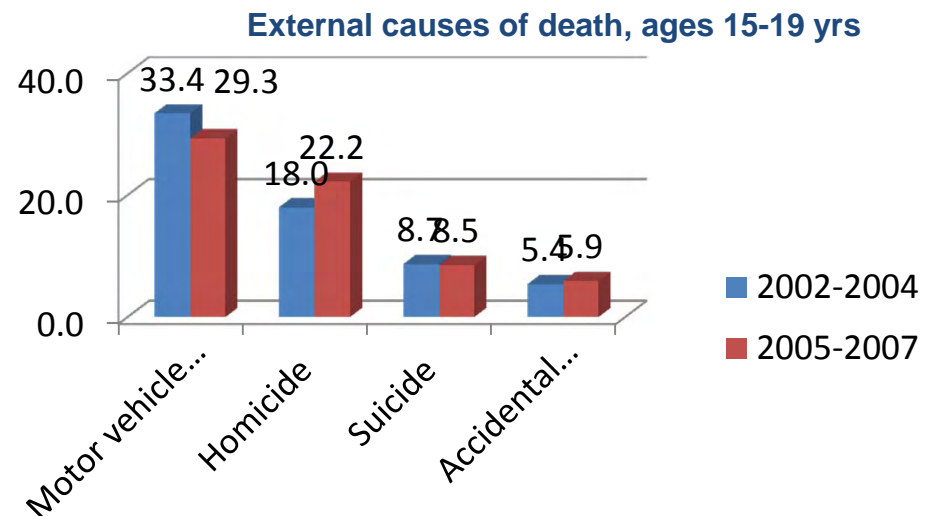
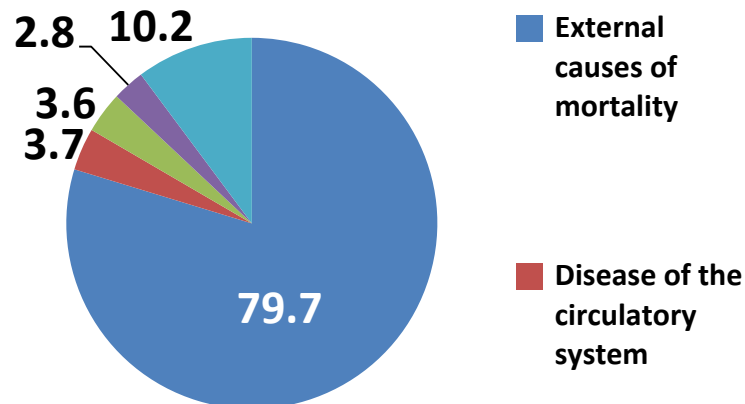


# Unintentional/Intentional Injuries

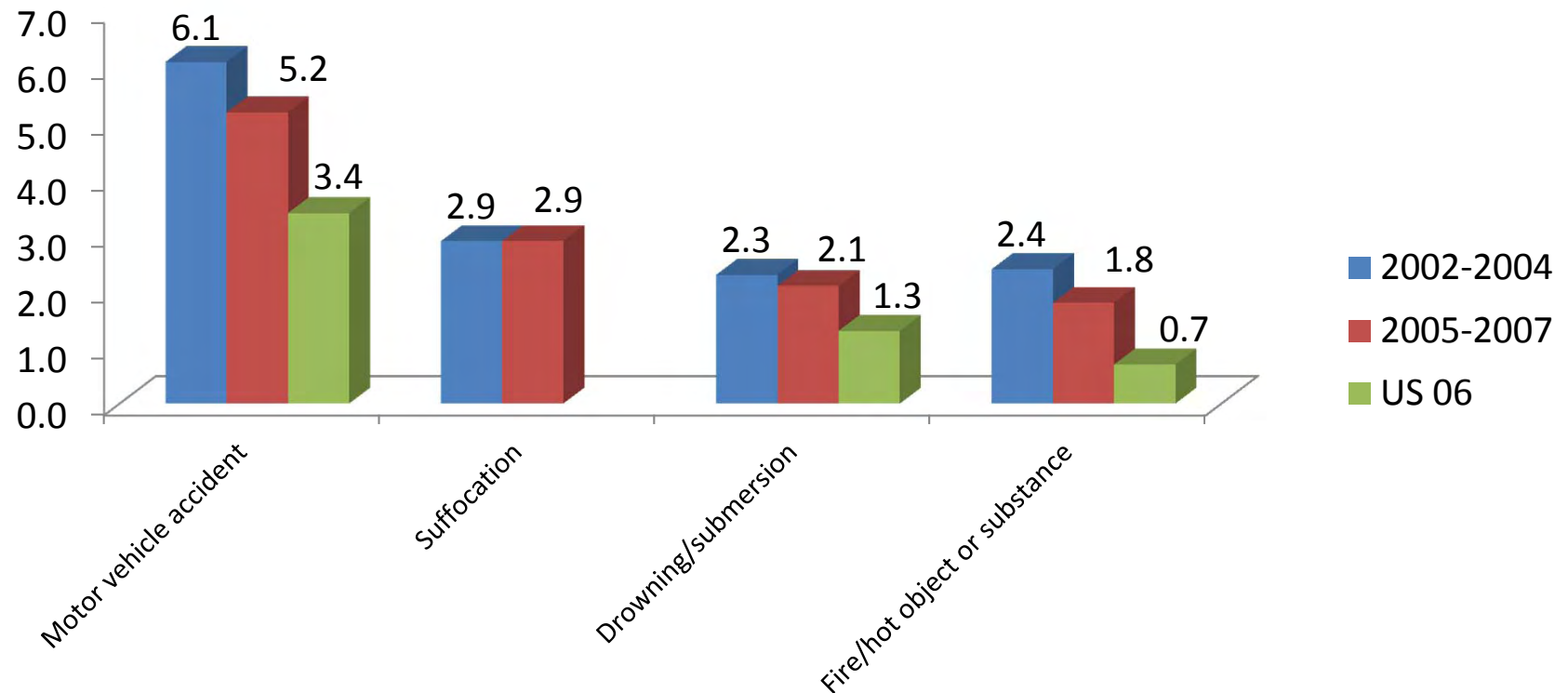
**Causes of deaths (%) among children ages 1-14 yrs, Louisiana 2002-2007**



**Causes of deaths (%) among children ages 15-19 yrs, Louisiana 2002-2007**



## Unintentional Injury Death Rates Among Children ages 0-14 yrs, Louisiana 2002-2007

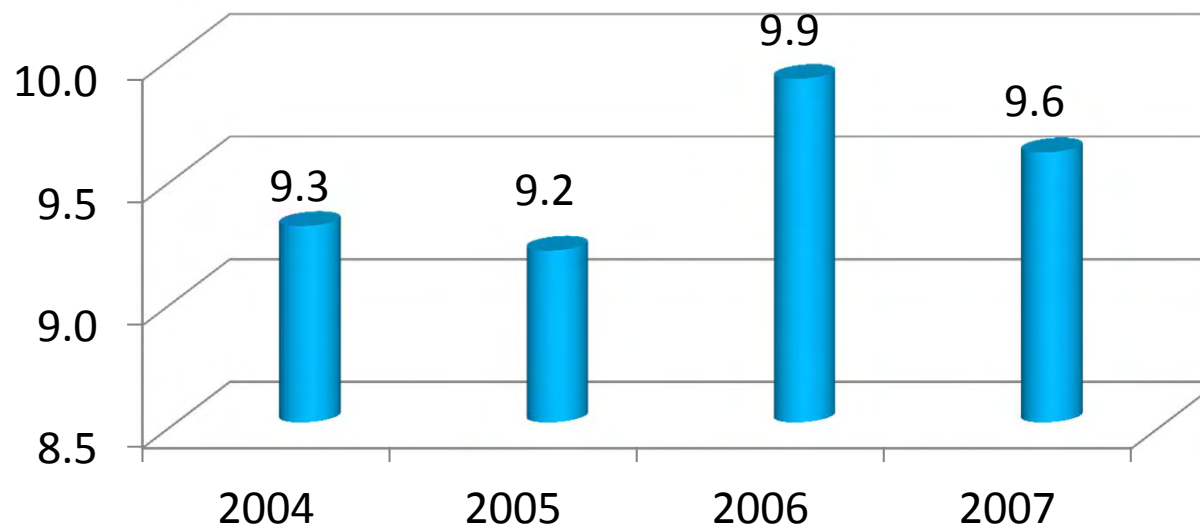


NSCH Health Statistics	2003	2007
Percent of children age 0-5 with injuries requiring medical attention in the past year	7.8%	9.2%

# Parenting Education/Family Support

- **A cross-cutting issue that can impact most of the priority needs of children**
- 2007 NSCH
  - 10.2% of children live with parents who experience high levels of stress from parenting
  - High stress is reported more often by the parents of children living in single-mother households
  - CSHCN have parents who are twice as likely to report high levels of stress
- The rate of child abuse and neglect is used as an indicator of the breakdown in the parent/child and family system.

**Percent Of Children Under Age 18 yrs Who've Been Abused Or Neglected (substantiated), Louisiana 2004-2007**



# Parenting Education/Family Support

□ 2007 NSCH

Indicator	Explanation	% 2003	% 2007
Mother's Health	of children who live with their mothers, the percentage whose mothers are in excellent or very good physical and emotional health	57.6	53.9
Father's Health	of children who live with their fathers, the percentage whose fathers are in excellent or very good physical and emotional health	66.4	60.6
Child Care	percent of children age 0-5 whose parents made emergency child care arrangements last month and/or a job change for child care reasons last year	37.9	39.7
Smoking in the Home	percent of children who live in households where someone smokes	34.2	33.4
Missed School Days	percent of children age 6-17 who missed 11 or more days of school in the past year	5.3	6.8
Activities Outside of School	percent of children age 6-17 who participate in activities outside of school	80.6	75.0
Screen Time	percent of children age 1-5 who watched more than one hour of TV or video during a weekday	NA	60.7
Reading to Young Children	percent of children age 0-5 whose families read to them everyday	41.2	42.2

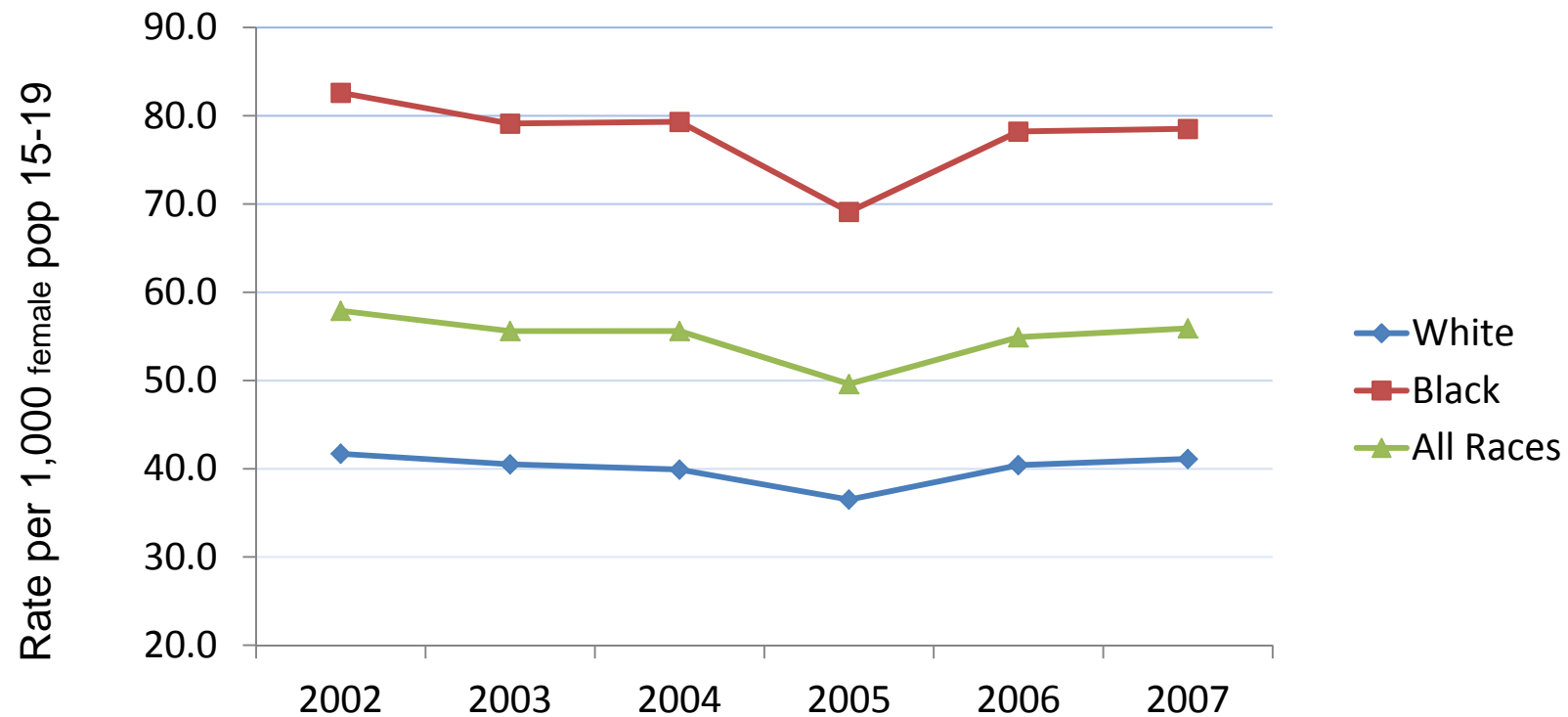
# Behavioral Health

## ■ NSCH

Indicator	Explanation	% 2003	% 2007
Developmental Screening	percent of children age 10 months to 5 years who received a standardized screening for developmental or behavioral problems	NA	28.7
Mental Health Care	percent of children age 2-17 with problems requiring counseling who received	44.2	55.3
Risk of Developmental or Behavior Problems	percent of children age 4 months to 5 years determined to be at moderate or high risk based on parents' specific concerns	32.9	35.2
Positive Social Skills	percent of children age 6-17 who exhibit two or more positive social skills	90.6	89.9
Repeating a Grade	percent of children age 6-17 who have repeated at least one grade	22.6	25.4



# Teen Birth Rates 15-19 yrs, Louisiana 2002-2007



	2002	2003	2004	2005	2006	2007	Annual % change	US 2006
White	41.7	40.5	39.9	36.5	40.4	41.1	-0.1	38.2
Black	82.6	79.1	79.3	69.1	78.2	78.5	-0.6	64.6
All Races	57.9	55.6	55.6	49.6	54.9	55.9	-0.4	41.9

2010 MCH Needs Assessment  
Priority Setting Meeting  
March 30, 2010

Adolescent Health

# Priorities

- Reproductive Health
  - Substance use/Abuse
  - Intentional and Unintentional Injury
  - Misuse of Cyberspace
-

# 2010 MCH Needs Assessment Priority Setting Meeting

March 30, 2010

## Oral Health

# Oral Health Coalition Meeting

- ❑ December, 2009 - 60 attendees representing NOGs, state agencies internal and external to DHH, dental and medical professional organizations, medical and dental providers (private and public- FQHC & community health centers), Dental and Dental Hygiene Schools, Medicaid
  - ❑ In Round Robin activity each participant had an opportunity to identified issues and strategies specific to Access, Prevention , Education and Policy
  - ❑ Each participant voted on their top three issues within each area.
-

# MCH Oral Health Survey Results Meeting

- January, 2010 - 12 attendees representing NOGs, medical and dental providers, and Medical , Dental and Dental Hygiene Schools
  - LPHI facilitator presented oral health consumer data from the survey
  - Oral Health Program Epidemiologist presented indicator data
  - Group discussion to review and discuss the summary key findings and develop a list of preliminary oral health needs
  - Each participant “voted” on their top five needs
  - Each need was tallied - top five were recorded
-

# Data Sources

- Primary Data - Basic Screening Survey
  - National Data Sources
    - ❑ Centers for Medicaid and Medicare Services,
    - ❑ CDC's National Oral Health Surveillance System (NOHSS)
    - ❑ Behavioral Risk Factor Surveillance System
    - ❑ CDC's Water Fluoridation Reporting System (WFRS)
    - ❑ U.S. Census Bureau
    - ❑ National Health and Nutrition Examination Survey
    - ❑ National Cancer Institute - State Cancer Profiles
  - State and Local Data
    - ❑ Consumer Survey Feedback
    - ❑ DHH Bureau of Primary Care and Rural Health - Medicaid data on EDSPW and EPDST usage
    - ❑ Louisiana Department of Social Services - Dental abuse and neglect
    - ❑ Louisiana State Board of Dentistry
    - ❑ Louisiana Youth Tobacco Survey
    - ❑ Behavioral Risk Factor Surveillance System
-

# Data Source

## Basic Screening Survey

- 2007 to 2009 School Year - To determine the oral health status of Louisiana's 3<sup>rd</sup> grade children.
  - Representative Sample
  - 75 schools in 34 parishes
  - 2,642 children screened
-



# MCH Consumer Survey

## ■ Access to Dental Services

Problem	Dental Health for Pregnant Women	Child/Adolescent Dental Health
No insurance/Medicaid	8.9	14.4
No providers close to home	5.2	6.2
Transportation problems	5.4	6.0
Language barriers	3.0	3.7
Provider disrespects me	0.3	6.9
No problems	77.9	63.1

# Summary of Priority Needs

1. Education & Awareness of the Importance of Oral Health, especially for children 6 years and younger
    - ❑ Oral health as it relates to good overall health
    - ❑ Good oral health during pregnancy
    - ❑ Connection between healthy eating and healthy teeth
    - ❑ Need for good oral hygiene
    - ❑ Oral health curriculum in schools
  2. Proliferation of Preventive Services, i.e. fluoride varnish, sealants, etc. to combat low numbers of Medicaid children seeing a dentist
    - ❑ Fluoride Varnish programs in Head Start and medical homes
    - ❑ Expansion of dental sealants in school-based settings
-

# Summary of Priority Needs

## 3. Fluoridation

- ❑ Funding Streams

## 4. Increase Oral Health Workforce, especially for children's services

- ❑ Increase Dental Pediatric Residency Program
- ❑ Increase the number of dentists accepting Medicaid patients for underserved populations
- ❑ Develop Rural Scholars Program in Dental School

## 5. Improve/Create Reimbursement for Dental Services in a medical setting

- ❑ Fluoride varnish by primary care or pediatrician
-

## 2010 Louisiana MCH Needs Assessment

### Community Partners

Adolescent School Health Initiative  
AHEC/ Healthy Start  
American Academy of Pediatrics-Louisiana Chapter  
American Cancer Society  
American Lung Association  
Bright Start  
Children's Cabinet  
Child Safety Regional Coalitions  
Children's Special Health Services  
Children's Coalition  
CHRISTUS St Frances Cabrini Hospital  
City of Lake Charles  
Coroner's Office (various parishes)  
Earl K. Long Medical Center  
Early Steps  
East Carroll Parish OFS  
Families Helping Families  
Family Road of Greater Baton Rouge  
Healthy Start New Orleans  
LA Tech University  
Law Enforcement (various parishes)  
Louisiana Bureau of Primary Care and Rural Health  
Louisiana Campaign for Tobacco Free Living  
Louisiana Dental Association  
Louisiana Department of Social Services  
Louisiana DHH Medicaid  
Louisiana DHH Oral Health Program  
Louisiana HIV/AIDS Program  
Louisiana Injury Prevention Program  
Louisiana Office of Addictive Disorders  
Louisiana Office of Family Planning  
Louisiana Office of Mental Health  
Louisiana Office of Public Health Regional Administration  
Louisiana OPH Center for Community Health (Parish Health Units)  
Louisiana Perinatal Commission  
Louisiana Regional FIMR  
Louisiana Tobacco Control Program

## **2010 Louisiana MCH Needs Assessment**

### **Community Partners**

Louisiana WIC Program  
LSU Ag Center  
LSU Health Sciences Center New Orleans  
LSU Health Sciences Center Monroe  
LSU Health Sciences Center Shreveport  
LSU School of Dentistry  
LSU School of Medicine  
LSU School of Public Health  
LSUHSC Family Practice Residency Training Program and Clinic  
LSUHSC Huey P Long Hospital  
March of Dimes  
MCH Coalition  
New Orleans Health Department  
North Monroe Medical Center  
Northwest Louisiana Coalition of Health for Women & Children  
Northwestern State University School of Nursing  
Nurse Family Partnership  
Ochsner Hospital  
Orleans Parish Medical Society  
Our Lady of the Lake Regional Medical Center  
Prevent Child Abuse Louisiana  
Private practice providers  
Rapides Foundation  
Rapides Regional Medical Center  
Southwest Louisiana Area Health Education Center  
St. Tammany Parish Hospital  
The Family Tree  
Thibodeaux Regional Medical Center  
Touro Infirmary  
Tulane University School of Medicine  
Tulane University School of Public Health & Tropical Medicine  
Unity Way of North Louisiana  
University of Louisiana Monroe  
Volunteers of America  
Woman's Hospital

# DHH Inter-agency Data Sharing Agreement

**DEPARTMENT OF HEALTH AND HOSPITALS  
BUREAU OF HEALTH SERVICES FINANCE AND OFFICE OF PUBLIC HEALTH  
INTER-AGENCY DATA-SHARING AGREEMENT  
State of Louisiana**

Requester: Sharon Howard, Assistant Secretary, OPH, DHH

Agency Name \_\_\_\_\_ DHH / Office of Public Health / Maternal & Child Health Program

Data User \_\_\_\_\_ Tri Tran, MD, MPH, Juan Acuna MD  
Title \_\_\_\_\_ Assistant Professor, Senior Medical epidemiologist  
Address \_\_\_\_\_ 325 Loyola Ave Room 612  
New Orleans, LA 70112  
Phone \_\_\_\_\_ 504-568-5073

Requester: Ronald Young, Director

Agency Name \_\_\_\_\_ DHH Division of Health Economics

Data User \_\_\_\_\_ Division of Health Economics Statistician and Economist  
Title \_\_\_\_\_ Economist, Statistician  
Address \_\_\_\_\_ P.O. Box 629, Bin #34  
Baton Rouge, LA 70821  
Phone \_\_\_\_\_ 225-342-5284

Data Provider: Ben Bearden, Medicaid Director

Agency Name \_\_\_\_\_ DHH / Bureau of Health Services Finance  
Custodian \_\_\_\_\_ Ruth Kennedy  
Title \_\_\_\_\_ Deputy Director, Medicaid  
Address \_\_\_\_\_ 1201 Capitol Access Rd 3<sup>rd</sup> Floor  
Baton Rouge, LA 70821  
Phone \_\_\_\_\_ 225-342-3032

## **I. PURPOSE**

*The Medicaid status variable linked to the birth certificate file will be used for the MCH Title V Block Grant and State Systems Development Initiative HRSA Grant annually. Specifically, factors that will be analyzed include percent of low birth weight babies by Medicaid status, prenatal care utilization by Medicaid status, infant mortality rates by Medicaid status, and regional distribution of Medicaid births.*

## **II. PERIOD OF AGREEMENT**

*The period of agreement shall extend from 6/1/2005 annually and thereafter as requested or as new Vital Records data becomes available to 5/31/2010.*

## **III. JUSTIFICATION FOR ACCESS**

*A. Federal requirements: Section 1902 (a) (7) of the Social Security Act (as amended) provides for safeguards which restrict the use or*

# DHH Inter-agency Data Sharing Agreement

*disclosure of information concerning Medicaid applicants and recipients to purposes directly connected with the administration of the State plan. Regulations at 42 CFR 431.302 specify the purposes directly related to State plan administration. These include (a) establishing eligibility; (b) determining the amount of medical assistance; providing services for recipients; and (d) conducting or assisting an investigation, prosecution, or civil or criminal proceeding related to the administration of the plan.*

*The linkage described below will assist the Division of Health Economics and Medicaid to better manage and analyze Medicaid case loads and Medicaid costs by estimating the percentage of Medicaid pregnant women receiving adequate prenatal care from the MCH perspective. In addition, Medicaid will benefit from such a linkage by identifying the percentage of Medicaid babies born of low birth weight, which is an indicator of negative birth outcomes of whom may require additional NICU care. Furthermore, the linkage will allow comparison of the infant mortality rates among Medicaid and non-Medicaid births. Identifying Medicaid and non-Medicaid populations will allow MCH to target interventions in reducing negative birth outcomes.*

## **B. State requirements**

*Protocols and procedures developed under this agreement will be consistent with the department's implementation of requirements associated with state statutes RS 40:41(D)(1) and RS 46:56.*

## **IV. DESCRIPTION OF DATA**

*In agreement with Health Statistics, annual birth and death certificate data will be shared with the Division of Health Economics (DHE) in order for DHE to effect linkage of key variables with Medicaid eligibility files. Key variables required for linkage include Date of Birth, Mother's Social Security Number, and Mother's first and last name. Additional variables may be added to improve matching efficiency.*

*The final data set ("fds") provided to Maternal & Child Health will consist of the birth certificate number variable and a Medicaid status variable. After the final data set is linked to a de-identified birth file, then aggregate level data will be reported for the MCH Title V Block Grant and State Systems Development Initiative HRSA Grant annually. The aggregate results will also be shared with the Division of Health Economics.*

## **V. METHOD OF DATA ACCESS OR TRANSFER**

*The final data set will be transferred from the Division of Health Economics to Maternal & Child Health via a secure FTP website. Identifiable information will not be included in the final data set.*

# DHH Inter-agency Data Sharing Agreement

## VI. LOCATION OF MATCHED DATA AND CUSTODIAL RESPONSIBILITY

*The parties mutually agree that the Office of Public Health/MCH be designated as "Custodian" of the "fds" and will be responsible for the observance of all conditions for use, for establishment, and for maintenance of security agreements as specified in this agreement to prevent unauthorized use. Once the "fds" has been downloaded from the secure FTP website, the MCH data custodian will store the data on his/her computer hard drive. Such data will be password protected.*

*All individually identifiable Medicaid data remains within the purview of the Louisiana Bureau of Health Services Finance (BHSF) and matching it with any other data is permissible. BHSF will retain a file identifying Medicaid records that have a matching birth record. That file will be zipped, password protected and stored in a limited access folder on a BHSF server. Any results of the data matching which contains individually identifiable data cannot be released outside the agency unless the release meets the conditions of Section III.*

*This agreement represents and warrants further that, except as authorized in writing, that the "fds" data shall not be disclosed, released, revealed, showed, sold, rented, leased, loaned or otherwise have access granted to the data covered by this agreement to any person. Access to the data covered by this agreement shall be limited to the minimum number of individuals necessary to achieve the purpose stated in this section and to those individuals on a need-to-know basis only.*

*Any summary results can be shared by both parties. Summary results are defined as those items which cannot be used to identify any individual. The stripping of an individual's name or individual identification number does not preclude the identification of that individual, and therefore is not sufficient to protect the confidentiality of individual data.*

## VII. CONFIDENTIALITY

*The Users agree to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it. The safeguards shall provide a level and scope of security that is not less than the level and scope of security established by the Office of Management and Budget (OMB) in OMB Circular No. A-130, Appendix III -- Security of Federal Automated Information System, which sets forth guidelines for security plans for automated information systems in Federal agencies.*

*Federal Privacy Act requirements will usually not apply if this agreement is entered into by agencies of the State and no Federal agencies are involved. The same applies to the Computer Matching and Privacy Protection Act of 1988. However, State laws, regulations, and guidelines governing privacy and confidentiality will apply.*

## VIII. DISPOSITION OF DATA

*At the end of the renewable agreement (5/31/2010), data provided to MCH will continue to be maintained in a secured area. A common data set or sets will be available to Medicaid and the Division of Health Economics for any research needs.*



# DHH Inter-agency Data Sharing Agreement

## IX. DATA-SHARING PROJECT COSTS

*Salary and expenses for MCH Program staff will be absorbed with no extra expenses assumed.*

## X. RESOURCES

*State Systems Development Initiative Data Manager (MCH Program): Tri Tran, MD, MPH (10% of time)*

*Senior Medical Epidemiologist (MCH Program): Juan Acuna, MD, MSc (5% of time)*

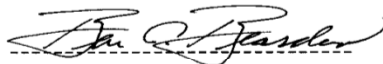
*DHE staff (5% of time)*

*Software required (other software added as needed): SAS, SPSS, LinkPro*

## XI. SIGNATURES

*In witness whereof, the Agencies' authorized representatives as designated by the Medicaid Director and the Office of Public Health Assistant Secretary attest to and execute this agreement effective with this signing for the period set forth in Article III.*

Signature

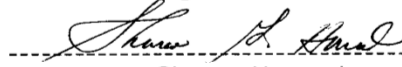


Ben A Bearden  
Louisiana Medicaid Director

Date

6-15-05

Signature

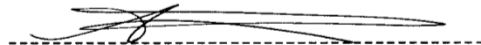


Sharon Howard  
Assistant Secretary, Office of Public Health

Date

6/15/05

Signature



Ron Young  
Director, Division of Health Economics

Date

6/15/2005

# SBHC Sponsors

SBHC SPONSORS	PARISH	SBHC Sites
Louisiana State University Health Science Center, Dept. of Pediatrics	Orleans	Science & Math® & McMain High®
Saint Gabriel Health Clinic, Inc – Eastside Community Health Center	Iberville	East Iberville Elementary/High
CHRISTUS Schumpert Health System	Caddo	Atkins Elementary Linwood Middle Woodlawn High School
Ouachita Parish School Board	Ouachita	Riser Middle/Elementary West Monroe High School
Richland Parish Hospital	Richland	Delhi High
Madison Parish Hospital	Madison	Madison High School
W/STRMC, LSUHSC, BMC	Washington	Bogalusa Junior High Bogalusa Senior High
Allen Parish School Board	Allen	Oakdale High/Oakdale Middle
CHRISTUS Saint Patrick Hospital	Calcasieu Cameron	J.D. Clifton Elementary Molo Middle Washington Marion High Combre Fondel Elem® Cameron
Our Lady of Lourdes	Lafayette	Northside High School
Saint Helena Community Health Center	Saint Helena	Central Elementary Central Middle Central High (Federally Funded)

# SBHC Sponsors (cont'd)

CHRISTUS Saint Frances Cabrini Hospital	Rapides LaSalle Grant Avoyelles Natchitoches	Buckeye High Northwood High Pineville Junior High Lessie Moore Elementary@ Tioga Junior High Tioga Senior High Glenmora High  Jena Senior High Jena Junior High@ Dry Prong Junior High Pollock Elementary@  Mansura Middle Avoyelles Charter@ Lakeview Jr/Sr High  Natchitoches Central High Marthaville Elementary/Jr. High @ Cloutierville Elementary/Jr High @
Saint Martin Parish School Board	Saint Martin	Breaux Bridge Junior High Cecilia Junior High St Martinville Primary
Health Care Centers in Schools	East Baton Rouge	Glen Oaks High Glen Oaks Middle Istrouma High Northeast Elementary Northeast High Prescott Middle Westdale Middle Capitol High Scottandville High (Privately Funded) Broadmoor High (Privately Funded) Glasgow Middle (Privately Funded)
Primary Care Providers for a Healthy Feliciana	East Feliciana	Clinton Middle son Complex Health Center (Privately Funded)
West Feliciana School Board	West Feliciana	West Feliciana Family Service Center
son Parish Hospital	son	Jonesboro-Hodge Middle/High
Jefferson Parish Public School System	Jefferson	Butler Elementary/Worley Junior Riverdale High School West Jefferson High School Bonnabel High (Kellogg Funded)
MCLNO	Orleans	O Perry Walker High School McDonogh 35 High School Douglass (Community Clinic-MCLNO Funded) Behrman (Community Clinic-MCLNO Funded) Henderson (Community Clinic-MCLNO Funded)

# SBHC Sponsors (cont'd)

Innis Community Health Ctr	Pointe Coupee	Pointe Coupee Central High School
Teche Action Board, Inc.	St. Mary	West St. Mary High School
Methodist Health System Foundation	St. Bernard	Chalmette High School
Richardson Medical Center	Richland	Rayville High School
St. Francis Medical Center	Ouachita	Carroll Jr. High School
Lafayette Parish School System	Lafayette	Carencro High School
St. Charles Community Health Center	St. Charles	Albert Cammon Middle
Morehouse Community Medical Center	Morehouse	Morehouse Jr. High
Tulane University Health Sciences Center	Orleans	Cohen High School (Multiple Private Funds)

# Survey of Women's and Children's Healthcare Needs

The Louisiana Office of Public Health's Maternal and Child Health Program is seeking your input regarding the needs of women, infants and children in the state. Please take a brief moment to complete this survey. We also ask that you forward the survey link to others interested in the health of mothers, infants and children.

## PRIORITIZING THE NEEDS OF LOUISIANA'S FAMILIES

**1) WOMEN'S HEALTH:** For each of the issues listed below, please select the circle that shows how important this issue is to you.

	Important	Somewhat Important	Not Important
Healthy Eating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obesity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic Disease Care (hypertension, diabetes)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prenatal Care (During Pregnancy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexually Transmitted Diseases (STDs) (HIV, Chlamydia, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health Education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Illegal Drug Use During Pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prescription Drug Use During Pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tobacco Use During Pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alcohol Use During Pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression and Stress During and After Pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grief Support (due to loss of a loved one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Planning/Pregnancy Spacing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**2) Please list additional issues not included above. (Limit additional issues to 3.)**

---

**3) INFANT & CHILD HEALTH:** For each of the issues listed below, please select the circle that shows how important this issue is to you.

	Important	Somewhat Important	Not Important
Breastfeeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healthy Eating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childhood Obesity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childhood Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childhood Lead Poisoning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Childhood Vaccinations (Immunizations)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health Education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sudden Infant Death Syndrome (SIDS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child Abuse and Neglect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Suicides	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Homicides	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motor Vehicle Crashes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drownings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fire	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poisoning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grief Support (due to loss of loved one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**4) Please list additional issues not included above. (Limit additional issues to 3.)**

---

**5) DENTAL HEALTH:** For each of the issues listed below, please select the circle that shows how important this issue is to you.

	Important	Somewhat Important	Not Important
Dental Sealants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dental Health Education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Water Fluoridation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dental Care (birth to 5 years old)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dental Care (children over 5 years old)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dental Care for Pregnant Women	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**6) Please list additional issues not included above. (Limit additional issues to 3.)**

---

**7) ADOLESCENT HEALTH:** For each of the issues listed below, please select the circle that shows how important this issue is to you.

	Important	Somewhat Important	Not Important
Healthy Eating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obesity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vaccinations (Immunizations)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health Education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexually Transmitted Diseases (STDs) and HIV, Chlamydia, etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tobacco Use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alcohol Use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Illegal Drug Use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teen Pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motor Vehicle Crashes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drownings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fire	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Falls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Suicides	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Homicides	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Abuse and Neglect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grief Support (due to loss of loved one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**8) Please list additional issues not included above. (Limit additional issues to 3.)**

---

**9) ACCESS TO SERVICES: Please check the box or boxes that most accurately describe what problems you had in accessing services for the following groups: (Choose All That Apply)**

	No Insurance/Medicaid	Health providers not available close to home	Transportation problems	Language barriers	Provider disrespects me	No Problems
HEALTHCARE for INFANTS AND CHILDREN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HEALTHCARE for ADOLESCENTS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HEALTHCARE for WOMEN BEFORE PREGNANCY	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HEALTHCARE for WOMEN DURING PREGNANCY	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HEALTHCARE for WOMEN AFTER PREGNANCY	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MENTAL HEALTH SERVICES FOR CHILDREN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MENTAL HEALTH SERVICES FOR ADOLESCENTS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MENTAL HEALTH SERVICES FOR WOMEN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DENTAL	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SERVICES FOR CHILDREN AND ADOLESCENTS						
DENTAL SERVICES FOR PREGNANT WOMEN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**10) Please list additional problems not included above. (Limit additional issues to 3.)**

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## HELPFUL INFORMATION ABOUT YOU

**11) Which best describes you? (Choose All That Apply)**

- ☐ Concerned Parent/Citizen
- ☐ Community Resource (i.e. Faith Based Organization, Community Center)
- ☐ Teacher/Instructor
- ☐ Healthcare Provider
- ☐ Local or State Agency
- ☐ Advocate for Women and Children
- ☐ Other (please specify)

If you selected other, please specify

**12) What is your age?**

- ☐ Under 18 years old
- ☐ 18-24
- ☐ 25-34
- ☐ 35-55
- ☐ over 55 years old

**13) What is your gender?**

- ☐ Female
- ☐ Male

**14) What is the zip code where you live?**

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**15) What is your highest education level completed?**

- ☐ Did not graduate from high school
- ☐ Graduated from high school
- ☐ Attended college



- ☐ Graduated college
- ☐ Attended graduate school
- ☐ Completed graduate school

**16) What is your area of expertise? (For healthcare providers only)**

- ☐ Women's Health
- ☐ Infant/Child Health
- ☐ Adolescent Health
- ☐ Dental Health
- ☐ Mental Health
- ☐ Other (please specify)

If you selected other, please specify

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Thank you for your time and your contribution to the health of Louisiana's women, infants and children!

# APPENDIX E

- I. Subspecialty Shortages
  - II. CSHS Program Collaborations
  - III. CSHS Program Activities by Performance Measure
-

# Subspecialty Shortages

**Table 1. Physician Survey Results: Percent of primary care physicians who report having difficulty accessing the listed subspecialty**

Specialty	Total (n=92)*	Region								
		1 (n=20)	2 (n=21)	3 (n=9)	4 (n=11)	5 (n=10)	6 (n=4)	7 (n=6)	8 (n=4)	9 (n=6)
Psychiatry	69 (75.0%)	9 (45.0%)	20 (95.2%)	7 (77.7%)	9 (81.8%)	9 (90.0%)	2 (50.0%)	5 (83.3%)	3 (75.0%)	5 (83.3%)
Developmental/ Behavioral pediatrician	62 (67.4%)	10 (50.0%)	15 (71.4%)	7 (77.7%)	6 (54.5%)	8 (80.0%)	3 (75.0%)	6 (100.0%)	1 (25.0%)	6 (100.0%)
Neurology	57 (62.0%)	11 (55.0%)	15 (71.4%)	5 (55.5%)	5 (45.5%)	8 (80.0%)	-	5 (83.3%)	2 (50.0%)	6 (100.0%)
Orthopedic	49 (53.3%)	3 (15.0%)	17 (80.9%)	4 (44.4%)	7 (63.6%)	7 (70.0%)	2 (50.0%)	3 (50.0%)	2 (50.0%)	4 (66.7%)
Dermatology	42 (45.7%)	5 (25.0%)	7 (33.3%)	4 (44.4%)	8 (72.7%)	8 (80.0%)	4 (100.0%)	3 (50.0%)	2 (50.0%)	1 (16.7%)
Endocrinology	38 (41.3%)	4 (20.0%)	11 (52.4%)	6 (66.6%)	4 (36.4%)	6 (60.0%)	1 (25.0%)	2 (33.3%)	1 (25.5%)	3 (50.0%)
Rheumatology	36 (39.1%)	3 (15.0%)	11 (52.4%)	2 (22.2%)	4 (36.4%)	4 (40.0%)	3 (75.5%)	5 (83.3%)	2 (50.0%)	2 (33.3%)
Pulmonology	27 (29.3%)	-	6 (28.6%)	4 (44.4%)	7 (63.6%)	4 (40.0%)	1 (25.0%)	-	3 (75.0%)	2 (33.3%)
Neurosurgery	23 (25.0%)	4 (20.0%)	4 (19.0%)	2 (22.2%)	3 (27.3%)	3 (30.0%)	2 (50.0%)	1 (16.7%)	1 (25.0%)	3 (50.0%)
Gastroenterology	20 (21.7%)	2 (10.0%)	4 (19.0%)	3 (33.3%)	2 (18.2%)	5 (50.0%)	1 (25.0%)	-	-	3 (50.0%)
Infectious Disease	20 (21.7%)	1 (5.0%)	5 (23.8%)	2 (22.2%)	5 (45.5%)	5 (50.0%)	-	-	-	2 (33.3%)
Urology	20 (21.7%)	4 (20.0%)	4 (19.0%)	3 (33.3%)	1 (9.1%)	4 (40.0%)	-	-	1 (25.0%)	3 (50.0%)
Genetics	15 (16.3%)	2 (10.0%)	4 (19.0%)	2 (22.2%)	1 (9.1%)	4 (40.0%)	-	-	-	2 (33.3%)
General Surgery	13 (14.1%)	1 (5.0%)	2 (9.5%)	3 (33.3%)	2 (18.2%)	2 (20.0%)	-	-	-	3 (50.0%)
Hematology/Oncology	13 (14.1%)	1 (5.0%)	1 (4.8%)	2 (22.2%)	2 (18.2%)	4 (40.0%)	-	-	1 (25.0%)	2 (33.3%)
Ophthalmology	12 (13.0%)	1 (5.0%)	2 (9.5%)	3 (33.3%)	2 (18.2%)	2 (20.0%)	-	1 (16.7%)	-	1 (16.7%)
Allergy/Immunology	10 (10.9%)	1 (5.0%)	1 (4.8%)	3 (33.3%)	1 (9.1%)	2 (20.0%)	-	1 (16.7%)	1 (25.0%)	-
Otolaryngology	7 (7.6%)	1 (5.0%)	1 (4.8%)	2 (22.2%)	1 (9.1%)	1 (10.0%)	-	1 (16.7%)	-	-
Cardiology	6 (6.5%)	-	1 (4.8%)	2 (22.2%)	1 (9.1%)	2 (20.0%)	-	-	-	-
Other	4 (4.3%)	2 (10.0%)	1 (4.8%)	-	-	-	-	1 (16.7%)	-	-
Neonatology	2 (2.2%)	-	-	2 (22.2%)	-	-	-	-	-	-

\*Results include all respondents who reported “always,” “usually,” or “sometimes” having difficulty locating pediatric medical sub-specialists in their geographic area. One respondent that answered the question did not identify the region in which they work; this respondent is included in the total data, but not the regional data. Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

# Program Collaborations

	No collaboration or don't know	Networking	Cooperation	Coordination	Coalition	Collaboration	Missing, blank	Total
Early Steps	<b>39 (21.7%)</b>	19 (10.6%)	34 (18.9%)	37 (20.6%)	18 (10.0%)	29 (16.1%)	4 (2.2%)	180 (100.0%)
Supports and Services Center	37 (20.0%)	32 (17.3%)	<b>44 (23.8%)</b>	22 (11.9%)	17 (9.2%)	23 (12.4%)	10 (5.4%)	185 (100.0%)
Resource Centers on Developmental Disabilities	<b>51 (26.4%)</b>	38 (19.7%)	47 (24.4%)	11 (5.7%)	16 (8.3%)	23 (11.9%)	7 (3.6%)	193 (100.0%)
Hearing, Speech, and Vision	<b>85 (41.5%)</b>	30 (14.6%)	26 (12.7%)	19 (9.3%)	5 (2.4%)	26 (12.7%)	14 (6.8%)	205 (100.0%)
Children's Special Health Services	<b>66 (39.5%)</b>	21 (12.6%)	21 (12.6%)	18 (10.8%)	8 (4.8%)	21 (12.6%)	12 (7.2%)	167 (100.0%)
Independent Living Program	<b>79 (38.5%)</b>	36 (17.6%)	20 (9.8%)	22 (10.7%)	14 (6.8%)	23 (11.2%)	11 (5.4%)	205 (100.0%)
Vocational Rehabilitation Program	<b>70 (37.2%)</b>	38 (20.2%)	25 (13.3%)	24 (12.8%)	8 (4.3%)	14 (7.5%)	9 (4.8%)	188 (100.0%)
Family Care or Foster Services	33 (22.8%)	<b>35 (24.1%)</b>	32 (22.1%)	20 (13.8%)	8 (5.5%)	13 (9.0%)	4 (2.8%)	145 (100.0%)
Families Helping Families	28 (14.8%)	30 (15.9%)	29 (15.3%)	27 (14.3%)	16 (8.5%)	<b>53 (28.0%)</b>	6 (3.2%)	189 (100.0%)

<sup>[1]</sup> The total represents the number of respondents who provide a usable response to the question; it does not include respondents that were excluded from identifying their own program of employment.

# CSHS Program Activities by Performance Measure

Table 3. Activities for Each Performance Measure

Person writing this measure for the block grant: Angie

National Performance Measure #1: CYSHCN whose families are partners in decision-making at all levels, and who are satisfied with the services they receive.

<i>Theoretical Assumptions</i>	<i>Program Activities</i>	<i>Responsible Party</i>	<i>Activity Measured Outcome</i>	<i>Data Source/Data Person</i>
Families/YSHCN who partner with their service providers on the plan of care are more likely to follow through with the service plan activities, and thus are more likely to attain positive outcomes. Satisfaction with services is associated with obtaining the needed services, understanding the need for services, and having the services delivered in a culturally	Direct Services	Direct Services	Direct Services	Direct Services
	1. Amend PL contact logs (NPM 1, NPM 5, SPM)	1. Dionka, Nicole & Angie	1. PL contact log amended (NPM 1, NPM 5, SPM)	1. N/A
	2. PLs will provide self-advocacy skills information to CSHS patients/families (NPM 1)	2. CSHS PLs	2. # of times the PLs provided self-advocacy skills info to families/patients (NPM 1)	2. Contact Logs/Carl
	Enabling Services	Enabling Services	Enabling Services	Enabling Services
	1. Amend FHF contract to include specific deliverables associated w/self-advocacy skills info, health insurance info, dissemination and outreach (NPM 1, NPM 3)	1. Dionka	1. Contracts amended (NPM 1, NPM 3)	1. Contracts/Dionka
	2. FHF will incorporate self-advocacy skills info into current community outreach events (NPM 1)	2. FHF	2. # of outreach events where self-advocacy skills info was covered (NPM 1)	2. FHF Monthly Summary Reports/Carl
<i>Program Resources</i>	Pop-based Services	Pop-based Services	Pop-based Services	Pop-based Services
Central Office Staff CSHS Field Staff CSHS Parent Liaisons Contract Monies CSHS Website FHF contact Student Worker for data entry FHF contact logs/summary reports	1. Disseminate poster w/ tear sheet including FHF contact info to, PCPs & appropriate providers (high risk groups) (NPM 1, NPM 5, NPM 6)	1. Betsey & Arleen	1. # of practices mailed/ received poster (NPM 1, NPM 5, NPM 6)	1. Roster spreadsheet /Betsey & Arleen
	2. Publish Family Matters newsletter w/ tips on self-advocacy skills (NPM 1)	2. Esther & Angie	2. # of quarters where Family Matters published self-advocacy skills tips (NPM 1)	2. Family Matters /Esther & Angie
	Infrastructure Building	Infrastructure Building	Infrastructure Building	Infrastructure Building
	1. Contract w/ social marketing firm for consulting services (NPM 1)	1. Dionka	1. Social Marketing consultant (?) (NPM 1)	1. Dionka
	2. Develop social marketing plan w/ FHF or F2FHIC (NPM 1)	2. Dionka & Angie	2. Social Marketing plan collaboratively created with FHF or F2FHIC (NPM 1)	2. Dionka & Angie

# CSHS Program Activities by Performance Measure

Person writing this measure for the block grant: Dr. Berry

National Performance Measure #2: CYSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

<i>Theoretical Assumptions</i>	<i>Program Activities</i>	<i>Responsible Party</i>	<i>Activity Measured Outcome</i>	<i>Data Source/Data Person</i>
CYSHCN who receive MH services decrease their risk for many poor health outcomes	Direct Services	Direct Services	Direct Services	Direct Services
	1. CSHS nurses will assess MH status for patients (NPM 2, SPM)	1. CSHS Nurses	1. % patients linked to MH (SPM, NPM 2)	1. COMPASS/Nicole
	2. Info on MH providers will be provided by SW staff when MH status is unknown or none (NPM 2, SPM)	2. CSHS Social Work Staff	2. % patients linked to MH (SPM, NPM 2)	2. COMPASS/Nicole
	3. CSHS clinic transcripts will be mailed to patient's MH (NPM 2, SPM)	3. CSHS clinic Staff	3. # of patients who attended face to face clinic visit (SPM, NPM 2)	3. COMPASS/Nicole
<i>Program Resources</i>	<i>Enabling Services</i>	<i>Enabling Services</i>	<i>Enabling Services</i>	<i>Enabling Services</i>
Central Office Staff CSHS Field Staff CSHS Parent Liaisons Contract Monies Staff to develop RRGs Regional Resource Guides (RRGs) CSHS Website Medicaid Liaison MH Orientation Materials	1. CCs will provide MH orientation info to physician practices (NPM 2, SPM)	1. Arleen	1. # of physician practices provided MH orientation info (NPM 2, NPM 3)	1. Contract & Kelly/Arleen
	2. Develop roster of PCP practices to disseminate RRGs (NPM 2, NPM 5)	2. Arleen	2. Roster developed (NPM 2, NPM 5)	2. RRG spreadsheet/Arleen
	3. Disseminate RRGs to PCP practices (NPM 2, NPM 5)	3. Arleen	3. # of PCP practices that were mailed RRGs (NPM 2, NPM 5)	3. RRG spreadsheet/Arleen
	4. Annually update RRGs (NPM 2, NPM 5)	4. Arleen	4. Date Regional RG was updated (NPM 2, NPM 5)	4. RRG spreadsheet/Arleen
	Pop-based Services	Pop-based Services	Pop-based Services	Pop-based Services
	1. Establish MH incentive contracts w/pediatric primary care practices that teach residents (NPM 2)	1. Arleen	1. # of practices contracted (NPM 2)	1. Contracts/Arleen
	2. Hire/Designate CC for contracted practices (NPM 2)	2. Arleen	2. # of designated CCs (NPM 2)	2. Contracts/Arleen
	3. Post RRGs on CSHS website (NPM 2)	3. Arleen & Nicole	3. Date RRGs posted on website (NPM 2)	3. Website/Nicole
	Infrastructure Building	Infrastructure Building	Infrastructure Building	Infrastructure Building
	1. Engage in meetings w/ Medicaid to increase reimbursement for CC (NPM 3, NPM 2, SPM)	1. Dr. Berry	1. N/A	1. N/A
	2. Collaborate with AAP president during Medicaid meetings?(NPM 3, NPM 2, SPM)	2. Dr. Berry	2. N/A	2. N/A

# CSHS Program Activities by Performance Measure

Person writing this measure for the block grant: Michelle

National Performance Measure #3: CYSHCN whose families have adequate private and/or public insurance to pay for the services they need.

<i>Theoretical Assumptions</i>	<i>Program Activities</i>	<i>Responsible Party</i>	<i>Activity Measured Outcome</i>	<i>Data Source/Data Person</i>
CYSHCN with adequate insurance coverage are able to reduce the risk for morbidity/mortality because they can see the needed provider and afford to receive the needed healthcare.	Direct Services	Direct Services	Direct Services	Direct Services
	1. CSHS PLs and SWs will assist patients & families w/insurance plans, forms and direct them to appropriate resources (NPM 3)	1. CSHS PLs	1. Number of times PLs assisted families with insurance information (NPM 3)	1. Contact logs/Carl
	2. CSHS will pay insurance co-pays for clinic patients according to policy (NPM 3)	2. CSHS Clerks & Carl	2. Number of clients that CSHS paid for their co-pays (NPM 3)	2. Co-pay log/Carl
	3. PLs will link CSHS patients & families to the advocacy ctr to teach families self-advocacy skills for negotiating insurance claims/issues (NPM 3)	3. CSHS PLs	3. Number of referrals by PLs to the advocacy center (NPM 3)	3. Contact logs/Carl
<i>Program Resources</i>	<i>Enabling Services</i>	<i>Enabling Services</i>	<i>Enabling Services</i>	<i>Enabling Services</i>
Central Office Staff CSHS Field Staff CSHS Parent Liaisons Contract Monies CSHS Website Medicaid Liaison	1. Amend FHF contract to include specific deliverables associated w/self-advocacy skills info, health insurance info, dissemination and outreach (NPM 1, NPM 3)	1. Dionka	1. Contracts Amended (NPM 1, NPM 3)	1. Contracts/Dionka
Contracts with FHF's Central Office insurance guru	2. Develop Insurance pamphlet for families (NPM 3)	2. Michelle	2. Date Insurance pamphlet was developed (NPM 3)	2. Michelle

# CSHS Program Activities by Performance Measure

Person writing this measure for block grant: Michelle

National Performance Measure #5: CYSHCN whose services are organized in ways that families can use them easily.

Theoretical Assumptions	Program Activities	Responsible Party	Activity Measured Outcome	Data Source/Data Person
<p>CYSHCN use five times more health services than non-CYSHCN.</p> <p>Therefore, knowledge of the service system, having skills to navigate the system, and the ability to use the system will increase the likelihood that the health needs will be addressed and decrease the risk for morbidity.</p>	Direct Services	Direct Services	Direct Services	Direct Services
	1. Amend PL contact logs (NPM 1, NPM 5, SPM)	1. Dionka, Nicole, & Angie	1. PL contact log amended (NPM 1, NPM 5, SPM)	1. N/A
	2. PLs will provide direct consultation to families/patients on community resources (NPM 5, SPM)	2. CSHS PLs	2. # of times PLs provided community resource information (NPM 5, SPM)	2. Contact Logs/Carl
	Enabling Services	Enabling Services	Enabling Services	Enabling Services
	1. Develop roster of PCP practices to disseminate RRGs (NPM 2, NPM 5)	1. Arleen	1. Roster developed (NPM 2, NPM 5)	1. RRG spreadsheet/Arleen
<p><b>Program Resources</b></p> <p>Central Office Staff</p> <p>CSHS Field Staff</p> <p>CSHS Parent Liaisons</p> <p>Contract Monies</p> <p>Staff to develop RRGs</p> <p>Regional Resource Guides (RRGs)</p> <p>CSHS Website</p> <p>FHF contact</p> <p>Staff to develop LBDMN Family RG</p> <p>LBDMN Family Resource Guide</p> <p>CSHS Stakeholder Group</p> <p>CSHS Stakeholder frontline staff</p>	2. Disseminate RRGs to PCP practices (NPM 2, NPM 5)	2. Arleen	2. # of PCP practices that were mailed RRGs (NPM 2, NPM 5)	2. RRG spreadsheet/Arleen
	3. Annually update RRGs (NPM 2, NPM 5)	3. Arleen	3. Date Regional RG was updated (NPM 2, NPM 5)	3. RRG spreadsheet/Arleen
	4. Amend Bayouland FHF contract to pilot information workshop for front-line stakeholder staff (NPM 5)	4. Dionka	4. Contract amended (NPM 5)	4. Contract/Dionka
	5. Engage CSHS stakeholder staff to attend multi-program community resource info workshop (NPM 5)	5. Bayouland FHF	5. # of workshops, # front-line staff attended, # programs attended (NPM 5)	5. Contract/Dionka
	Pop-based Services	Pop-based Services	Pop-based Services	Pop-based Services
	1. Develop roster of FQHCs to disseminate CSHS brochures and RRGs (SPM, NPM 5)	1. Betsey	1. FQHC Roster developed (SPM, NPM 5)	1. Roster spreadsheet/ Betsey
	2. Develop roster of SBHCs to disseminate CSHS brochures and RRGs (SPM, NPM 5)	2. Michelle	2. SBHC Roster developed (SPM, NPM 5)	2. Roster spreadsheet/ Michelle
	3. Disseminate CSHS brochures, FHF brochures, & RRGs to FQHCs & SBHCs (SPM, NPM 5)	3. Betsey	3. # of FQHCs mailed FHF/CSHS brochures, RRGs (SPM, NPM 5)	3. Roster spreadsheet/ Betsey
	4. Disseminate CSHS brochures, FHF brochures, & RRGs to SBHCs (SPM, NPM 5)	4. Michelle	4. # of SBHCs received FHF/CSHS brochures, RRGs (SPM, NPM 5)	4. Roster spreadsheet/ Michelle
	5. Disseminate poster w/ tear sheet including FHF contact info to PCPs & appropriate providers (high risk groups) (NPM 1, NPM 5, NPM 6)	5. Betsey & Arleen	5. # of practices mailed/received poster (NPM 1, NPM 5, NPM 6)	5. Roster spreadsheet/ Betsey & Arleen
	6. Develop a roster that specifies hospitals eligible to receive LBDMN Family Resource Guide flyer (NPM 5)	6. Cheryl	6. LBDMN Roster developed (NPM 5)	6. LBDMN Roster / Cheryl
	7. Disseminate LBDMN Family Resource Guide flyers to birthing hospitals (NPM 5)	7. Cheryl	7. # of hospitals given LBDMN flyer (NPM 5)	7. LBDMN Roster/ Cheryl
	8. Pilot test LBDMN Family Resource Guide (NPM 5)	8. Cheryl	8. LBDMN Pilot test conducted (NPM 5)	8. LBDMN Evaluation cards/ Cheryl
	9. Annually update LBDMN Family Resource Guide (NPM 5)	9. Cheryl	9. Date LBDMN RG was updated (NPM 5)	9. LBDMN/ Cheryl
	Infrastructure Building	Infrastructure Building	Infrastructure Building	Infrastructure Building
	1. FHF will establish a Community resource workshop training manual (NPM 5)	1. Bayouland FHF	1. Training manual for community resource workshop training (NPM 5)	1. Contract/Dionka



# CSHS Program Activities by Performance Measure

Person writing this measure for block grant: Betsey

National Performance Measure #6: YSHCN who receive the services necessary to make appropriate transitions to adult health care, work, and independence.

<i><b>Theoretical Assumptions</b></i>	<i><b>Program Activities</b></i>	<i><b>Responsible Party</b></i>	<i><b>Activity Measured Outcome</b></i>	<i><b>Data Source/Data Person</b></i>
YSHCN who receive the necessary transition services reduce the likelihood of dependency, morbidity, and/or mortality.	Direct Services	Direct Services	Direct Services	Direct Services
	1. Provide Transition Care Coordination to YSHCN attending CSHS clinics (NPM 6, SPM)	1. CSHS Clinic Staff	1. # of patients who receive transition services (NPM 6, SPM)	1. PCCD & COMPASS/ Nicole
<i><b>Program Resources</b></i>	<i><b>Enabling Services</b></i>	<i><b>Enabling Services</b></i>	<i><b>Enabling Services</b></i>	<i><b>Enabling Services</b></i>
Central Office Staff	1. CCs will provide Transition Service Information to physician practices (NPM 6)	1. Arleen	1. # of physicians provided Transition information (NPM 6)	1. Contracts & Kelly/Arleen
CSHS Field Staff	2. Develop roster of both adult & pediatric orthopedic & neurology subspecialist physician practices to receive RRGs (NPM 6)	2. Betsey	2. Roster developed (NPM 6)	2. Roster spreadsheet/Betsey
CSHS Parent Liaisons	3. Provide RRGs to both adult & pediatric orthopedic and neurology subspecialist physician practices (NPM 6)	3. Betsey	3. # of subspecialist physician practices mailed RRGs (NPM 6)	3. Roster spreadsheet/Betsey
Contract Monies	4. Develop Transition Brochures (NPM 6)	4. Betsey	4. Date transition brochure was developed (NPM 6)	4. Betsey
Staff to develop RRGs	Pop-based Services	Pop-based Services	Pop-based Services	Pop-based Services
Regional Resource Guides (RRGs)	1. Disseminate poster w/tear sheet including FHF contact info to PCPs & appropriate providers (high risk groups) (NPM 1, NPM 5, NPM 6)	1. Betsey & Arleen	1. # of practices mailed/received poster (NPM 1, NPM 5, NPM 6)	1. Roster spreadsheet/ Betsey & Arleen
CSHS Website	2. Create Transition section on CSHS website (NPM 6)	2. Betsey & Nicole	2. CSHS website has a designated transition section (NPM 6)	2. Website/Nicole
FHF contact	Infrastructure Building	Infrastructure Building	Infrastructure Building	Infrastructure Building
AAP & LAFP Contact	1. Submit and publish articles on community-based resources and transition to AAP and LAFP (SPM, NPM 6)	1. Dr. Berry, Betsey & Arleen	1. # of articles submitted to AAP and LAFP newsletter (SPM, NPM 6)	1. Dr. Berry
Staff develop Transition Brochures				
Transition Brochures				
PCCD				

# CSHS Program Activities by Performance Measure

Person writing this measure for block grant: Dr. Berry

State Performance Measure #1: CYSHCN who families did not need additional care coordination services (increase quality comprehensive care coordination capacity statewide).

Theoretical Assumptions	Program Activities	Responsible Party	Activity Measured Outcome	Data Source/Data Person
A significant disparity between privately and publically insured CYSHCN exists for need of extra care coordination services. This signifies a deficit in the quality of comprehensive services available statewide, and especially for the publically insured population who have significantly higher rates of complex conditions, and poorer health outcomes. Improving the quality and comprehensive nature of care coordination services will minimize risk for poorer health outcomes for Louisiana's CYSHCN population.	Direct Services	Direct Services	Direct Services	Direct Services
	1. Amend PL contact logs (NPM 1, NPM 5, SPM)	1. Dionka, Nicole, & Angie	1. PL contact log amended (NPM 1, NPM 5, SPM)	1. N/A
	2. CSHS nurses will assess MH status for patients (NPM 2, SPM)	2. CSHS Nurses	2. % patients linked to MH (SPM, NPM 2)	2. COMPASS/Nicole
	3. Info on MH providers will be provided by SW staff when MH status is unknown or none (NPM 2, SPM)	3. CSHS Social Work Staff	3. % patients linked to MH (SPM, NPM 2)	3. COMPASS/Nicole
	4. CSHS clinic transcripts will be mailed to patient's MH (NPM 2, SPM)	4. CSHS clinic Staff	4. # of patients who attended face to face clinic visit (SPM, NPM 2)	4. COMPASS/Nicole
	5. PLs will provide direct consultation to families/patients on community resources (NPM 5, SPM)	5. CSHS PLs	5. # of times PLs provided community resource information (NPM 5, SPM)	5. Contact Logs/Carl
<b>Program Resources</b>  Central Office Staff CSHS Field Staff CSHS Parent Liaisons Contract Monies MH Orientation Materials CSHS Brochures (SPM) Staff to develop RRGs  Regional Resource Guides (RRGs) CSHS Website Medicaid Liaison FHF contact AAP Collaboration Staff to identify lists of schools, SBHCs, Physician offices, FQHCs	6. Provide Transition Care Coordination to YSHCN attending CSHS clinics (NPM 6, SPM)	6. CSHS Clinic Staff	6. # of patients who receive transition services (NPM 6, SPM)	6. PCCD & COMPASS/Nicole
	Enabling Services	Enabling Services	Enabling Services	Enabling Services
	1. CCs will provide MH orientation info to physician practices (NPM 2, SPM)	1. Arleen	1. # of physician practices provided MH orientation info (NPM 2, NPM 3)	1. Contract & Kelly/Arleen
	Pop-based Services	Pop-based Services	Pop-based Services	Pop-based Services
	1. Develop roster of FQHCs to disseminate CSHS brochures and RRGs (SPM, NPM 5)	1. Betsey	1. FQHC Roster developed (SPM, NPM 5)	1. Roster spreadsheet/Betsey
	2. Develop roster of SBHCs to disseminate CSHS brochures and RRGs (SPM, NPM 5)	2. Michelle	2. SBHC Roster developed (SPM, NPM 5)	2. Roster spreadsheet/Michelle
	3. Disseminate CSHS brochures, FHF brochures, & RRGs to FQHCs & SBHCs (SPM, NPM 5)	3. Betsey	3. # of FQHCs mailed FHF/CSHS brochures, RRGs (SPM, NPM 5)	3. Roster spreadsheet/Betsey
	4. Disseminate CSHS brochures, FHF brochures, & RRGs to SBHCs (SPM, NPM 5)	4. Michelle	4. # of SBHCs received FHF/CSHS brochures, RRGs (SPM, NPM 5)	4. Roster spreadsheet/Michelle
	Infrastructure Building	Infrastructure Building	Infrastructure Building	Infrastructure Building
	1. Engage in meetings w/ Medicaid to increase reimbursement for CC (NPM 3, NPM 2, SPM)	1. Dr. Berry	1. N/A	1. N/A
	2. Collaborate with AAP president during Medicaid meetings?(NPM 3, NPM 2, SPM)	2. Dr. Berry	2. N/A	2. N/A
	3. Engage in meetings with new policy director in charge of DHH /DSS Data Integration (SPM)	3. Dr. Berry	3. # DHH/DSS Data Integration Meetings (SPM)	3. Dr. Berry
	4. Submit and publish articles on community-based resources and transition to AAP and LAFP (SPM, NPM 6)	4. Dr. Berry, Betsey & Arleen	4. # of articles submitted to AAP and LAFP newsletter (SPM, NPM 6)	4. Dr. Berry

# APPENDIX F

- I. CSHS Agency Survey
- II. CSHS Family Survey
- III. CSHS Physician Survey

# Needs Assessment Descriptive Report – Agency Survey

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Louisiana Department of Health and Hospitals  
Office of Public Health – Children's Special Health Services

April 2010

The Policy & Research Group  
8434 Oak Street  
New Orleans, LA 70118  
[www.policyandresearch.com](http://www.policyandresearch.com)  
504.865.1545



The  
Policy & Research  
Group

## **Needs Assessment Overview**

The Louisiana Office of Public Health Children's Special Health Services (CSHS) contracted with The Policy & Research Group (PRG) to assist in conducting their 2010 Statewide Needs Assessment. As part of the needs assessment, PRG administered an online survey of frontline staff members from ten programs identified by CSHS as stakeholders in the provision of services to children and youth with special health care needs (CYSHCN) in Louisiana.

### **Instrument**

In initial discussions about the needs assessment, CSHS expressed interest in assessing the knowledge and perceptions of frontline staff that provide direct services to CYSHCN and their families, including social workers, nurses, and therapists. To this end, PRG and CSHS formulated the following three objectives for the survey:

- 1) To measure the extent to which frontline staff members serving CYSHCN have knowledge of the range of services available and agencies and programs providing those services to CYSHCN and their families.
- 2) To measure the extent to which frontline staff members serving CYSHCN perceive that they collaborate with other agencies/programs.
- 3) To assess the extent to which frontline staff members' perceive barriers to collaboration between agencies and programs that serve CYSHCN.

CSHS identified ten programs, including state agencies and non-governmental organizations, as stakeholders in the provision of services to CYSHCN in Louisiana and therefore as potential participants in the needs assessment. As part of the initial preparation for the survey, representatives from each of the identified programs were recruited to participate in a focus group in order to provide insight on topics of interest for the survey. On October 30, 2009, PRG conducted an hour-long focus group discussion with representatives from eight of the programs about the current state of collaboration between their programs, barriers to collaboration, and barriers to providing comprehensive services to CYSHCN and their families. Focus group discussions helped to inform questions and response options on the *Agency Survey*.

PRG then created a survey questionnaire with feedback from CSHS. The survey was administered online and a link to the survey was provided in an email invitation. Respondents were initially asked to provide basic information on their program as well as their professional function. Then respondents were given a preliminary question that asked them to identify which programs they know offer services to CYSHCN. This question served as the primary branching question. Respondents were then directed to questions that refer to only those programs. The preponderance of the questionnaire addresses respondent awareness, frequency of referrals, and perceived barriers to specific services provided by each of the ten stakeholder programs. The survey automatically skips the series of questions for the respondent's identified program of employment. The entire instrument consists of 36 closed-ended questions and could take up to 35 minutes if all questions are answered, though because the branching, most respondents were not expected to answer every question.

Two CSHS staff members not involved in the survey design were identified by CSHS central office staff to pretest the survey. Based on this feedback slight changes were made to the wording of questions and answer options. The instrument can be found in Appendix A.

### **Respondents**

Potential survey respondents include frontline staff members from each of the ten stakeholder programs identified by CSHS who provide direct services to children and youth, including CYSHCN, and/or their families. Stakeholder agencies/programs identified by CSHS are:

- Louisiana Office for Citizens with Developmental Disabilities
  - Early Steps
  - Supports and Services Centers
  - Resource Centers on Developmental Disabilities
- Louisiana Department of Social Services
  - Independent Living Program
  - Vocational Rehabilitation Program
  - Family Services
  - Foster Care
- Louisiana Office of Public Health
  - Children’s Special Health Services
  - Hearing, Speech, and Vision
- Families Helping Families

Managers from each of the programs were contacted and asked to submit names and email addresses of all potential respondents directly to PRG. Frequencies of the email addresses provided by programs are presented in Table 1. In all, PRG received a total of 873 email addresses. The distribution of the number of respondents from each program ranges from three to 423.

**Table 1.** Distribution of Potential Respondents and Response Rates from Participating Programs

	Email Addresses Received	Number of Responses	Program Response Rate	Percent of Total Responses
OCDD – Early Steps	56	27	48.2%	11.4%
OCDD – Supports and Services Center	89	22	24.7%	9.3%
OCDD – Resource Centers on Developmental Disabilities	60	14	23.3%	5.9%
OPH – Hearing, Speech, and Vision	3	2	66.6%	0.8%
OPH – Children's Special Health Services	60	40	66.6%	16.9%
LRS – Independent Living Program	16	2	12.5%	0.8%
LRS – Vocational Rehabilitation Program	121	19	15.7%	8.0%
OCS – Foster Care and Family Services	423	62	14.7%	26.2%
Families Helping Families	45	18	40.0%	7.6%
Respondent ineligible or did not identify program	n/a	31	n/a	13.1%
<b>Total</b>	<b>873</b>	<b>237</b>	<b>n/a</b>	<b>100.0%</b>

Invitations to participate were sent out to the entire population of potential respondents, though only eligible respondents were permitted to complete the full survey. Respondents are eligible if they indicate that they provide direct services to children, youth, and/or their families. Direct services are defined by CSHS as “a face-to-face visit with a client where you and/or your organization provide social, medical, and/or supportive care for children, youth, and/or their families.”

Response rates for each of the programs are also presented in Table 1 alongside the total number of email addresses received by PRG. Note that calculations in the table underestimate response rates by program. First, only eligible respondents who also voluntarily identified their program of employment are included in the program response numbers. Second, we calculate response rates based on the number email addresses provided to us, not on the smaller number of invitations actually sent out (see the Data Collection Procedures section for more detail).

## **Data Collection Procedures**

The preliminary schedule for the administration of the survey was one month, from February 17 through March 19, 2010. An initial email invitation to participate in the survey, containing a link to the survey, was sent out by PRG to all valid email addresses on February 17, 2010. Three reminder emails were sent by PRG to all remaining recipients with valid email addresses that had not yet completed the survey on March 1, March 15, and March 25, 2010. Following the second reminder email, CSHS's director contacted program managers by email and asked them to encourage their staff to participate in the survey. In the final week of the survey, the preliminary deadline for completion was extended by two weeks to increase the number of responses to the survey. The survey closed on April 2, 2010.

PRG received a total of 873 email addresses from CSHS stakeholders. When we removed all duplicate and non-working email addresses, a total of 832 valid email addresses remained.<sup>1</sup> After six and one half weeks in the field, one invitation and three reminder emails, and one director reminder, 237 people responded to the survey for a 28.5% response rate. Of those, 207 were eligible to complete the full survey (87.3%).

## **Descriptive Statistics**

In this report we present tables that contain the frequencies and proportion (in percent) of categorical responses for each question asked in the survey. This provides an overall description of the levels of awareness, frequency of referrals, and perceptions of collaboration and barriers to that collaboration as perceived by frontline staff from CSHS stakeholder programs. Only those respondents that are eligible to complete the survey are included in the analysis.

Based on initial formative reporting and for the purposes of strategic planning, CSHS asked PRG to provide some analysis of responses to questions about levels of collaboration and knowledge of programs serving CYSHCN. PRG provided CSHS with cross-tabulations of responses by respondents' identified program of employment. These results were presented to CSHS and their stakeholders at a meeting in April 2010. They are reproduced in this report in Appendix B (collaboration) and Appendix C (knowledge of other programs). Results for levels of collaboration are presented as graphic diagrams; results for knowledge of programs are presented as tables.

Aggregate responses to each question in the *Agency Survey* are presented below.

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<sup>1</sup> Email tracking software allows PRG to track in the aggregate the proportion of emails that are actually delivered to recipients' mailboxes.

## Results

### Q1. In which parish(es) do you work? *(Select all that apply)*

	Number of Respondents	Percent of Respondents
Acadia	9	4.3%
Allen	9	4.3%
Ascension	7	3.4%
Assumption	6	2.9%
Avoyelles	11	5.3%
Beauregard	11	5.3%
Bienville	8	3.9%
Bossier	9	4.3%
Caddo	16	7.7%
Calcasieu	19	9.2%
Caldwell	10	4.8%
Cameron	9	4.3%
Catahoula	9	4.3%
Claiborne	9	4.3%
Concordia	9	4.3%
DeSoto	7	3.4%
East Baton Rouge	25	12.1%
East Carroll	11	5.3%
East Feliciana	6	2.9%
Evangeline	9	4.3%
Franklin	11	5.3%
Grant	11	5.3%
Iberia	8	3.9%
Iberville	8	3.9%
Jackson	13	6.3%
Jefferson	14	6.8%
Jefferson Davis	10	4.8%
Lafayette	19	9.2%
Lafourche	19	9.2%
LaSalle	9	4.3%
Lincoln	15	7.2%
Livingston	16	7.7%
Madison	12	5.8%
Morehouse	11	5.3%
Natchitoches	7	3.4%
Orleans	17	8.2%



	Number of Respondents	Percent of Respondents
Ouachita	20	9.7%
Plaquemines	6	2.9%
Pointe Coupee	6	2.9%
Rapides	23	11.1%
Red River	6	2.9%
Richland	12	5.8%
Sabine	5	2.4%
St. Bernard	6	2.9%
St. Charles	5	2.4%
St. Helena	13	6.3%
St. James	6	2.9%
St. John	7	3.4%
St. Landry	9	4.3%
St. Martin	9	4.3%
St. Mary	6	2.9%
St. Tammany	15	7.2%
Tangipahoa	19	9.2%
Tensas	11	5.3%
Terrebonne	8	3.9%
Union	11	5.3%
Vermilion	9	4.3%
Vernon	9	4.3%
Washington	14	6.8%
Webster	15	7.2%
West Baton Rouge	8	3.9%
West Carroll	11	5.3%
West Feliciana	5	2.4%
Winn	10	4.8%
Missing, blank	8	3.9%
<b>Total responses (total respondents)</b>	<b>693 (207)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

**Supplement 1.1. Public health region in which respondents work**

	Number of Respondents	Percent of Respondents
Region 1	22	10.6%
Region 2	30	14.5%
Region 3	21	10.1%
Region 4	27	13.0%
Region 5	19	9.2%
Region 6	26	12.6%
Region 7	27	13.0%
Region 8	26	12.6%
Region 9	22	10.6%
Missing, blank	8	3.9%
<b>Total responses (total respondents)</b>	<b>228 (207)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

**Q2. Which of the following best describes your professional position at your agency/organization?**

	Number of Respondents	Percent of Respondents
Social services professional (ex. social service counselor, social worker, behavioral professional)	124	59.9%
Other professional (ex. parent liaison, vocational trainer/counselor, health educator)	42	20.3%
Medical professional (ex. nurse, personal care attendant, nutritionist, hearing/language professional, OT/PT)	41	19.8%
<b>Total</b>	<b>207</b>	<b>100.0%</b>

**Q3. Do you provide direct services for children, youth (up through 21 years old), and/or their families through your agency?**

	Number of Respondents	Percent of Respondents
Yes	207	100.0%
No	0	0.0%
<b>Total</b>	<b>207</b>	<b>100.0%</b>

**Q3a. Do you provide direct services for CYSHCN and/or their families through your agency?**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
Yes	180	87.0%
No	27	13.0%
<b>Total</b>	<b>207</b>	<b>100.0%</b>

*Supplement 3a.1. Number of respondents that serve CYSHCN, by respondent's program of employment*

	<b>Yes</b>	<b>Percent</b>	<b>No</b>	<b>Percent</b>	<b>Total</b>
Early Steps	24	88.9%	3	11.1%	27 (100.0%)
Supports and Services Center	22	100.0%	0	0.0%	22 (100.0%)
Resource Centers on Developmental Disabilities	13	92.9%	1	7.1%	14 (100.0%)
Hearing, Speech, and Vision	2	100.0%	0	0.0%	2 (100.0%)
Children's Special Health Services	39	97.5%	1	2.5%	40 (100.0%)
Independent Living Program	2	100.0%	0	0.0%	2 (100.0%)
Vocational Rehabilitation Program	11	57.9%	8	42.1%	19 (100.0%)
Family Services	9	69.2%	4	30.8%	13 (100.0%)
Foster Care	41	83.7%	8	16.3%	49 (100.0%)
Families Helping Families	16	88.9%	2	11.1%	18 (100.0%)
Program not identified	1	100.0%	0	0.0%	1 (100.0%)

**Q4. How do you learn about other agencies or programs that provide services that your clients could benefit from using? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
Trainings through work	181	87.4%
Word of mouth	171	82.6%
Personal contacts	169	81.6%
From clients	120	58.0%
Internet	103	49.8%
Other (specify)	44	21.3%
N/A – I do not need information about other programs to do my job	2	1.0%
<b>Total responses (total respondents)</b>	<b>790 (207)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

<b>Other</b>	<b>Number of Respondents</b>
Networking meetings	6
Families Helping Families Resource Centers	4
Emails	3
Co-workers or colleagues	3
Other agencies	3
Previous employment	2
Post-secondary education	2
The local newspaper(s)	2
Schools	1
Calling for information	1
Research	1
Office staff meetings	1
Seminars and conferences	1
232-help	1
Professionals trainings outside of work	1
Books and literature	1
Seeing signs and checking out the program	1
Parish-wide resource #211	1
Parish social services meetings	1
Resource manual	1
Continuing education	1
Other social workers	1
We are a statewide federal grant to 1 FHF Center. We provide information.	1
Parent liaison	1

<b>Other</b>	<b>Number of Respondents</b>
Team meetings	1
Cil Suite	1
News/Television	1
Agency provider list	1
Brochures in the mail	1
<b>Total responses</b>	<b>46</b>

**Q5. For which program do you work?**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
OCDD - Early Steps	27	13.0%
OCDD - Supports and Services Center	22	10.6%
OCDD - Resource Centers on Developmental Disabilities	14	6.7%
OPH - Hearing, Speech, and Vision	2	1.0%
OPH - Children's Special Health Services	40	19.3%
LRS - Independent Living Program	2	1.0%
LRS - Vocational Rehabilitation Program	19	9.2%
OCS - Family Services	13	6.3%
OCS - Foster Care	49	23.7%
Families Helping Families	18	8.7%
Missing, blank	1	0.5%
<b>Total</b>	<b>207</b>	<b>100.0%</b>

**Q6. Thinking about collaboration with other programs in the past 12 months, on a scale of 1 to 10, how effective do you think overall collaboration between programs is in meeting the needs of your program's clients and families?**

The mean effectiveness rating is 6.5 on a scale of one to ten where one is *very ineffective* and ten is *very effective* (n=207) (sd=2.2).

**Q7. Below are descriptions of levels of collaboration that can happen between two programs. For each of the programs listed at the bottom of the page, please choose the level of collaboration that you feel best describes how your program as a whole has collaborated with that program in the past 12 months.** (See the survey in Appendix A for a definition of each category.)

	No collaboration or don't know	Networking	Cooperation	Coordination	Coalition	Collaboration	Missing, blank	Total <sup>2</sup>
Early Steps	<b>39 (21.7%)</b>	19 (10.6%)	34 (18.9%)	37 (20.6%)	18 (10.0%)	29 (16.1%)	4 (2.2%)	180 (100.0%)
Supports and Services Center	37 (20.0%)	32 (17.3%)	<b>44 (23.8%)</b>	22 (11.9%)	17 (9.2%)	23 (12.4%)	10 (5.4%)	185 (100.0%)
Resource Centers on Developmental Disabilities	<b>51 (26.4%)</b>	38 (19.7%)	47 (24.4%)	11 (5.7%)	16 (8.3%)	23 (11.9%)	7 (3.6%)	193 (100.0%)
Hearing, Speech, and Vision	<b>85 (41.5%)</b>	30 (14.6%)	26 (12.7%)	19 (9.3%)	5 (2.4%)	26 (12.7%)	14 (6.8%)	205 (100.0%)
Children's Special Health Services	<b>66 (39.5%)</b>	21 (12.6%)	21 (12.6%)	18 (10.8%)	8 (4.8%)	21 (12.6%)	12 (7.2%)	167 (100.0%)
Independent Living Program	<b>79 (38.5%)</b>	36 (17.6%)	20 (9.8%)	22 (10.7%)	14 (6.8%)	23 (11.2%)	11 (5.4%)	205 (100.0%)
Vocational Rehabilitation Program	<b>70 (37.2%)</b>	38 (20.2%)	25 (13.3%)	24 (12.8%)	8 (4.3%)	14 (7.5%)	9 (4.8%)	188 (100.0%)
Family Care or Foster Services	33 (22.8%)	<b>35 (24.1%)</b>	32 (22.1%)	20 (13.8%)	8 (5.5%)	13 (9.0%)	4 (2.8%)	145 (100.0%)
Families Helping Families	28 (14.8%)	30 (15.9%)	29 (15.3%)	27 (14.3%)	16 (8.5%)	<b>53 (28.0%)</b>	6 (3.2%)	189 (100.0%)

Bold typeface indicates modal response category. Respondents were excluded from identifying their own program of employment.

<sup>2</sup> The total represents the number of respondents eligible to respond to each question; respondents are excluded from rating their own program.

**Q8. Below is a list of barriers that can happen when programs try to collaborate. Please choose the TOP FIVE barriers listed below that you feel your program has experienced in the past 12 months when trying to collaborate with other programs in order to meet the needs of clients/families. Rank the five barriers in order from 1 to 5, where 1 is the biggest barrier your program faces in its efforts at collaboration.**

Barriers	Rank					Total Responses
	1	2	3	4	5	
Services that my clients need are not available	65 (43.0%)	24 (15.9%)	28 (18.5%)	17 (11.3%)	17 (11.3%)	151 (100.0%)
Lack of transportation for clients to get to program/services	46 (32.6%)	34 (24.1%)	28 (19.9%)	16 (11.3%)	17 (12.1%)	141 (100.0%)
Shortage of services in rural areas	41 (29.1%)	34 (24.1%)	24 (17.0%)	25 (17.7%)	17 (12.1%)	141 (100.0%)
Shortage of staff; high workload/caseload	39 (31.5%)	19 (15.3%)	18 (14.5%)	24 (19.4%)	24 (19.4%)	124 (100.0%)
Funding issues related to Medicaid/health insurance	29 (23.6%)	36 (29.3%)	25 (20.3%)	18 (14.6%)	15 (12.2%)	123 (100.0%)
Lack of communication between programs	21 (19.1%)	22 (20.0%)	33 (30.0%)	22 (20.0%)	12 (10.9%)	110 (100.0%)
Client/family needs are complex and it is difficult to coordinate needed services	16 (16.5%)	17 (17.5%)	32 (33.0%)	18 (18.6%)	14 (14.4%)	97 (100.0%)
Agencies have differing methods of serving clients/families	14 (18.4%)	9 (11.8%)	29 (38.2%)	9 (11.8%)	15 (19.7%)	76 (100.0%)
Complex eligibility requirements for programs/services	12 (14.6%)	15 (18.3%)	24 (29.3%)	21 (25.6%)	10 (12.2%)	82 (100.0%)
Lack of knowledge of services provided by other Programs	9 (7.8%)	19 (16.4%)	41 (35.3%)	27 (23.3%)	20 (17.2%)	116 (100.0%)
My program does not have a form that captures all client/family needs and services that would allow me to easily communicate this with other program staff	9 (17.3%)	4 (7.7%)	15 (28.8%)	11 (21.2%)	13 (25.0%)	52 (100.0%)
Providers/physicians do not know how or where to refer CYSCHN to programs/services	8 (11.3%)	15 (21.1%)	20 (28.2%)	16 (22.5%)	12 (16.9%)	71 (100.0%)
Confidentiality or legal issues (ex. HIPAA/FERPA requirements)	5 (9.1%)	11 (20.0%)	11 (20.0%)	18 (32.7%)	10 (18.2%)	55 (100.0%)
State or federal reporting requirements limit ability to collaborate	3 (6.1%)	8 (16.3%)	23 (46.9%)	12 (24.5%)	3 (6.1%)	49 (100.0%)
Other (specify)	2 (20.0%)	1 (10.0%)	2 (20.0%)	3 (30.0%)	2 (20.0%)	10 (100.0%)

Other	Rank
Trying to get families involved and educated about resources is difficult, difficult to get them to participate	1
Lack of funding in programs therefore all my clients are getting the necessary resources.	1
Early Intervention & school services are essential for CYSHCN but there is little accountability for services being provided that will appropriately meet the unique needs of each child as required by federal law. Early Interventionists refuse the Medicaid payment rates. School districts don't welcome collaboration and claim an inability to provide services due to funding while sitting on surplus funds.	2
Continuation of services between agencies. Having all providers on the same 'page' and assessing the case appropriately.	3
Ability of other program staff to travel to family	3
Poverty	4
Some services are only provided at night	4
Incompetent and political based supervisors	5
Program refusing to make referrals	5

**Q9. To begin, please select all of the programs listed below that you know offer services for children and/or youth that may have special health care needs. Please skip your program. (Select all that apply)**

	Number of Respondents	Percent of Respondents
Early Steps	157	87.2%
Families Helping Families	153	81.0%
Resource Centers on Developmental Disabilities	136	70.5%
Supports and Services Center	119	64.3%
Family Services and/or Foster Care	113	77.9%
Hearing, Speech, and Vision	102	49.8%
Vocational Rehabilitation Program	100	53.2%
Independent Living Program	93	45.4%
Children's Special Health Services	89	53.3%
None of the above	1	0.5%

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Respondents were excluded from identifying their own program of employment; percents are calculated using only those respondents eligible to answer the question.



## OCDD - Early Steps

**Q10. OCDD - Early Steps** offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

	Not aware	Somewhat aware	Aware	Very aware	Missing, blank	Total <sup>3</sup>
Assistive technology	<b>46</b> (29.3%)	44 (28.0%)	29 (18.5%)	24 (15.3%)	14 (8.9%)	157 (100.0%)
Audiology	38 (24.2%)	<b>39</b> (24.8%)	35 (22.3%)	32 (20.4%)	13 (8.3%)	157 (100.0%)
Nutrition services	<b>43</b> (27.4%)	40 (25.5%)	33 (21.0%)	30 (19.1%)	11 (7.0%)	157 (100.0%)
Occupational and physical therapy	26 (16.6%)	24 (15.3%)	43 (27.4%)	<b>53</b> (33.8%)	11 (7.0%)	157 (100.0%)
Psychological services	<b>41</b> (26.1%)	29 (18.5%)	38 (24.2%)	35 (22.3%)	14 (8.9%)	157 (100.0%)
Service coordination	31 (19.8%)	35 (22.3%)	<b>41</b> (26.1%)	37 (23.6%)	13 (8.3%)	157 (100.0%)
Social work services	30 (19.1%)	33 (21.0%)	39 (24.8%)	<b>42</b> (26.8%)	13 (8.3%)	157 (100.0%)
Speech language pathology	17 (10.8%)	39 (24.8%)	39 (24.8%)	<b>48</b> (30.6%)	14 (8.9%)	157 (100.0%)
Transportation to and from Early Steps services	<b>81</b> (51.6%)	25 (15.9%)	21 (13.4%)	12 (7.6%)	18 (11.5%)	157 (100.0%)
Translation/interpreter services	<b>65</b> (41.4%)	34 (21.7%)	20 (12.7%)	16 (10.2%)	22 (14.0%)	157 (100.0%)
Vision services	<b>45</b> (28.7%)	<b>45</b> (28.7%)	30 (19.1%)	19 (12.1%)	18 (11.5%)	157 (100.0%)

Bold typeface indicates modal response category.

<sup>3</sup> The total represents the number of respondents eligible to answer the question; respondents are excluded from rating their own program and from rating any program they reported being unaware of in question nine.

**Q11. Then, for those services you marked that you are *SOMEWHAT AWARE*, *AWARE*, or *VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you have referred clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
Assistive technology <sup>4</sup>	30 (30.9%)	<b>37</b> <b>(38.1%)</b>	19 (19.6%)	8 (8.3%)	3 (3.1%)	97 (100.0%)
Audiology	31 (29.3%)	<b>42</b> <b>(39.6%)</b>	15 (14.2%)	12 (11.3%)	6 (5.7%)	106 (100.0%)
Nutrition services	<b>40</b> <b>(38.8%)</b>	29 (28.2%)	15 (14.6%)	11 (10.7%)	8 (7.8%)	103 (100.0%)
Occupational and physical therapy	21 (17.5%)	<b>43</b> <b>(35.8%)</b>	27 (22.5%)	23 (19.2%)	6 (5.0%)	120 (100.0%)
Psychological services	22 (21.6%)	<b>37</b> <b>(36.3%)</b>	27 (26.5%)	11 (10.8%)	5 (4.9%)	102 (100.0%)
Service coordination	27 (23.9%)	<b>42</b> <b>(37.2%)</b>	23 (20.4%)	15 (13.3%)	6 (5.3%)	113 (100.0%)
Social work services	26 (22.8%)	<b>37</b> <b>(32.5%)</b>	26 (22.8%)	18 (15.8%)	7 (6.1%)	114 (100.0%)
Speech language pathology	32 (25.4%)	<b>42</b> <b>(33.3%)</b>	26 (20.6%)	22 (17.5%)	4 (3.2%)	126 (100.0%)
Transportation to and from Early Steps services	19 (32.8%)	<b>24</b> <b>(41.4%)</b>	12 (20.7%)	2 (3.5%)	1 (1.7%)	58 (100.0%)
Translation/interpreter services	27 (38.6%)	<b>30</b> <b>(42.9%)</b>	6 (8.6%)	4 (5.7%)	3 (4.3%)	70 (100.0%)
Vision services	31 (33.0%)	<b>39</b> <b>(42.5%)</b>	14 (14.9%)	5 (5.3%)	5 (5.3%)	94 (100.0%)

Bold typeface indicates modal response category.

<sup>4</sup> Instructions for the frequency of referrals questions state to skip the question if the respondent indicated they were "not aware" of the service. The survey does not force this skip pattern. Several respondents provided an answer to the referral question even though they indicated they were "not aware" of the service. We have excluded those respondents from the results in the expectation that this is a more reliable representation of the frequency of referrals.

**Q12. You have indicated that you are aware of at least one *Early Steps* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
My clients generally do not fit the eligibility requirements because of age or condition	42	31.8%
My clients generally do not need the service(s) they provide	38	28.8%
My clients don't have transportation to get to the program/service(s)	28	21.2%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	27	20.5%
The service(s) are a duplication of something my program offers	24	18.2%
Other (specify)	24	18.2%
The service(s) are not available in my clients' area/parish/region	21	15.9%
The wait time for an appointment is long	13	9.8%
The service(s) are not covered by Medicaid	10	7.6%
The agency that provides the service(s) does not accept referrals from my program	9	6.8%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	3	2.3%
Our reporting requirements don't allow us to refer to the program and/or service(s)	2	1.5%
<b>Total responses (total respondents)</b>	<b>241 (132)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 10 and indicated that they rarely or never refer clients to those services in question 11. A total of 75 respondents skipped this question.

<b>Other</b>	<b>Number of Responses</b>
I do not have clients under the age of three	6
Clients are usually already receiving the services	4
In my position I do not make referrals; someone else in my office is responsible	4
I always refer when appropriate	2
I rarely have cases that involve children that needs these kinds of services with the exception of Early Steps	1
I have not been with the agency long	1
As Community Outreach Specialist, I refer to the SPOE who then takes over the case and continues the process	1
I do not answer the calls at the office so I do not speak to the people in need of the services	1
It reads transportation to/from Early Steps	1
I know and tell many families about Early Steps & provide training on Part C. I only indicated one service that I have not passed on-transportation. Probably because I had not thought about that as much as other services.	1

Other	Number of Responses
Too long to initiate services or at all	1
<b>Total</b>	<b>23</b>

### OCDD – Supports and Services Center

**Q13. OCDD – Supports and Services Center offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."**

	Not aware	Somewhat aware	Aware	Very aware	Missing, blank	Total
Residential or group homes for individuals with developmental disabilities	11 (9.2%)	30 (25.2%)	31 (26.1%)	<b>43</b> <b>(36.1%)</b>	4 (3.4%)	119 (100.0%)
Supported independent and extended family living	15 (12.6%)	30 (25.2%)	31 (26.1%)	<b>39</b> <b>(32.8%)</b>	4 (3.4%)	119 (100.0%)
Health care services	20 (16.8%)	27 (22.7%)	<b>33</b> <b>(27.7%)</b>	<b>33</b> <b>(27.7%)</b>	6 (5.0%)	119 (100.0%)
Psychological services	15 (12.6%)	32 (26.9%)	30 (25.2%)	<b>35</b> <b>(29.4%)</b>	7 (5.9%)	119 (100.0%)
Physical and occupational therapy	19 (16.0%)	23 (19.3%)	33 (27.7%)	<b>38</b> <b>(31.9%)</b>	6 (5.0%)	119 (100.0%)
Vocational services	11 (9.2%)	<b>34</b> <b>(28.5%)</b>	<b>34</b> <b>(28.6%)</b>	32 (26.9%)	8 (6.7%)	119 (100.0%)
Speech and language services	19 (16.0%)	28 (23.5%)	29 (24.4%)	<b>33</b> <b>(27.7%)</b>	10 (8.4%)	119 (100.0%)

Bold typeface indicates modal response category.

**Q14. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
Residential or group homes for individuals with developmental disabilities	<b>48</b> <b>(46.2%)</b>	34 (32.7%)	14 (13.5%)	2 (1.9%)	6 (5.8%)	104 (100.0%)
Supported independent and extended family living	<b>35</b> <b>(35.0%)</b>	34 (34.0%)	17 (17.0%)	6 (6.0%)	8 (8.0%)	100 (100.0%)
Health care services	22 (23.7%)	<b>29</b> <b>(31.2%)</b>	18 (19.4%)	18 (19.4%)	6 (6.5%)	93 (100.0%)
Psychological services	27 (27.8%)	<b>32</b> <b>(33.0%)</b>	21 (21.7%)	14 (14.4%)	3 (3.1%)	97 (100.0%)
Physical and occupational therapy	22 (23.4%)	<b>31</b> <b>(33.0%)</b>	17 (18.1%)	18 (19.2%)	6 (6.4%)	94 (100.0%)
Vocational services	32 (32.0%)	<b>33</b> <b>(33.0%)</b>	17 (17.0%)	9 (9.0%)	9 (9.0%)	100 (100.0%)
Speech and language services	26 (28.9%)	<b>28</b> <b>(31.1%)</b>	13 (14.4%)	15 (16.7%)	8 (8.9%)	90 (100.0%)

Bold typeface indicates modal response category.

**Q15. You have indicated that you are aware of at least one *Supports and Services Center* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	Number of Respondents	Percent of Respondents
My clients generally do not need the service(s) they provide	35	35.7%
My clients generally do not fit the eligibility requirements because of age or condition	32	32.7%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	19	19.4%
The service(s) are a duplication of something my program offers	17	17.3%
My clients don't have transportation to get to the program/service(s)	16	16.3%
The service(s) are not available in my clients' area/parish/region	16	16.3%
Other (specify)	14	14.3%
The wait time for an appointment is long	14	14.3%
The agency that provides the service(s) does not accept referrals from my program	10	10.2%
The service(s) are not covered by Medicaid	7	7.1%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	4	4.1%
Our reporting requirements don't allow us to refer to the program and/or service(s)	2	2.0%
<b>Total responses (total respondents)</b>	<b>186 (98)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 13 and indicated that they rarely or never refer clients to those services in question 14. A total of 109 respondents skipped this question.

Other	Number of Respondents
Most already have the services before they are referred to us	2
I provide families with the resources	2
It is the parent/family's decision	2
It is not my position to refer clients; someone else in my agency does necessary referrals	2
I deal with ages 0-5 and usually do not have to deal with those issues and when I do I collaborate with my supervisor	1
I don't make recommendations on living arrangements within my program; I do recommend all OCDD health-related services	1
Have tried to refer clients in the past and have had no success accessing the services (especially psychological services - community support team)	1
OCDD is reluctant to house our clients that are still in our custody. However they will provide services to individuals living with relatives that can receive the services at home.	1
We usually receive referrals from those agencies	1
<b>Total</b>	<b>13</b>

## OCDD – Resource Centers on Developmental Disabilities

**Q16. OCDD – Resource Centers on Developmental Disabilities offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."**

	Not aware	Somewhat aware	Aware	Very aware	Missing, blank	Total
Occupational and physical therapy evaluation and treatment	29 (21.3%)	<b>37</b> <b>(27.2%)</b>	29 (21.3%)	31 (22.8%)	10 (7.4%)	136 (100.0%)
Nutrition services	<b>41</b> <b>(30.2%)</b>	36 (26.5%)	23 (16.9%)	23 (16.9%)	13 (9.6%)	136 (100.0%)
Speech services	33 (24.3%)	<b>36</b> <b>(26.5%)</b>	28 (20.6%)	27 (19.9%)	12 (8.8%)	136 (100.0%)
Dental treatment and care	<b>46</b> <b>(33.8%)</b>	28 (20.6%)	25 (18.4%)	26 (19.1%)	11 (8.1%)	136 (100.0%)
Psychology community support team	31 (22.8%)	<b>33</b> <b>(24.3%)</b>	25 (18.4%)	35 (25.7%)	12 (8.8%)	136 (100.0%)
Wheelchair assessment	<b>56</b> <b>(41.2%)</b>	28 (20.6%)	18 (13.2%)	22 (16.2%)	12 (8.8%)	136 (100.0%)

Bold typeface indicates modal response category.

**Q17. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
Occupational and physical therapy evaluation and treatment	29 (29.9%)	<b>31</b> <b>(32.0%)</b>	14 (14.4%)	14 (14.4%)	9 (9.3%)	97 (100.0%)
Nutrition services	29 (35.4%)	<b>30</b> <b>(36.6%)</b>	12 (14.6%)	7 (8.5%)	4 (4.9%)	82 (100.0%)
Speech services	<b>35</b> <b>(38.5%)</b>	22 (24.2%)	16 (17.6%)	12 (13.2%)	6 (6.6%)	91 (100.0%)
Dental treatment and care	19 (24.1%)	<b>30</b> <b>(38.0%)</b>	17 (21.5%)	7 (8.9%)	6 (7.6%)	79 (100.0%)
Psychology community support team	23 (24.7%)	<b>33</b> <b>(35.5%)</b>	16 (17.2%)	13 (14.0%)	8 (8.6%)	93 (100.0%)
Wheelchair assessment	<b>28</b> <b>(41.2%)</b>	20 (29.4%)	8 (11.8%)	7 (10.3%)	5 (7.4%)	68 (100.0%)

Bold typeface indicates modal response category.

**Q18. You have indicated that you are aware of at least one *Resource Centers on Developmental Disabilities* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
My clients generally do not need the service(s) they provide	27	30.3%
The service(s) are a duplication of something my program offers	25	28.1%
My clients generally do not fit the eligibility requirements because of age or condition	23	25.8%
My clients don't have transportation to get to the program/service(s)	21	23.6%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	18	20.2%
The service(s) are not available in my clients' area/parish/region	17	19.1%
The wait time for an appointment is long	16	18.0%
Other (specify)	11	12.4%
The service(s) are not covered by Medicaid	10	11.2%
The agency that provides the service(s) does not accept referrals from my program	5	5.6%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	2	2.2%
Our reporting requirements don't allow us to refer to the program and/or service(s)	2	2.2%
<b>Total responses (total respondents)</b>	<b>177 (89)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 16 and indicated that they rarely or never refer clients to those services in question 17. A total of 118 respondents skipped this question.

<b>Other</b>	<b>Number of Responses</b>
Clients are generally already referred	2
Did not realize about wheelchair assessments	1
Have tried to refer to community support team in the past and have not been able to get past the person answering the phone for OCDD.	1
My position is managerial thus I do not personally refer clients	1
I give families information	1
They need to apply in person/waiting list on Waiver program	1
My clients usually only have education issues and are directed by others in the office for these services	1
These services were based on people experiencing institutional care and these "resource centers" are often based out of institutions. We do not promote institutions even if they are given friendlier sounding names. I only refer for dental because it is so difficult for CYSHCN to access dental care anywhere but I am not comfortable doing so.	1
<b>Total</b>	<b>12</b>



## OPH – Hearing, Speech, and Vision

**Q19. OPH – Hearing, Speech, and Vision** offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

	Not aware	Somewhat aware	Aware	Very aware	Missing, blank	Total
General information on deafness and hearing loss	10 (9.8%)	28 (27.5%)	30 (29.4%)	<b>31</b> <b>(30.4%)</b>	3 (2.9%)	102 (100.0%)
Information on communication modalities	21 (20.6%)	26 (25.5%)	<b>30</b> <b>(29.4%)</b>	22 (21.6%)	3 (2.9%)	102 (100.0%)
Information on educational opportunities	24 (23.5%)	21 (20.6%)	<b>30</b> <b>(29.4%)</b>	21 (20.6%)	6 (5.9%)	102 (100.0%)
Connection with family support groups	<b>28</b> <b>(27.5%)</b>	27 (26.5%)	20 (19.6%)	22 (21.6%)	5 (4.9%)	102 (100.0%)

Bold typeface indicates modal response category.

**Q20. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
General information on deafness and hearing loss	17 (19.1%)	<b>31</b> <b>(34.8%)</b>	19 (21.4%)	18 (20.2%)	4 (4.5%)	89 (100.0%)
Information on communication modalities	15 (19.2%)	<b>26</b> <b>(33.3%)</b>	21 (26.9%)	11 (14.1%)	5 (6.4%)	78 (100.0%)
Information on educational opportunities	12 (16.7%)	<b>23</b> <b>(31.9%)</b>	<b>23</b> <b>(31.9%)</b>	10 (13.9%)	4 (5.6%)	72 (100.0%)
Connection with family support groups	12 (17.4%)	<b>22</b> <b>(31.9%)</b>	19 (27.5%)	12 (17.4%)	4 (5.8%)	69 (100.0%)

Bold typeface indicates modal response category.

**Q21. You have indicated that you are aware of at least one *Hearing, Speech, and Vision* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
My clients generally do not need the service(s) they provide	19	33.3%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	15	26.3%
The service(s) are a duplication of something my program offers	12	21.0%
My clients generally do not fit the eligibility requirements because of age or condition	12	21.0%
My clients don't have transportation to get to the program/service(s)	9	15.8%
The service(s) are not available in my clients' area/parish/region	8	14.0%
Other (specify)	7	12.3%
The service(s) are not covered by Medicaid	6	10.5%
The wait time for an appointment is long	2	3.5%
The agency that provides the service(s) does not accept referrals from my program	2	3.5%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	1	1.8%
Our reporting requirements don't allow us to refer to the program and/or service(s)	0	0.0%
<b>Total responses (total respondents)</b>	<b>93 (57)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 19 and indicated that they rarely or never refer clients to those services in question 20. A total of 150 respondents skipped this question.

<b>Other</b>	<b>Number of Responses</b>
We have our own audiologist	1
We refer families to other family support groups. Support requests for hearing are infrequent as this is a low incidence population.	1
Never ran across the need	1
Some families exceed the income requirement	1
My job description does not require me to make referrals to the services provided by this agency.	1
Application made not acted upon.	1
<b>Total</b>	<b>6</b>

## **OPH – Children’s Special Health Services**

**Q22. OPH – Children’s Special Health Services** offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

	<b>Not aware</b>	<b>Somewhat aware</b>	<b>Aware</b>	<b>Very aware</b>	<b>Missing, blank</b>	<b>Total</b>
Medical tests and procedures	21 (23.6%)	21 (23.6%)	16 (18.0%)	<b>25</b> <b>(28.1%)</b>	6 (6.7%)	89 (100.0%)
Occupational and physical therapies	22 (24.7%)	22 (24.7%)	16 (18.0%)	<b>23</b> <b>(25.8%)</b>	6 (6.7%)	89 (100.0%)
Medical equipment and supplies	<b>26</b> <b>(29.2%)</b>	20 (22.5%)	16 (18.0%)	22 (24.7%)	5 (5.6%)	89 (100.0%)
Parent/family support services	<b>27</b> <b>(30.3%)</b>	22 (24.7%)	14 (15.7%)	20 (22.5%)	6 (6.7%)	89 (100.0%)
Medications and special diets	<b>28</b> <b>(31.5%)</b>	18 (20.2%)	18 (20.2%)	20 (22.5%)	5 (5.6%)	89 (100.0%)
Nursing, nutrition, and social services follow-up	22 (24.7%)	18 (20.2%)	17 (19.1%)	<b>24</b> <b>(27.0%)</b>	8 (9.0%)	89 (100.0%)
Care coordination and transition services	<b>27</b> <b>(30.3%)</b>	16 (18.0%)	12 (13.5%)	25 (28.1%)	9 (10.1%)	89 (100.0%)

Bold typeface indicates modal response category.

**Q23. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
Medical tests and procedures	14 (22.6%)	<b>21</b> <b>(33.9%)</b>	9 (14.5%)	14 (22.6%)	4 (6.5%)	62 (100.0%)
Occupational and physical therapies	14 (23.0%)	<b>23</b> <b>(37.7%)</b>	9 (14.8%)	10 (16.4%)	5 (8.2%)	61 (100.0%)
Medical equipment and supplies	13 (22.4%)	<b>17</b> <b>(29.3%)</b>	15 (25.9%)	10 (17.2%)	3 (5.2%)	58 (100.0%)
Parent/family support services	12 (21.4%)	<b>19</b> <b>(33.9%)</b>	12 (21.4%)	9 (16.1%)	4 (7.1%)	56 (100.0%)
Medications and special diets	<b>19</b> <b>(33.9%)</b>	<b>19</b> <b>(33.9%)</b>	5 (8.9%)	9 (16.1%)	4 (7.1%)	56 (100.0%)
Nursing, nutrition, and social services follow-up	15 (25.4%)	<b>18</b> <b>(30.5%)</b>	9 (15.3%)	13 (22.0%)	4 (6.8%)	59 (100.0%)
Care coordination and transition services	15 (28.3%)	<b>16</b> <b>(30.2%)</b>	6 (11.3%)	12 (22.6%)	4 (7.6%)	53 (100.0%)

Bold typeface indicates modal response category.

**Q24. You have indicated that you are aware of at least one *Children's Special Health Services* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	21	38.9%
My clients generally do not need the service(s) they provide	19	35.2%
The service(s) are a duplication of something my program offers	11	20.4%
My clients generally do not fit the eligibility requirements because of age or condition	9	16.7%
The service(s) are not available in my clients' area/parish/region	7	13.0%
The service(s) are not covered by Medicaid	7	13.0%
The wait time for an appointment is long	7	13.0%
My clients don't have transportation to get to the program/service(s)	4	7.4%
Other (specify)	3	5.6%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	2	3.7%
The agency that provides the service(s) does not accept referrals from my program	1	1.9%
Our reporting requirements don't allow us to refer to the program and/or service(s)	1	1.9%
<b>Total responses (total respondents)</b>	<b>92 (54)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 22 and indicated that they rarely or never refer clients to those services in question 23. A total of 153 respondents skipped this question.

<b>Other</b>	<b>Number of Responses</b>
My client was already linked to a provider	1
Never needed to access	1
This is good and we make use of it	1
<b>Total</b>	<b>3</b>

## LRS – Independent Living Program

**Q25. LRS – Independent Living Program** offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

	<b>Not aware</b>	<b>Somewhat aware</b>	<b>Aware</b>	<b>Very aware</b>	<b>Missing, blank</b>	<b>Total</b>
Counseling	15 (16.1%)	<b>28</b> <b>(30.1%)</b>	23 (24.7%)	21 (22.6%)	6 (6.5%)	93 (100.0%)
Mobility training	20 (21.5%)	<b>28</b> <b>(30.1%)</b>	26 (28.0%)	9 (9.7%)	10 (10.8%)	93 (100.0%)
Physical rehabilitation	20 (21.5%)	<b>27</b> <b>(29.0%)</b>	25 (26.9%)	12 (12.9%)	9 (9.7%)	93 (100.0%)
Provision of needed prosthesis, other applications and devices	<b>26</b> <b>(28.0%)</b>	23 (24.7%)	20 (21.5%)	12 (12.9%)	12 (12.9%)	93 (100.0%)
Interpreter and reader services	<b>30</b> <b>(32.3%)</b>	22 (23.7%)	22 (23.7%)	9 (9.7%)	10 (10.8%)	93 (100.0%)
Individual and group social and recreational services	25 (26.9%)	19 (20.4%)	<b>29</b> <b>(31.2%)</b>	11 (11.8%)	9 (9.7%)	93 (100.0%)
Personal assistance services to help with daily living	13 (14.0%)	19 (20.4%)	<b>35</b> <b>(37.6%)</b>	20 (21.5%)	6 (6.5%)	93 (100.0%)

Bold typeface indicates modal response category.

**Q26. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
Counseling	<b>28</b> <b>(38.9%)</b>	16 (22.2%)	15 (20.8%)	9 (12.5%)	4 (5.6%)	72 (100.0%)
Mobility training	<b>28</b> <b>(44.4%)</b>	17 (27.0%)	12 (19.1%)	2 (3.2%)	4 (6.4%)	63 (100.0%)
Physical rehabilitation	<b>30</b> <b>(46.9%)</b>	15 (23.4%)	10 (15.6%)	4 (6.3%)	5 (7.8%)	64 (100.0%)
Provision of needed prosthesis, other applications and devices	<b>25</b> <b>(45.5%)</b>	15 (27.3%)	8 (14.6%)	4 (7.3%)	3 (5.5%)	55 (100.0%)
Interpreter and reader services	<b>22</b> <b>(41.5%)</b>	12 (22.6%)	13 (24.5%)	2 (3.8%)	4 (7.6%)	53 (100.0%)
Individual and group social and recreational services	<b>22</b> <b>(37.3%)</b>	13 (22.0%)	15 (25.4%)	4 (6.8%)	5 (8.5%)	59 (100.0%)
Personal assistance services to help with daily living	<b>28</b> <b>(37.8%)</b>	18 (24.3%)	13 (17.6%)	9 (12.2%)	6 (8.1%)	74 (100.0%)

Bold typeface indicates modal response category.

**Q27. You have indicated that you are aware of at least one *Independent Living Program* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
My clients generally do not need the service(s) they provide	30	44.1%
My clients generally do not fit the eligibility requirements because of age or condition	17	25.0%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	15	22.1%
The service(s) are a duplication of something my program offers	10	14.7%
Other (specify)	9	13.2%
My clients don't have transportation to get to the program/service(s)	8	11.8%
The service(s) are not available in my clients' area/parish/region	5	7.4%
The wait time for an appointment is long	5	7.4%
The agency that provides the service(s) does not accept referrals from my program	4	5.9%
The service(s) are not covered by Medicaid	3	4.4%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	0	0.0%
Our reporting requirements don't allow us to refer to the program and/or service(s)	0	0.0%
<b>Total responses (total respondents)</b>	<b>106 (68)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 25 and indicated that they rarely or never refer clients to those services in question 26. A total of 139 respondents skipped this question.

<b>Other</b>	<b>Number of Respondents</b>
Communication with this agency is poor and the community is seldom given knowledge of changes in program services or criteria	1
Family against the idea of independent living	1
I usually refer them to other programs that then take care of services	1
Client needs to apply on their own	1
Our social workers utilize this program	1
My position is managerial thus I do not personally refer clients	1
Programs are not marketed enough?	1
Already receiving the services on entrance to this program or coordinated by the social service department of this program	1
<b>Total</b>	<b>8</b>



## LRS – Vocational Rehabilitation Program

**Q28. LRS – Vocational Rehabilitation Program** offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

	Not aware	Somewhat aware	Aware	Very aware	Missing, blank	Total
Vocational guidance and career counseling	4 (4.0%)	20 (20.0%)	<b>37</b> <b>(37.0%)</b>	31 (31.0%)	8 (8.0%)	100 (100.0%)
Evaluation of rehabilitation potential	10 (10.0%)	21 (21.0%)	<b>31</b> <b>(31.0%)</b>	28 (28.0%)	10 (10.0%)	100 (100.0%)
Vocational and other training services	6 (6.0%)	23 (23.0%)	<b>31</b> <b>(31.0%)</b>	30 (30.0%)	10 (10.0%)	100 (100.0%)
Occupational tools and equipment	18 (18.0%)	22 (22.0%)	<b>27</b> <b>(27.0%)</b>	26 (26.0%)	7 (7.0%)	100 (100.0%)
Rehabilitation technology	16 (16.0%)	<b>26</b> <b>(26.0%)</b>	<b>26</b> <b>(26.0%)</b>	23 (23.0%)	9 (9.0%)	100 (100.0%)
Transportation to access other vocational rehabilitation services	23 (23.0%)	25 (25.0%)	<b>26</b> <b>(26.0%)</b>	17 (17.0%)	9 (9.0%)	100 (100.0%)

Bold typeface indicates modal response category.

**Q29. Then, for those services you marked that you are *SOMEWHAT AWARE*, *AWARE*, OR *VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
Vocational guidance and career counseling	18 (20.5%)	<b>32</b> <b>(36.4%)</b>	19 (21.6%)	13 (14.8%)	6 (6.8%)	88 (100.0%)
Evaluation of rehabilitation potential	20 (25.0%)	<b>26</b> <b>(32.5%)</b>	16 (20.0%)	13 (16.3%)	5 (6.3%)	80 (100.0%)
Vocational and other training services	16 (19.1%)	<b>30</b> <b>(35.7%)</b>	18 (21.4%)	14 (16.7%)	6 (7.1%)	84 (100.0%)
Occupational tools and equipment	<b>25</b> <b>(33.3%)</b>	23 (30.7%)	14 (18.7%)	9 (12.0%)	4 (5.3%)	75 (100.0%)
Rehabilitation technology	<b>24</b> <b>(32.0%)</b>	23 (30.7%)	12 (16.0%)	10 (13.3%)	6 (8.0%)	75 (100.0%)
Transportation to access other vocational rehabilitation services	<b>24</b> <b>(35.3%)</b>	23 (33.8%)	9 (13.2%)	8 (11.8%)	4 (5.9%)	68 (100.0%)

Bold typeface indicates modal response category.

**Q30. You have indicated that you are aware of at least one *Vocational Rehabilitation Program* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
My clients generally do not fit the eligibility requirements because of age or condition	24	37.5%
My clients generally do not need the service(s) they provide	21	32.8%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	15	23.4%
My clients don't have transportation to get to the program/service(s)	14	21.9%
The service(s) are not available in my clients' area/parish/region	12	18.8%
The wait time for an appointment is long	8	12.5%
The service(s) are a duplication of something my program offers	8	12.5%
Other (specify)	7	10.9%
The agency that provides the service(s) does not accept referrals from my program	4	6.3%
The service(s) are not covered by Medicaid	2	3.1%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	0	0.0%
Our reporting requirements don't allow us to refer to the program and/or service(s)	0	0.0%
<b>Total responses (total respondents)</b>	<b>115 (64)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 28 and indicated that they rarely or never refer clients to those services in question 29. A total of 143 respondents skipped this question.

<b>Other</b>	<b>Number of Respondents</b>
It is not my position to make the referral	3
Those eligible have already been evaluated	2
Families believe LRS has a reputation of not serving youth with developmental disabilities although their website says they do. In actuality it is a rare occasion that any person with developmental disabilities receives any service at all. This may be a regional decision but none the less.	1
All clients that are eligible for VR services are referred during transitional counseling; we have a VR counselor and Tech Training Center in all of our parishes.	1
<b>Total</b>	<b>7</b>

## OCS – Family Services and Foster Care

**Q31. OCS – Family Services and Foster Care** programs offer the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

	Not aware	Somewhat aware	Aware	Very aware	Missing, blank	Total
Temporary care, for a planned period of time, when a child must be separated from his own parents or relatives	16 (14.2%)	22 (19.5%)	28 (24.8%)	<b>46</b> <b>(40.7%)</b>	1 (0.9%)	113 (100.0%)
Individualized services that are provided to families and children in their own homes in order to address problems of abuse/neglect and promote the safety of the children within the family unit	13 (11.5%)	26 (23.0%)	27 (23.9%)	<b>44</b> <b>(38.9%)</b>	3 (2.7%)	113 (100.0%)

Bold typeface indicates modal response category.

**Q32. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	Never	Rarely	Sometimes	Frequently	Missing, blank	Total
Temporary care, for a planned period of time, when a child must be separated from his own parents or relatives	<b>39</b> <b>(40.6%)</b>	36 (37.5%)	12 (12.5%)	2 (2.1%)	7 (7.3%)	96 (100.0%)
Individualized services that are provided to families and children in their own homes in order to address problems of abuse/neglect and promote the safety of the children within the family unit	30 (30.9%)	<b>38</b> <b>(39.2%)</b>	18 (18.6%)	4 (4.1%)	7 (7.2%)	97 (100.0%)

Bold typeface indicates modal response category.

**Q33. You have indicated that you are aware of at least one *Family Services or Foster Care* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
My clients generally do not need the service(s) they provide	45	58.4%
My clients generally do not fit the eligibility requirements because of age or condition	12	15.6%
Other (specify)	11	14.3%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	7	9.1%
The service(s) are not available in my clients' area/parish/region	3	3.9%
The agency that provides the service(s) does not accept referrals from my program	3	3.9%
My clients don't have transportation to get to the program/service(s)	2	2.6%
The service(s) are a duplication of something my program offers	2	2.6%
The service(s) are not covered by Medicaid	1	1.3%
The wait time for an appointment is long	1	1.3%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	1	1.3%
Our reporting requirements don't allow us to refer to the program and/or service(s)	0	0.0%
<b>Total responses (total respondents)</b>	<b>88 (77)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 31 and indicated that they rarely or never refer clients to those services in question 32. A total of 130 respondents skipped this question.

<b>Other</b>	<b>Number of Responses</b>
It is not my position to make these referrals; someone else makes these referrals when necessary	3
We make appropriate referrals	2
Medical neglect that we observe is often not severe enough by their criteria to accept the case as valid.	1
<b>Total</b>	<b>6</b>

## Families Helping Families

**Q34. *Families Helping Families* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."**

	<b>Not aware</b>	<b>Somewhat aware</b>	<b>Aware</b>	<b>Very aware</b>	<b>Missing, blank</b>	<b>Total</b>
Health care financing information	<b>42</b> (27.5%)	27 (17.7%)	41 (26.8%)	31 (20.3%)	12 (7.8%)	153 (100.0%)
Referral services	13 (8.5%)	33 (21.6%)	48 (31.4%)	<b>50</b> (32.7%)	9 (5.9%)	153 (100.0%)
Education and training for families about their child's special health care needs	13 (8.5%)	24 (15.7%)	50 (32.7%)	<b>57</b> (37.3%)	9 (5.9%)	153 (100.0%)
Peer-to-peer support	26 (17.0%)	21 (13.7%)	<b>49</b> (32.0%)	46 (30.1%)	11 (7.2%)	153 (100.0%)
Advocacy assistance	11 (7.2%)	23 (15.0%)	51 (33.3%)	<b>57</b> (37.3%)	11 (7.2%)	153 (100.0%)

Bold typeface indicates modal response category.

**Q35. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.**

	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Frequently</b>	<b>Missing, blank</b>	<b>Total</b>
Health care financing information	22 (22.2%)	25 (25.3%)	18 (18.2%)	<b>28</b> (28.3%)	6 (6.1%)	99 (100.0%)
Referral services	18 (13.7%)	35 (26.7%)	26 (19.9%)	<b>43</b> (32.8%)	9 (6.9%)	131 (100.0%)
Education and training for families about their child's special health care needs	21 (16.0%)	33 (25.2%)	28 (21.4%)	<b>41</b> (31.3%)	8 (6.1%)	131 (100.0%)
Peer-to-peer support	21 (18.1%)	31 (26.7%)	23 (19.8%)	<b>35</b> (30.2%)	6 (5.2%)	116 (100.0%)
Advocacy assistance	22 (16.8%)	36 (27.5%)	23 (17.6%)	<b>39</b> (29.8%)	11 (8.4%)	131 (100.0%)

Bold typeface indicates modal response category.

**Q36. You have indicated that you are aware of at least one *Families Helping Families* service, but that you rarely or never refer clients to these service(s). Why is this? (Select all that apply)**

	<b>Number of Respondents</b>	<b>Percent of Respondents</b>
My clients generally do not need the service(s) they provide	27	32.1%
I don't know enough about the program to make an appropriate referral (ex. eligibility requirements, services provided)	22	26.2%
My clients generally do not fit the eligibility requirements because of age or condition	14	16.7%
Other (specify)	13	15.5%
The service(s) are a duplication of something my program offers	12	14.3%
My clients don't have transportation to get to the program/service(s)	8	9.5%
The service(s) are not available in my clients' area/parish/region	5	6.0%
The agency that provides the service(s) does not accept referrals from my program	4	4.8%
The wait time for an appointment is long	3	3.6%
Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)	3	3.6%
The service(s) are not covered by Medicaid	2	2.4%
Our reporting requirements don't allow us to refer to the program and/or service(s)	0	0.0%
<b>Total responses (total respondents)</b>	<b>113 (84)</b>	

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100. Results include respondents that indicated they are aware of at least one service listed in question 34 and indicated that they rarely or never refer clients to those services in question 35. A total of 123 respondents skipped this question.

<b>Other</b>	<b>Number of Responses</b>
We call for education advocacy whenever a client needs it and they always help	1
I have only had a few instances where I needed to make referrals	1
Feedback from families is that they do not always get very good results	1
Clients decline referrals	1
We have a small caseload	1
Client would need to apply on their own	1
I am fairly new and still learning.	1
Referrals needed are usually identified by one of our FHF staff	1
Families are mostly already aware and have been in contact with them	1
The program is not marketed enough?	1
No barriers	1
<b>Total</b>	<b>11</b>

## Appendix A: Agency Survey

### Children's Special Health Services Program: 2010 Statewide Needs Assessment

*The Louisiana Office of Public Health Maternal and Child Health Program and Children's Special Health Services (CSHS) Program are conducting a statewide needs assessment to learn more about the agencies that provide services in Louisiana for children and adolescents with special health care needs.*

*All answers to the questions are **STRICTLY CONFIDENTIAL AND ANONYMOUS**. Your name or contact information will not be linked in any way to the answers you provide. Your feedback will help programs meet the needs of children and families.*

*If you have any questions about this survey, please feel free to contact Carrie at The Policy & Research Group at (504) 865-1545.*

1. In which parish(es) do you work? (*Select all that apply*)
2. Which of the following best describes your professional position at your agency/organization?
  - a. Medical professional (e.g., nurse, personal care attendant, nutritionist, hearing/language professional, OT/PT, etc.)
  - b. Social services professional (e.g., social service counselor, social worker, behavioral professional, etc.)
  - c. Other professional (e.g., parent liaison, vocational trainer/counselor, health educator, etc.)
3. Do you provide direct services for children, youth (up through 21 years old), and/or their families through your agency?

When we say direct services, we mean: A face to face visit with a client where you, and/or your organization provide social, medical, and/or supportive care for children, youth, and/or their families.

- a. Yes
- b. No (*Respondent is ineligible to complete the survey*)

**3a.** Children and Youth with Special Health Care Needs (CYSHCN) are defined by the Maternal and Child Health Bureau as: *Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*

Do you provide direct services for CYSHCN and/or their families through your agency?

- a. Yes
- b. No

**RESPONDENTS ARE BRANCHED BASED ON QUESTION 3.**

4. Children and youth sometimes require many different services to address complex needs. We would like to learn about the common ways staff become familiar with other programs. How do you learn about other agencies or programs that provide services that your clients could benefit from using? *(Select all that apply)*

- a. Trainings through work
- b. Personal contacts
- c. Word of mouth
- d. From clients
- e. Internet
- f. Other (specify): \_\_\_\_\_
- g. N/A - I do not need information about other programs and services to do my job

5. For which program do you work?

- a. OCDD – Early Steps
- b. OCDD – Supports and Services Center
- c. OCDD – Resource Centers on Developmental Disabilities
- d. OPH - Hearing, Speech and Vision
- e. OPH – Children’s Special Health Services
- f. LRS – Independent Living Program
- g. LRS – Vocational Rehabilitation Program
- h. OCS – Family Services
- i. OCS – Foster Care
- j. Families Helping Families

As a representative of your program, we would like you to think generally about the program where you work and how much it collaborates with other programs that provide services to children and youth that may have special health care needs.

6. Thinking about collaboration with other programs **in the past 12 months**, on a scale of 1 to 10, how effective do you think overall collaboration between programs is in meeting the needs of your program’s clients and families?

Very ineffective    1   2   3   4   5   6   7   8   9   10    Very effective

7. Below are descriptions of levels of collaboration that can happen between two programs. For each of the programs listed at the bottom of the page, please choose the level of collaboration that you feel best describes how **your program as a whole** has collaborated with that program in the **past 12 months**.

**Remember to skip the row for your program.**



**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

	No collaboration or don't know	Networking	Cooperation	Coordination	Coalition	Collaboration
OCDD – Early Steps	0	1	2	3	4	5
OCDD – Supports and Services Center	0	1	2	3	4	5
OCDD – Resource Centers on Developmental Disabilities	0	1	2	3	4	5
OPH – Hearing, Speech, and Vision	0	1	2	3	4	5
OPH – Children's Special Health Services	0	1	2	3	4	5
LRS – Independent Living Program	0	1	2	3	4	5
LRS – Vocational Rehabilitation Program	0	1	2	3	4	5
OCS – Family Care and/or Foster Services	0	1	2	3	4	5
Families Helping Families	0	1	2	3	4	5

8. Below is a list of barriers that can happen when programs try to collaborate. Please choose the **TOP FIVE** barriers listed below that you feel **your program** has experienced **in the past 12 months** when trying to collaborate with other programs in order to meet the needs of clients/families.

Rank the five barriers in order from 1 to 5, where **1 is the biggest barrier** your program faces in its efforts at collaboration.

Please choose each number 1 through 5 only once and leave the rest blank.

Barrier	Top five barriers (option button to select and rank five)
Services that my clients need are not available	
Lack of knowledge of services provided by other programs	
Client/family needs are complex and it is difficult to coordinate needed services	
Lack of communication between programs	
Funding issues related to Medicaid/health insurance	
Complex eligibility requirements for programs/services	
Agencies have differing methods of serving clients/families	
Shortage of staff; high workload/caseload	
Shortage of services in rural areas	
Lack of transportation for clients to get to program/services	
Providers/physicians do not know how or where to refer CYSCHN to programs/services	
State or federal reporting requirements limit ability to collaborate	
Confidentiality or legal issues (e.g. HIPAA/FERPA requirements)	
My program does not have a form that captures all client/family needs and services that would allow me to easily communicate this with other program staff.	
Other (specify) _____	

Now we would like you to think about your experiences on a more individual level. The next questions are going to ask about your own level of awareness of other programs and how often you refer clients to those programs.

9. To begin, please select all of the programs listed below that you know offer services for children and/or youth that may have special health care needs. Please skip your program. (*Select all that apply*)

- a. OCDD – Early Steps
- b. OCDD – Supports and Services Center
- c. OCDD – Resource Centers on Developmental Disabilities
- d. OPH - Hearing, Speech, and Vision
- e. OPH – Children’s Special Health Services
- f. LRS – Independent Living Program
- g. LRS – Vocational Rehabilitation Program
- h. OCS – Family Services and/or Foster Care
- i. Families Helping Families

### **OCDD - Early Steps**

10. *OCDD - Early Steps* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service." When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

11. Then, for those services you marked that you are *SOMEWHAT AWARE*, *AWARE*, or *VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you have referred clients to those services *in the past 12 months*.

Service	Awareness of service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Assistive technology								
Audiology								
Nutrition services								
Occupational and physical therapy								
Psychological services								
Service coordination								
Social work services								
Speech language pathology								
Transportation to and from Early Steps services								
Translation/interpreter services								
Vision services								

12. You have indicated that you are aware of at least one *Early Steps* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

**Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

**Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide
- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements because of age or condition
- l. Other (specify) \_\_\_\_\_

**OCDD – Supports and Services Center**

13. *OCDD – Supports and Services Center* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

14. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Residential or group homes for individuals with developmental disabilities								
Supported independent and extended family living								
Health care services								
Psychological services								
Physical and occupational therapy								
Vocational services								
Speech and language services								

**15.** You have indicated that you are aware of at least one *Supports and Services Center* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

**Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

**Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide
- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements because of age or condition
- l. Other (specify) \_\_\_\_\_

## **OCDD – Resource Centers on Developmental Disabilities**

- 16.** *OCDD – Resource Centers on Developmental Disabilities* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

- 17.** Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Occupational and physical therapy evaluation and treatment								
Nutrition services								
Speech services								
Dental treatment and care								
Psychology community support team								
Wheelchair assessment								

- 18.** You have indicated that you are aware of at least one *Resource Centers on Developmental Disabilities* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

### **Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

### **Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

### **Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide

- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements because of age or condition
- l. Other (specify) \_\_\_\_\_

### **OPH – Hearing, Speech, and Vision**

**19.** *OPH – Hearing, Speech, and Vision* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

**20.** Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
General information on deafness and hearing loss								
Information on communication modalities								
Information on educational opportunities								
Connection with family support groups								

**21.** You have indicated that you are aware of at least one *Hearing, Speech, and Vision* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

#### **Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

#### **Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide
- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements because of age or condition
- l. Other (specify) \_\_\_\_\_

**OPH – Children's Special Health Services**

**22.** *OPH – Children's Special Health Services* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

**23.** Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Medical tests and procedures								
Occupational and physical therapies								
Medical equipment and supplies								
Parent/family support services								
Medications and special diets								
Nursing, nutrition, and social services follow-up								
Care coordination and transition services								



24. You have indicated that you are aware of at least one *Children's Special Health Services* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

**Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

**Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide
- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements because of age or condition
- l. Other (specify) \_\_\_\_\_

**LRS – Independent Living Program**

25. *LRS – Independent Living Program* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

26. Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Counseling								
Mobility training								
Physical rehabilitation								
Provision of needed prosthesis, other applications and devices								
Interpreter and reader services								

Individual and group social and recreational services								
Personal assistance services to help with daily living								

**27.** You have indicated that you are aware of at least one *Independent Living Program* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

**Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

**Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide
- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements
- l. Other (specify) \_\_\_\_\_

**LRS – Vocational Rehabilitation Program**

**28.** *LRS – Vocational Rehabilitation Program* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

**29.** Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Vocational guidance and career counseling								
Evaluation of rehabilitation potential								
Vocational and other training services								
Occupational tools and equipment								
Rehabilitation technology								
Transportation to access other vocational rehabilitation services								

**30.** You have indicated that you are aware of at least one *Vocational Rehabilitation Program* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

**Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

**Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide
- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements because of age or condition
- l. Other (specify) \_\_\_\_\_

## **OCS – Family Services and Foster Care**

- 31.** *OCS – Family Services and Foster Care* programs offer the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

- 32.** Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Temporary care, for a planned period of time, when a child must be separated from his own parents or relatives								
Individualized services that are provided to families and children in their own homes in order to address problems of abuse/neglect and promote the safety of the children within the family unit.								

- 33.** You have indicated that you are aware of at least one *Family Services or Foster Care* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

### **Barriers to access**

- The service(s) are not available in my clients' area/parish/region
- The service(s) are not covered by Medicaid
- My clients don't have transportation to get to the program/service(s)

- d. The wait time for an appointment is long

**Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program  
 f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)  
 g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers  
 i. My clients generally do not need the service(s) they provide  
 j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)  
 k. My clients generally do not fit the eligibility requirements because of age or condition  
 l. Other (specify) \_\_\_\_\_

**Families Helping Families**

- 34.** *Families Helping Families* offers the services listed below. For each service listed, please select the level that best describes your awareness of that service by clicking the appropriate circle under "Awareness of Service."

When we say awareness, we mean such things as: eligibility/enrollment requirements, if there is a waiting list for services, locations for services, etc.

- 35.** Then, for those services you marked that you are *SOMEWHAT AWARE, AWARE, OR VERY AWARE* of, click the circle under "Frequency of Referrals" that best describes how often you currently refer clients to those services *in the past 12 months*.

Service	Awareness of Service				Frequency of Referrals			
	Not aware	Somewhat aware	Aware	Very aware	Never	Rarely	Sometimes	Frequently
Health care financing information								
Referral services								
Education and training for families about their child's special health care needs								
Peer-to-peer support								
Advocacy assistance								

**36.** You have indicated that you are aware of at least one *Families Helping Families* service, but that you rarely or never refer clients to these service(s). Why is this? (*Select all that apply*)

**Barriers to access**

- a. The service(s) are not available in my clients' area/parish/region
- b. The service(s) are not covered by Medicaid
- c. My clients don't have transportation to get to the program/service(s)
- d. The wait time for an appointment is long

**Restrictions on referrals**

- e. The agency that provides the service(s) does not accept referrals from my program
- f. Confidentiality requirements (HIPAA/FERPA) don't allow us to refer clients to these service(s)
- g. Our reporting requirements don't allow us to refer to the program and/or service(s)

**Other barriers**

- h. The service(s) are a duplication of something my program offers
- i. My clients generally do not need the service(s) they provide
- j. I don't know enough about the program to make an appropriate referral (e.g., eligibility requirements, services provided, etc.)
- k. My clients generally do not fit the eligibility requirements because of age or condition
- l. Other (specify) \_\_\_\_\_

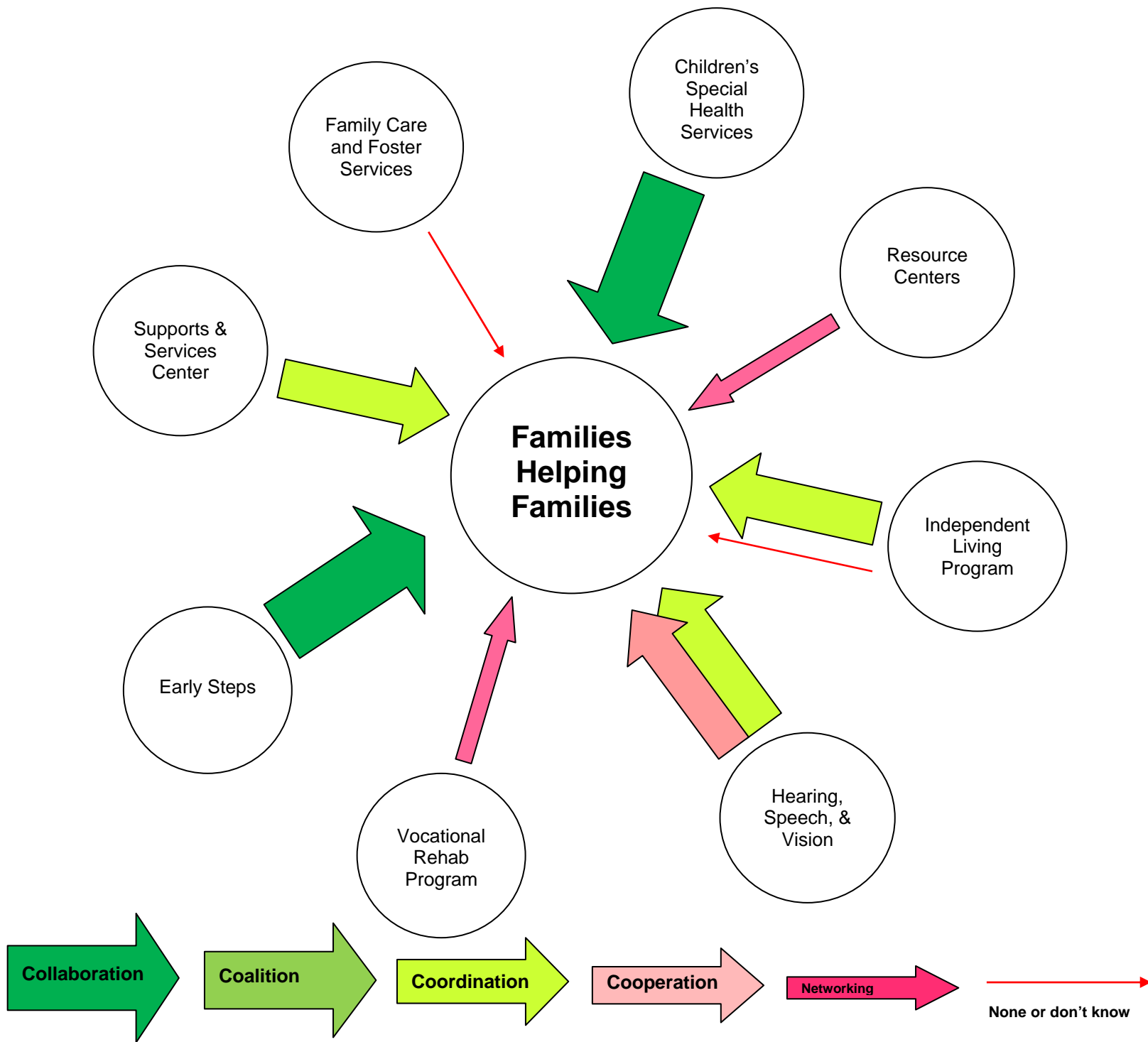
## Appendix B – Levels of Collaboration Diagrams, by Respondent Program of Employment

The following diagrams offer a graphic description of the levels of collaboration as reported by respondents to the *Agency Survey*. Respondents from each of the nine stakeholder programs are asked to rate the level of collaboration that they have with each of the other eight. Their responses are presented visually in the following nine graphics. The agency that is being rated is presented in the center of the graphical diagram; the remaining eight agencies are placed around the rated agency. The arrows visually represent a descriptive account (modal category) of the perceived level of collaboration as reported by all respondents from the eight other agencies.<sup>5</sup> The size and color of the arrow corresponds with the degree of perceived collaboration. Narrow arrows depict a lower level of collaboration and thicker arrows a higher level; a color scale from red (low collaboration) to dark green (high collaboration) reinforce the visual representation. The arrows thus represent the perceived level of collaboration that each program has with the other eight programs. In some cases, usually when there were very few respondents, one program's rating of another may have two or more modal categories – that is, two or more categorical responses are tied as the most frequently identified by respondents. In these cases we include multiple, overlapped arrows to reflect this condition.<sup>6</sup> In these cases data are limited and ratings should be considered indefinite. Nine graphics are presented in which each program is rated by the respondents from the other eight. Detailed descriptions of the levels of collaboration scale (as seen by survey respondents) and the percent for each modal response category are provided on the second page of each diagram.

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<sup>5</sup> The modal category represents a descriptive measure of central tendency. The modal category is the response option that is most frequently selected by respondents. Other such measures include the mean or average. Since the categories are ordinal in nature, the modal category was determined to be the most appropriate descriptive statistic.

<sup>6</sup> It should be noted that several programs had a very small number of respondents; therefore, when results are broken down by respondent program of employment, modal categories may represent the perception of a single respondent.





## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Early Steps:** Collaboration 33% (n=27)

**Children's Special Health Services:** Collaboration 68% (n=40)

**Supports & Services Center:** Coordination 27% (n=22)

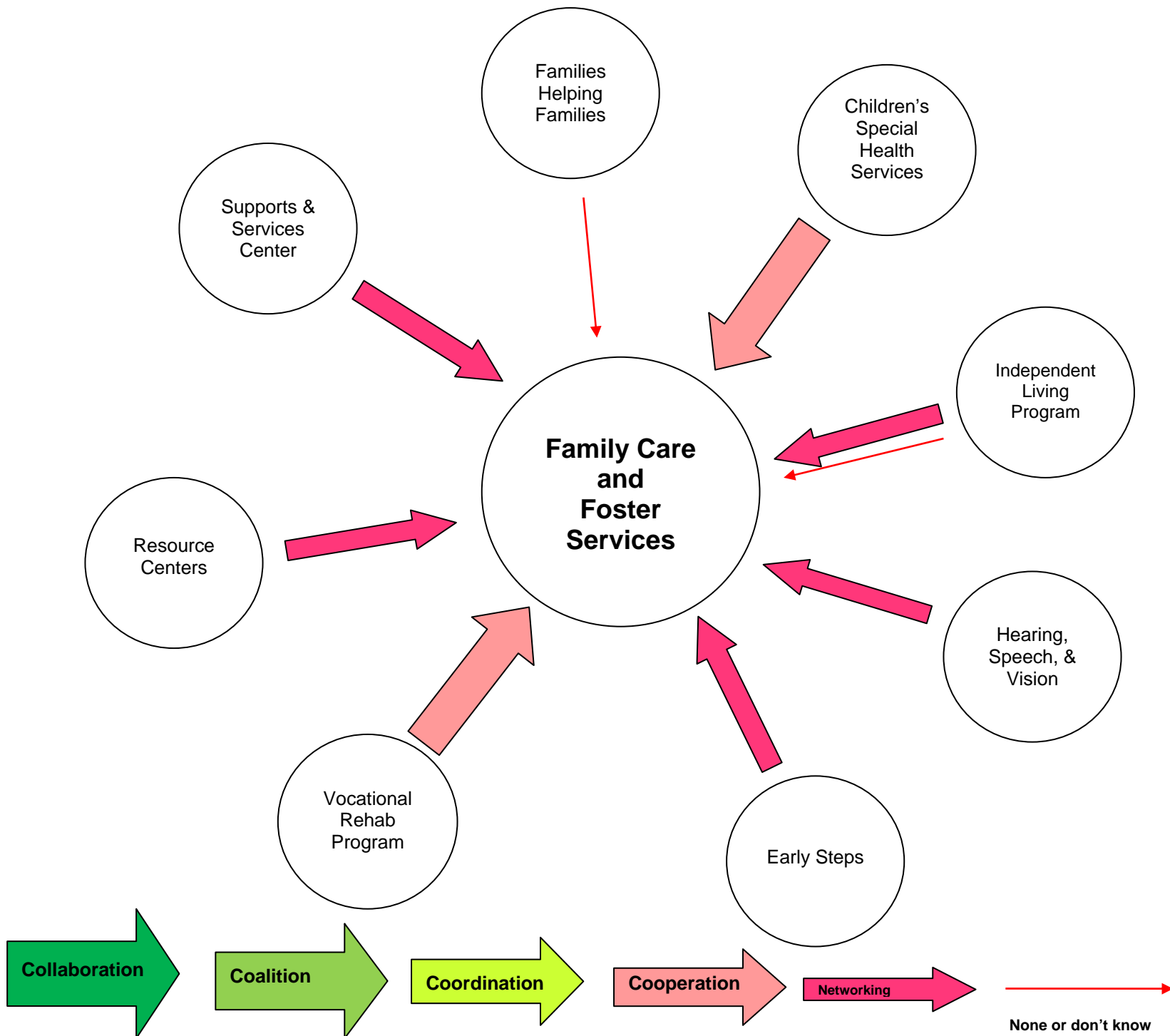
**Hearing, Speech, & Vision:** Cooperation & coordination 50% (n=2)

**Vocational Rehabilitation:** Networking 32% (n=19)

**Resource Centers:** Networking 36% (n=14)

**Independent Living Program:** None & coordination 50% (n=2)

**Family Care and Foster Services:** None or don't know 19% (n=62)



## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Children's Special Health Services:** Cooperation 33% (n=40)

**Vocational Rehabilitation:** Cooperation 47% (n=19)

**Resource Centers:** Networking 36% (n=14)

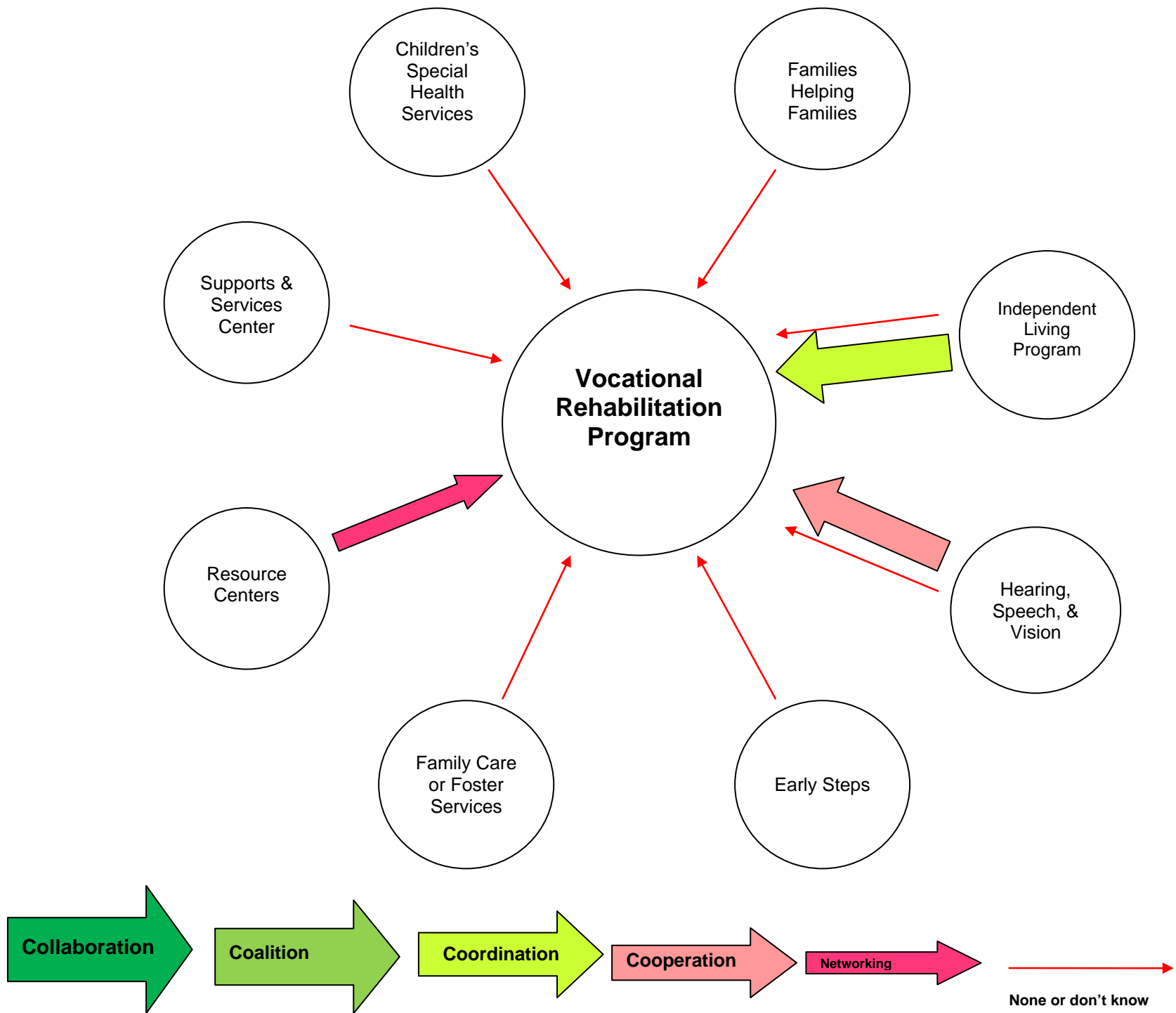
**Hearing, Speech, & Vision:** Networking 100% (n=2)

**Early Steps:** Networking 26% (n=27)

**Supports & Services Center:** Networking 27% (n=22)

**Independent Living Program:** None & networking 50% (n=2)

**Families Helping Families:** None or don't know 33% (n=18)



## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Resource Centers:** Networking 36% (n=14)

**Independent Living Program:** None & coordination 50% (n=2)

**Hearing, Speech, & Vision:** None & cooperation 50% (n=2)

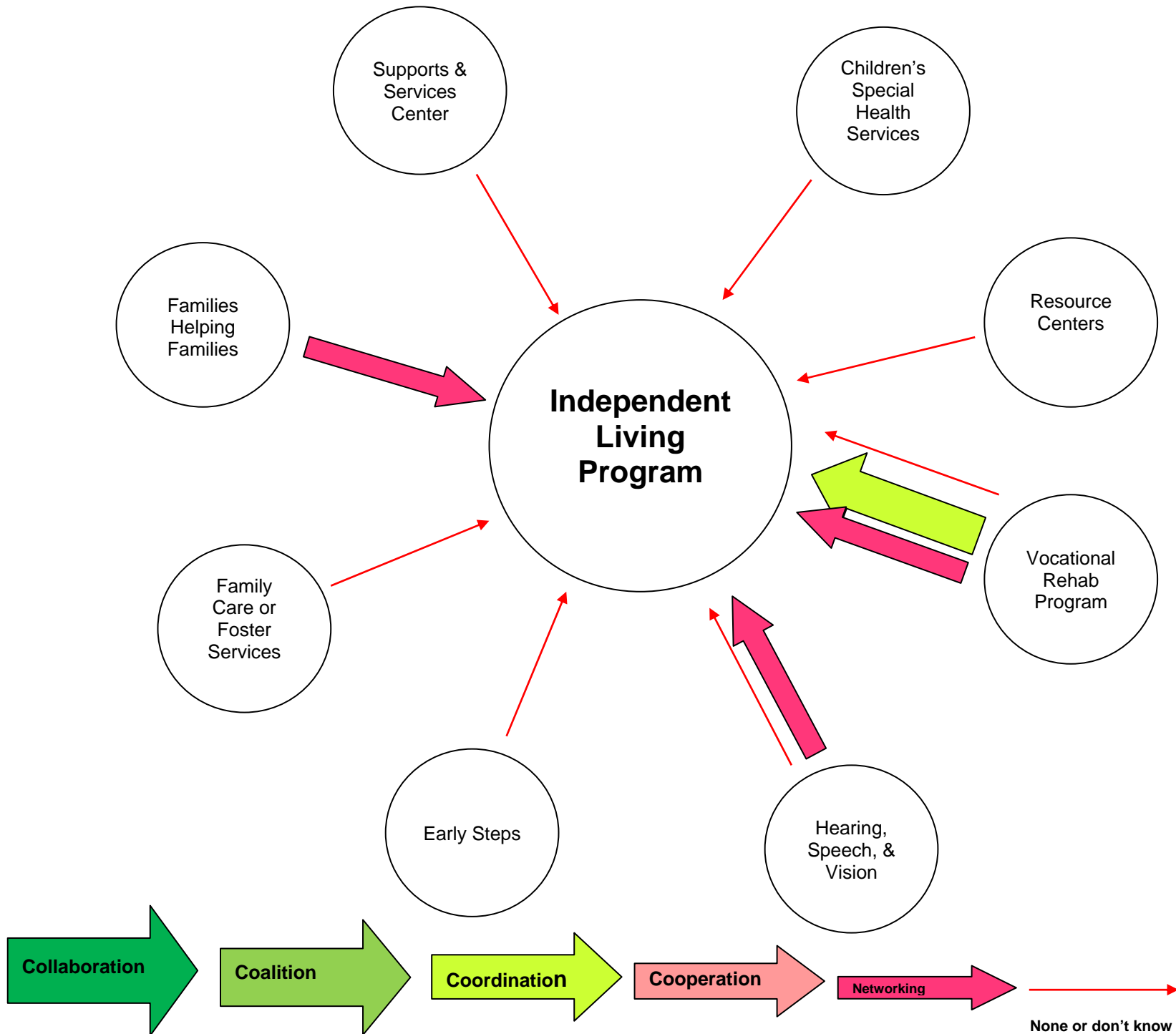
**Early Steps:** None or don't know 78% (n=27)

**Supports & Services Center:** None or don't know 32% (n=22)

**Children's Special Health Services:** None or don't know 25% (n=40)

**Families Helping Families:** None or don't know 33% (n=18)

**Family Care and Foster Services:** None or don't know 34% (n=62)



## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Families Helping Families:** Networking 33% (n=18)

**Vocational Rehabilitation Program:** None, networking, & coordination 21% (n=19)

**Hearing, Speech, & Vision:** None & networking 50% (n=2)

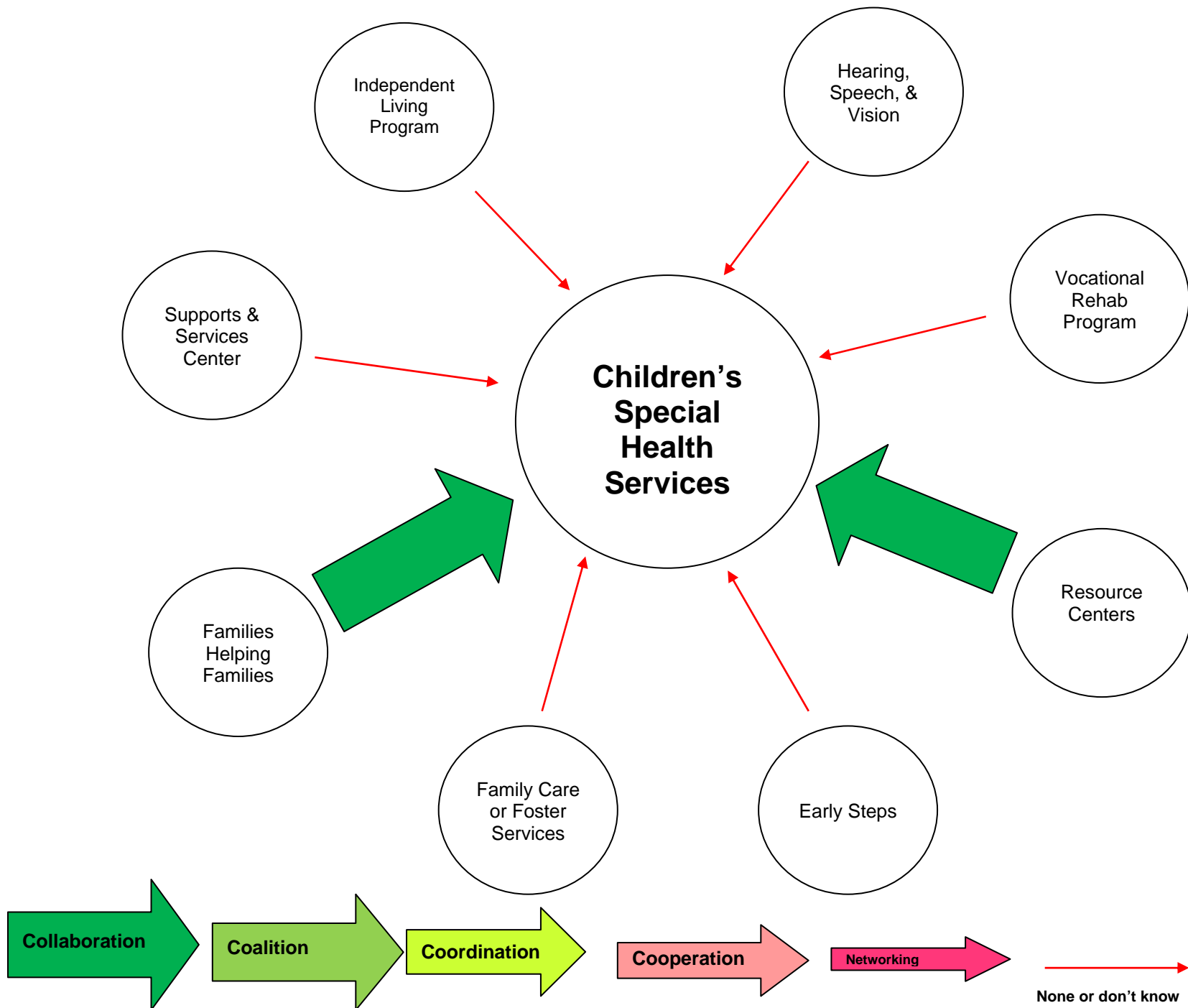
**Early Steps:** None or don't know 78% (n=27)

**Supports & Services Center:** None or don't know 27% (n=22)

**Resource Centers:** None or don't know 50% (n=14)

**Children's Special Health Services:** None or don't know 50% (n=40)

**Family Care and Foster Services:** None or don't know 24% (n=62)





## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Families Helping Families:** Collaboration 61% (n=18)

**Hearing, Speech, & Vision:** Collaboration 100% (n=2)

**Early Steps:** None or don't know 26% (n=27)

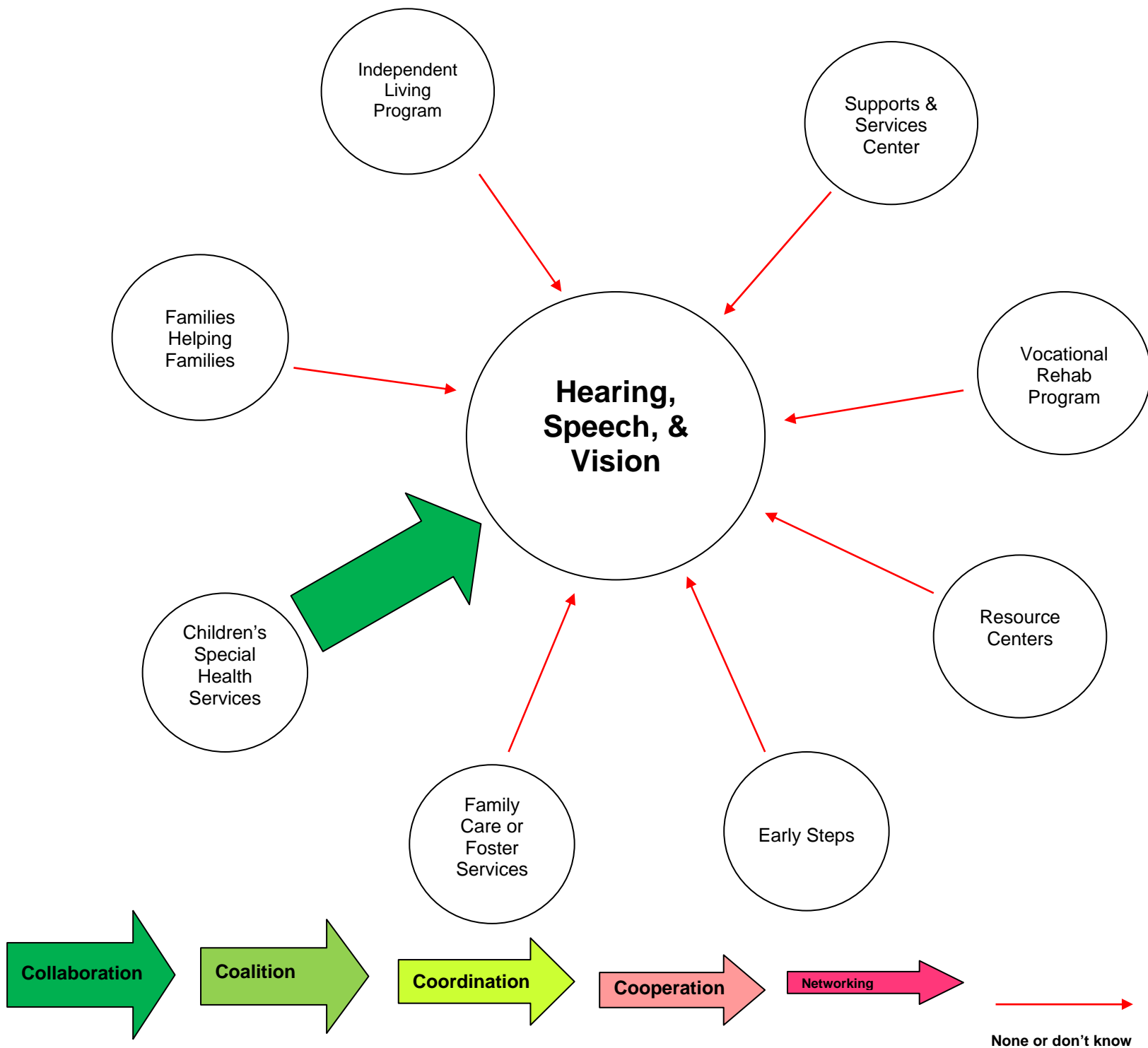
**Supports & Services Center:** None or don't know 50% (n=22)

**Resource Centers:** None or don't know 64% (n=14)

**Independent Living Program:** None or don't know 100% (n=2)

**Vocational Rehabilitation Program:** None or don't know 63% (n=19)

**Family Care and Foster Services:** None or don't know 37% (n=62)



## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Children's Special Health Services:** Collaboration 40% (n=40)

**Early Steps:** None or don't know 33% (n=27)

**Supports & Services Center:** None or don't know 36% (n=22)

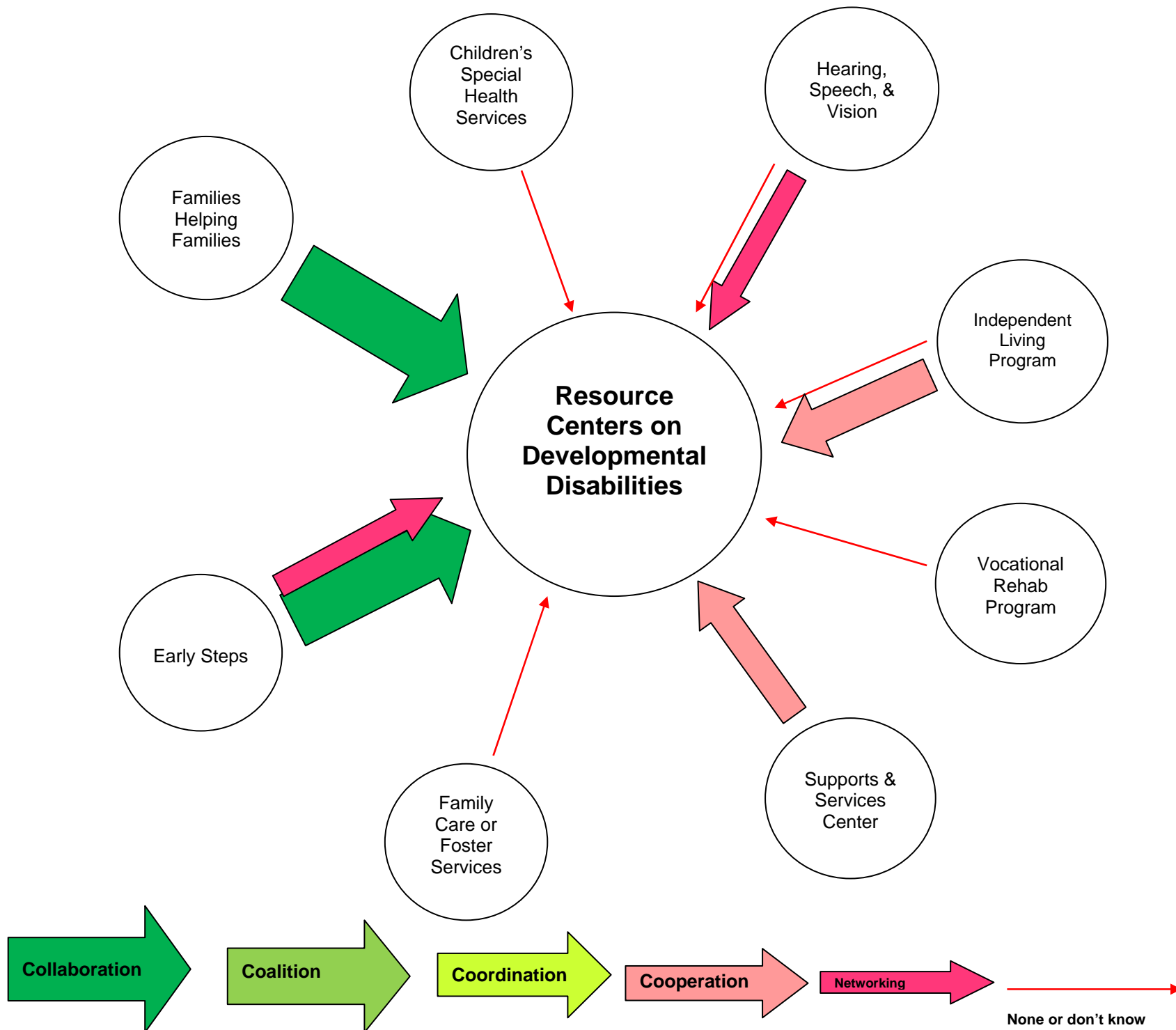
**Resource Centers:** None or don't know 64% (n=14)

**Independent Living Program:** None or don't know 100% (n=2)

**Vocational Rehabilitation Program:** None or don't know 79% (n=19)

**Family Care and Foster Services:** None or don't know 48% (n=62)

**Families Helping Families:** None or don't know 33% (n=18)



## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Families Helping Families:** Collaboration 50% (n=18)

**Early Steps:** Networking & collaboration 22% (n=27)

**Supports & Services Center:** Cooperation 32% (n=22)

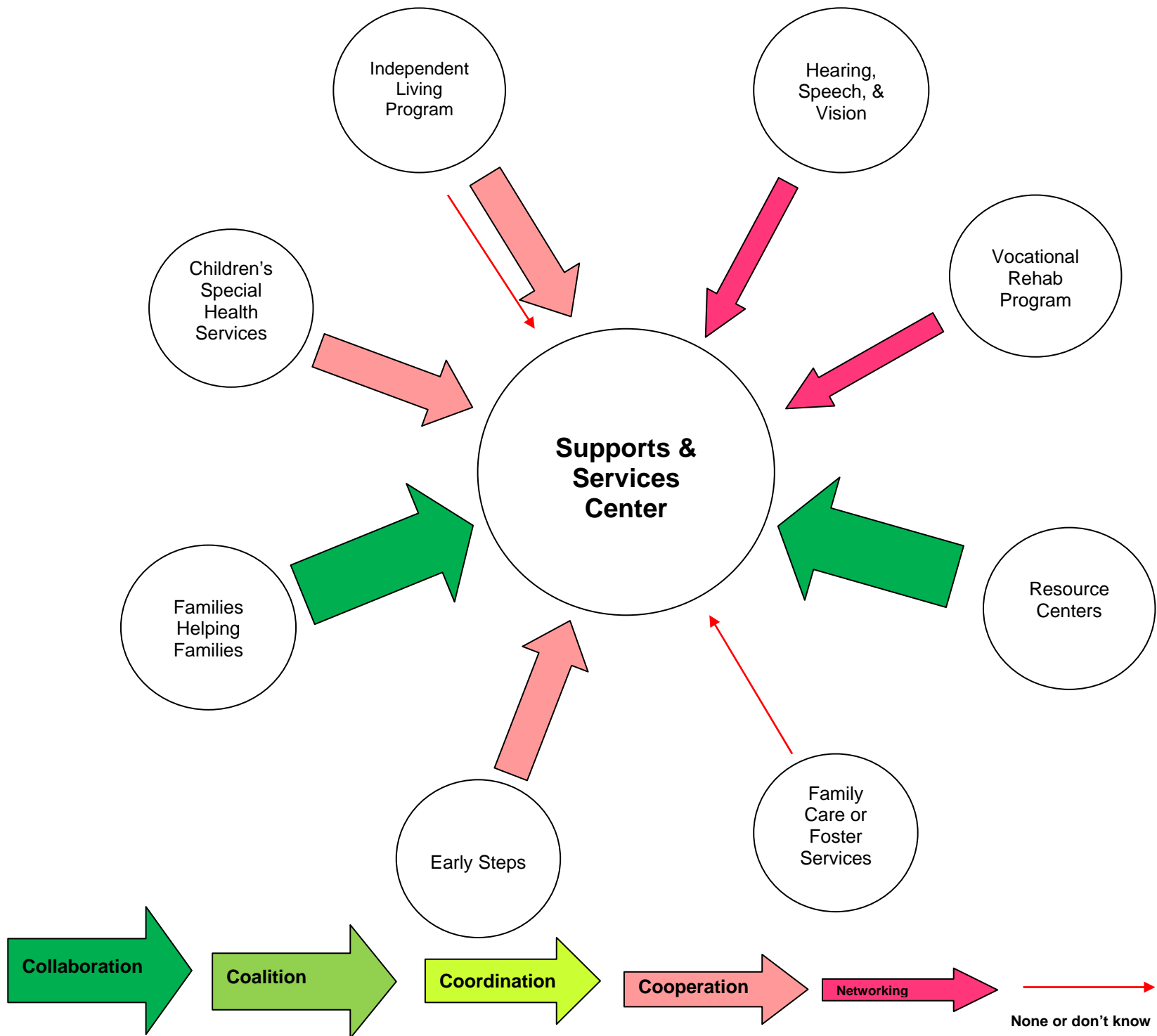
**Independent Living Program:** None & cooperation 50% (n=2)

**Hearing, Speech, & Vision:** None & networking 50% (n=2)

**Children's Special Health Services:** None or don't know 33% (n=40)

**Vocational Rehabilitation Program:** None or don't know 42% (n=19)

**Family Care and Foster Services:** None or don't know 31% (n=62)



## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Resource Centers:** Collaboration 64% (n=14)

**Families Helping Families:** Collaboration 28% (n=18)

**Early Steps:** Cooperation 30% (n=27)

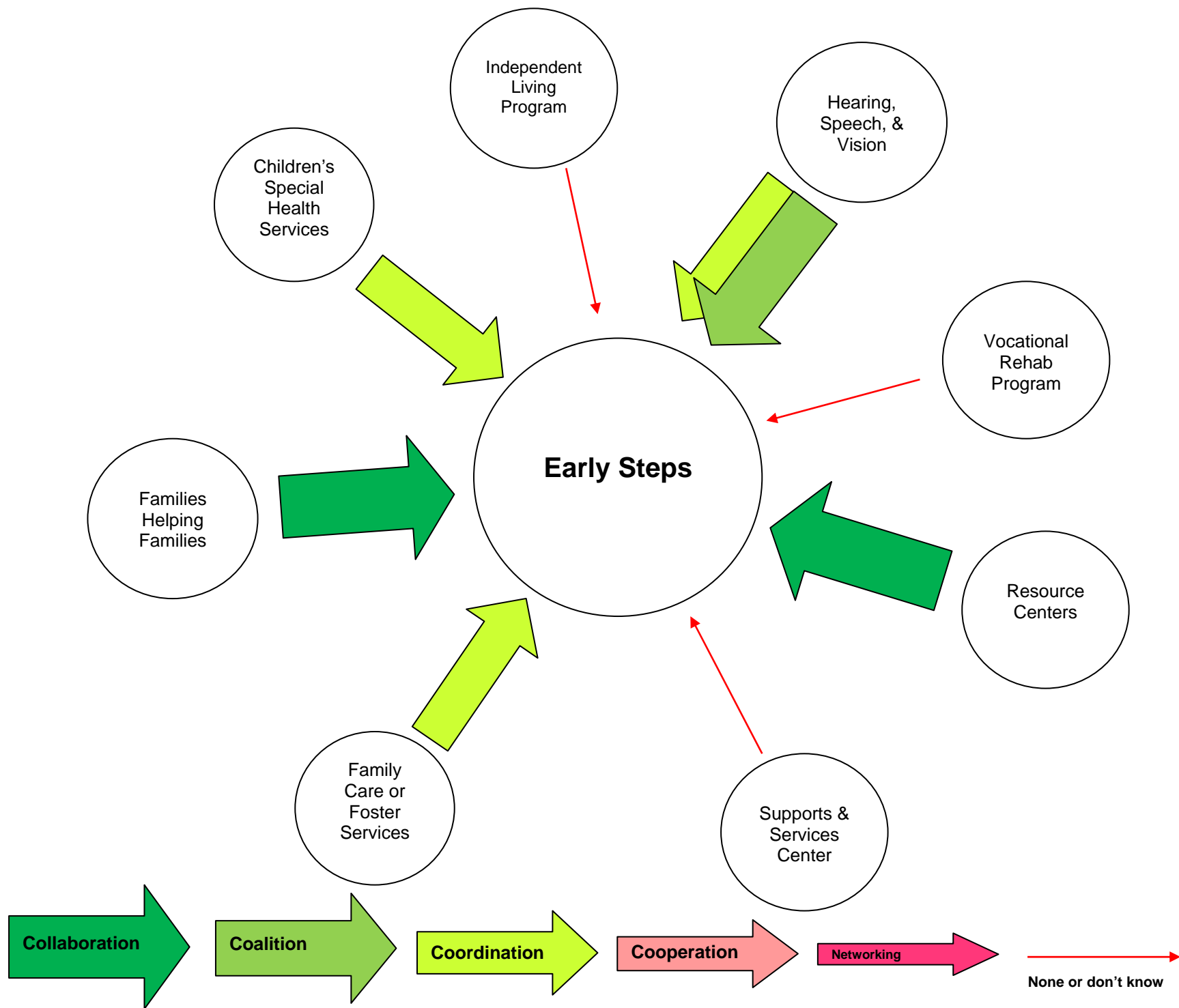
**Children's Special Health Services:** Cooperation 30% (n=40)

**Hearing, Speech, & Vision:** Networking 100% (n=2)

**Vocational Rehabilitation Program:** Networking 42% (n=19)

**Independent Living Program:** None & cooperation 50% (n=2)

**Family Care and Foster Services:** None or don't know 31% (n=62)





## **Levels of Collaboration Descriptions**

**No collaboration or don't know** - There is *no contact* or I am *not aware* of the program.

**1. Networking** - There is *little communication* between my program and theirs. *No referrals* are made and all decisions for clients' care are made *independently*.

**2. Cooperation** - There is *some communication* between my program and theirs. *Few referrals* are made and all decisions for clients' care are made *independently*.

**3. Coordination** - *Communication is frequent* between my program and theirs. *Referrals are made and accepted* and there is *some shared decision making* regarding clients' care.

**4. Coalition** - *Communication is frequent* between my program and theirs. *Referrals are frequently made and accepted* and there is *shared decision making* regarding clients' care.

**5. Collaboration** - *Communication is frequent* and *resources are shared* between my program and theirs. *Referrals are frequently made and accepted* and there is *follow-up communication* after a referral is made. Decisions about clients' care are made *collaboratively* between my program and theirs.

### **Modal Response Categories:**

**Families Helping Families:** Collaboration 39% (n=18)

**Resource Centers:** Collaboration 36% (n=14)

**Hearing, Speech, & Vision:** Coordination & coalition 50% (n=2)

**Family Care and Foster Services:** Coordination 24% (n=62)

**Children's Special Health Services:** Coordination 40% (n=40)

**Supports & Services Center:** None or don't know 36% (n=22)

**Independent Living Program:** None or don't know 100% (n=2)

**Vocational Rehabilitation Program:** None or don't know 89% (n=19)



## Appendix C – Knowledge of Programs that Serve CYSHCN, by Respondent Program of Employment

### Knowledge of Programs that Serve CYSHCN, by Respondent-Identified Program of Employment

**Table 1.** Respondents that Know Early Steps, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Supports and Services Center	19	86.4%	22
Resource Centers on Developmental Disabilities	13	92.8%	14
Hearing, Speech, and Vision	2	100.0%	2
Children's Special Health Services	40	100.0%	40
Independent Living Program	1	50.0%	2
Vocational Rehabilitation Program	11	57.9%	19
Family Services and/or Foster Care	53	85.5%	62
Families Helping Families	17	94.4%	18

**Table 2.** Respondents that Know Supports and Services Center, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	22	81.5%	27
Resource Centers on Developmental Disabilities	11	78.6%	14
Hearing, Speech, and Vision	2	100.0%	2
Children's Special Health Services	32	80.0%	40
Independent Living Program	1	50.0%	2
Vocational Rehabilitation Program	11	57.9%	19
Family Services and/or Foster Care	27	43.5%	62
Families Helping Families	13	72.2%	18

**Table 3.** Respondents that Know Resource Centers on Developmental Disabilities, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	20	74.1%	27
Supports and Services Center	18	81.8%	22
Hearing, Speech, and Vision	1	50.0%	2
Children's Special Health Services	27	67.5%	40
Independent Living Program	1	50.0%	2
Vocational Rehabilitation Program	13	68.4%	19
Family Services and/or Foster Care	41	66.1%	62
Families Helping Families	14	77.8%	18

**Table 4.** Respondents that Know Hearing, Speech, and Vision, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	16	59.3%	27
Supports and Services Center	11	50.0%	22
Resource Centers on Developmental Disabilities	7	50.0%	14
Children's Special Health Services	32	80.0%	40
Independent Living Program	0	0.0%	2
Vocational Rehabilitation Program	5	26.3%	19
Family Services and/or Foster Care	17	27.4%	62
Families Helping Families	14	77.8%	18

**Table 5.** Respondents that Know Children's Special Health Services, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	21	77.7%	27
Supports and Services Center	14	63.6%	22
Resource Centers on Developmental Disabilities	8	57.1%	14
Hearing, Speech, and Vision	2	100.0%	2
Independent Living Program	0	0.0%	2
Vocational Rehabilitation Program	10	52.6%	19
Family Services and/or Foster Care	20	32.3%	62
Families Helping Families	16	88.9%	18

**Table 6.** Respondents that Know Independent Living Program, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	8	29.6%	27
Supports and Services Center	6	27.3%	22
Resource Centers on Developmental Disabilities	5	35.7%	14
Hearing, Speech, and Vision	0	0.0%	2
Children's Special Health Services	24	60.0%	40
Vocational Rehabilitation Program	5	26.3%	19
Family Services and/or Foster Care	36	58.1%	62
Families Helping Families	8	44.4%	18

**Table 7.** Respondents that Know Vocational Rehabilitation Program, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	6	22.2%	27
Supports and Services Center	5	22.7%	22
Resource Centers on Developmental Disabilities	5	35.7%	14
Hearing, Speech, and Vision	1	50.0%	2
Children's Special Health Services	35	87.5%	40
Independent Living Program	1	50.0%	2
Family Services and/or Foster Care	36	58.1%	62
Families Helping Families	11	61.1%	18

**Table 8.** Respondents that Know Family Services and/or Foster Care, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	23	85.2%	27
Supports and Services Center	14	63.6%	22
Resource Centers on Developmental Disabilities	13	92.9%	14
Hearing, Speech, and Vision	2	100.0%	2
Children's Special Health Services	30	75.0%	40
Independent Living Program	1	50.0%	2
Vocational Rehabilitation Program	17	89.5%	19
Families Helping Families	13	72.2%	18

**Table 9.** Respondents that Know Families Helping Families, by Program of Employment

	<b>Number of Respondents</b>	<b>Percent</b>	<b>Total Respondents</b>
Early Steps	24	88.9%	27
Supports and Services Center	16	72.7%	22
Resource Centers on Developmental Disabilities	14	100.0%	14
Hearing, Speech, and Vision	2	100.0%	2
Children's Special Health Services	40	100.0%	40
Independent Living Program	1	50.0%	2
Vocational Rehabilitation Program	16	84.2%	19
Family Services and/or Foster Care	40	64.5%	62

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
<u>COMMUNITY-BASED RESOURCES</u>						
F2FHIC	75.1	17.2	4.5	0.5	2.6	2.6
SICC	74.6	18.7	2.9	0.5	3.4	2.8
SIBSHOPS	74.2	19.1	3.6	0.0	3.1	2.6
LBPAO	73.7	15.8	6.7	1.2	2.6	2.6
LOUISIANA PLANNING COUNCIL ON DD	72.7	18.2	4.3	1.9	2.9	2.8
RESIDENTAL OPTIONS WAIVER	72.2	16.3	2.9	1.0	7.7	2.6
BCSS	70.7	14.4	10.3	1.4	3.1	2.8
SUPPORTS WAIVER	69.3	15.1	6.7	1.0	7.9	2.8
NEW OPPORTUNITIES WAIVER	67.6	13.7	9.8	1.0	7.9	2.8
COMMUNITY SUPPORT TEAMS	67.0	17.6	8.7	1.2	5.5	3.3
TH&SC INJURY TRUST	65.9	24.9	3.1	0.7	5.3	2.8
EXTENDED FAMILY LIVING	65.9	20.4	6.5	0.7	6.5	2.8
INTERMEDIATE CARE DD	65.6	23.7	5.0	1.0	4.8	2.6
LA PARENT TRAINING INFORMATION CENTERS	64.8	21.4	9.9	0.2	3.6	3.3
PEER PARENT TRAINING	64.7	26.6	3.6	0.2	4.8	2.8
COMMISSION FOR THE DEAF	64.3	25.9	2.6	1.0	6.2	2.8
BIRTH DEFECTS MONITORING NETWORK	63.6	27.0	3.3	0.7	5.3	2.6
RESOURCE CENTERS	62.2	16.5	16.0	1.2	4.1	2.6
CHILDREN'S CHOICE WAIVER	61.9	13.7	15.6	0.5	8.4	2.8
CSHS CARE COORDINATION & TRANSITION	61.7	18.4	15.6	1.0	3.3	2.6
SUPPORTED LIVING	61.6	22.5	7.2	1.0	7.7	2.8
CRISIS MANAGEMENT SERVICES	61.0	29.9	3.3	1.9	3.8	2.6
VOCATIONAL REHABILITATION	58.6	25.1	7.9	2.6	5.7	2.6
PEER SUPPORT GROUP	57.3	27.1	10.3	1.0	4.3	2.8
LONG TERM PERSONAL CARE SERVICES	57.3	26.9	7.4	1.0	7.4	2.8
MENTAL HEALTH REHABILITATION SERVICES	56.9	28.8	7.1	1.7	5.5	2.1
INDEPENDENT LIVING PROGRAM	56.7	30.4	4.8	0.0	8.1	2.6
ADULT DAY HEALTH CARE WAIVER	56.5	32.5	3.1	1.4	6.5	2.6
CASH SUBSIDY	55.5	13.5	19.2	2.2	9.6	3.0
ELDERLY & DISABLED ADULTS WAIVER	55.2	34.1	3.8	0.2	6.7	2.8
INDEPENDENT LIVING	54.3	31.8	5.3	0.7	7.9	2.6
SUPPORT SERVICES	53.2	23.0	15.6	1.7	6.5	2.8
BLIND SERVICES	53.0	34.6	3.3	0.5	8.6	2.3
INDIVIDUAL AND FAMILY SUPPORT	52.6	20.1	18.9	2.4	6.0	2.6
EARLY CHILDHOOD SUPPORT SERVICES	51.7	26.8	12.7	1.2	7.7	2.6
RESPIRE CARE/SERVICES	51.1	23.1	18.6	2.3	5.0	48.5
ASSISTIVE TRANSPORTATION	51.1	29.3	11.0	2.2	6.5	2.8
DURABLE MEDICAL EQUIPMENT	49.2	23.3	19.9	2.2	5.5	2.8
CSHS SUBSPECIALITY CLINICS	49.0	15.6	30.1	1.2	4.1	2.6
HEARING, SPEECH & VISION	45.9	22.0	26.8	1.0	4.3	2.6
FOSTER CARE SERVICES	42.9	44.1	4.6	0.7	7.7	2.8
CHILD CARE ASSISTANCE PROGRAM	37.5	32.7	16.7	1.7	11.5	2.3
EARLY STEPS	36.2	27.6	28.1	1.4	6.7	2.8
DISABILITIES DETERMINATION SERVICES/SSI	26.7	13.6	46.1	2.4	11.2	2.3
HEAD START	24.2	41.7	22.1	1.4	10.6	2.8
WIC NUTRITIONAL ASSISTANCE PROGRAM	22.0	27.8	41.9	1.2	7.2	2.6
MEDICAID	15.3	10.3	68.1	1.9	4.3	2.8
FOOD STAMPS	12.0	20.1	47.4	2.9	17.7	2.6

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
<u>CSHCN: COMMUNITY-BASED RESOURCES</u>						
F2FHIC	79.9	13.7	3.4	0.5	2.5	2.9
SICC	79.4	13.2	2.9	0.5	3.9	2.9
SIBSHOPS	80.4	13.7	2.9	0.0	2.9	2.9
LBPAO	78.4	12.7	5.9	0.5	2.5	2.9
LOUISIANA PLANNING COUNCIL ON DD	77.0	14.7	3.4	1.5	3.4	2.9
RESIDENTAL OPTIONS WAIVER	74.0	13.7	2.0	1.0	9.9	2.9
BCSS	76.0	11.8	8.3	0.5	3.4	2.9
SUPPORTS WAIVER	74.0	12.7	2.9	1.0	9.3	2.9
NEW OPPORTUNITIES WAIVER	74.5	10.8	3.9	1.0	9.8	2.9
COMMUNITY SUPPORT TEAMS	70.8	15.3	7.4	0.5	5.9	3.8
TH&SC INJURY TRUST	71.6	21.6	1.5	0.5	4.9	2.9
EXTENDED FAMILY LIVING	71.9	15.3	4.9	0.5	7.4	3.3
INTERMEDIATE CARE DD	72.5	19.1	4.4	1.0	2.9	2.9
LA PARENT TRAINING INFORMATION CENTERS	72.4	14.8	9.4	0.0	3.4	3.3
PEER PARENT TRAINING	73.0	19.6	2.9	0.0	4.4	2.9
COMMISION FOR THE DEAF	68.1	24.5	1.0	0.5	5.9	2.9
BIRTH DEFECTS MONITORING NETWORK	69.6	21.6	2.5	1.0	5.4	2.9
RESOURCE CENTERS	64.7	12.7	17.2	1.0	4.4	2.9
CHILDREN'S CHOICE WAIVER	66.2	8.3	14.2	1.0	10.3	2.9
CSHS CARE COORDINATION & TRANSITION	64.7	16.7	15.2	0.0	3.4	2.9
SUPPORTED LIVING	65.5	20.7	4.9	0.5	8.4	3.3
CRISIS MANAGEMENT SERVICES	64.7	27.0	1.5	2.0	4.9	2.9
VOCATIONAL REHABILITATION	61.3	25.0	6.4	2.5	4.9	2.9
PEER SUPPORT GROUP	64.2	20.1	11.3	1.0	3.4	2.9
LONG TERM PERSONAL CARE SERVICES	61.1	25.6	4.4	0.0	8.9	3.3
MENTAL HEALTH REHABILITATION SERVICES	64.9	22.9	6.3	1.5	4.4	2.4
INDEPENDENT LIVING PROGRAM	62.3	24.5	4.9	0.0	8.3	2.9
ADULT DAY HEALTH CARE WAIVER	55.4	34.3	1.5	1.5	7.4	2.9
CASH SUBSIDY	58.1	10.3	18.2	1.0	12.3	3.3
ELDERLY & DISABLED ADULTS WAIVER	54.4	37.7	2.0	0.0	5.9	2.9
INDEPENDENT LIVING	58.3	27.9	4.4	0.5	8.8	2.9
SUPPORT SERVICES	56.4	21.1	13.7	1.0	7.8	2.9
BLIND SERVICES	57.6	29.8	3.4	0.0	9.3	2.4
INDIVIDUAL AND FAMILY SUPPORT	56.9	14.2	18.6	1.5	8.8	2.9
EARLY CHILDHOOD SUPPORT SERVICES	56.4	17.6	17.2	1.0	7.8	2.9
RESPIRE CARE/SERVICES	56.9	16.5	17.4	1.8	7.3	48.1
ASSISTIVE TRANSPORTATION	54.4	27.0	8.3	3.4	6.9	2.9
DURABLE MEDICAL EQUIPMENT	53.2	20.2	18.7	2.5	5.4	3.3
CSHS SUBSPECIALITY CLINICS	52.5	12.3	31.4	0.5	3.4	2.9
HEARING, SPEECH & VISION	48.0	17.2	31.4	1.0	2.5	2.9
FOSTER CARE SERVICES	43.1	43.1	4.4	1.0	8.3	2.9
CHILD CARE ASSISTANCE PROGRAM	35.6	27.3	20.0	2.0	15.1	2.4
EARLY STEPS	24.1	22.2	43.8	2.0	7.9	3.3
DISABILITIES DETERMINATION SERVICES/SSI	24.9	10.5	49.8	2.4	12.7	2.4
HEAD START	22.1	35.3	28.4	2.0	12.3	2.9
WIC NUTRITIONAL ASSISTANCE PROGRAM	16.2	20.6	54.4	1.5	7.4	2.9
MEDICAID	12.7	6.4	74.0	2.5	4.4	2.9
FOOD STAMPS	8.8	16.6	52.7	4.4	17.6	2.4



	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
<u>YSHCN: COMMUNITY-BASED RESOURCES</u>						
F2FHIC	70.6	20.6	5.6	0.5	2.8	2.3
SICC	70.0	23.9	2.8	0.5	2.8	2.7
SIBSHOPS	68.2	24.3	4.2	0.0	3.3	2.3
LBPAO	69.2	18.7	7.5	1.9	2.8	2.3
LOUISIANA PLANNING COUNCIL ON DD	68.5	21.6	5.2	2.3	2.3	2.7
RESIDENTAL OPTIONS WAIVER	70.6	18.7	3.7	0.9	6.1	2.3
BCSS	65.7	16.9	12.2	2.3	2.8	2.7
SUPPORTS WAIVER	64.8	17.4	10.3	0.9	6.6	2.7
NEW OPPORTUNITIES WAIVER	61.0	16.4	15.5	0.9	6.1	2.7
COMMUNITY SUPPORT TEAMS	63.4	19.7	9.9	1.9	5.2	2.7
TH&SC INJURY TRUST	60.6	28.2	4.7	0.9	5.6	2.7
EXTENDED FAMILY LIVING	60.3	25.2	7.9	0.9	5.6	2.3
INTERMEDIATE CARE DD	58.9	28.0	5.6	0.9	6.5	2.3
LA PARENT TRAINING INFORMATION CENTERS	57.5	27.8	10.4	0.5	3.8	3.2
PEER PARENT TRAINING	56.8	33.3	4.2	0.5	5.2	2.7
COMMISSION FOR THE DEAF	60.6	27.2	4.2	1.4	6.6	2.7
BIRTH DEFECTS MONITORING NETWORK	57.9	32.2	4.2	0.5	5.1	2.3
RESOURCE CENTERS	59.8	20.1	15.0	1.4	3.7	2.3
CHILDREN'S CHOICE WAIVER	57.7	18.8	16.9	0.0	6.6	2.7
CSHS CARE COORDINATION & TRANSITION	58.9	20.1	15.9	1.9	3.3	2.3
SUPPORTED LIVING	57.9	24.3	9.3	1.4	7.0	2.3
CRISIS MANAGEMENT SERVICES	57.5	32.7	5.1	1.9	2.8	2.3
VOCATIONAL REHABILITATION	56.1	25.2	9.3	2.8	6.5	2.3
PEER SUPPORT GROUP	50.7	33.8	9.4	0.9	5.2	2.7
LONG TERM PERSONAL CARE SERVICES	53.7	28.0	10.3	1.9	6.1	2.3
MENTAL HEALTH REHABILITATION SERVICES	49.3	34.4	7.9	1.9	6.5	1.8
INDEPENDENT LIVING PROGRAM	51.4	36.0	4.7	0.0	7.9	2.3
ADULT DAY HEALTH CARE WAIVER	57.5	30.8	4.7	1.4	5.6	2.3
CASH SUBSIDY	53.1	16.4	20.2	3.3	7.0	2.7
ELDERLY & DISABLED ADULTS WAIVER	55.9	30.5	5.6	0.5	7.5	2.7
INDEPENDENT LIVING	50.5	35.5	6.1	0.9	7.0	2.3
SUPPORT SERVICES	50.2	24.9	17.4	2.3	5.2	2.7
BLIND SERVICES	48.6	39.3	3.3	0.9	7.9	2.3
INDIVIDUAL AND FAMILY SUPPORT	48.6	25.7	19.2	3.3	3.3	2.3
EARLY CHILDHOOD SUPPORT SERVICES	47.2	35.5	8.4	1.4	7.5	2.3
RESPIRE CARE/SERVICES	45.5	29.5	19.6	2.7	2.7	48.9
ASSISTIVE TRANSPORTATION	47.9	31.5	13.6	0.9	6.1	2.7
DURABLE MEDICAL EQUIPMENT	45.3	26.2	21.0	1.9	5.6	2.3
CSHS SUBSPECIALTY CLINICS	45.8	18.7	29.0	1.9	4.7	2.3
HEARING, SPEECH & VISION	43.9	26.6	22.4	0.9	6.1	2.3
FOSTER CARE SERVICES	42.7	45.1	4.7	0.5	7.0	2.7
CHILD CARE ASSISTANCE PROGRAM	39.3	37.9	13.6	1.4	7.9	2.3
EARLY STEPS	47.7	32.7	13.1	0.9	5.6	2.3
DISABILITIES DETERMINATION SERVICES/SSI	28.5	16.8	42.5	2.3	9.8	2.3
HEAD START	26.3	47.9	16.0	0.9	8.9	2.7
WIC NUTRITIONAL ASSISTANCE PROGRAM	27.6	34.6	29.9	0.9	7.0	2.3
MEDICAID	17.8	14.1	62.4	1.4	4.2	2.7
FOOD STAMPS	15.0	23.5	42.3	1.4	17.8	2.7

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
<u>AA/BLACK: COMMUNITY-BASED RESOURCES</u>						
F2FHIC	77.5	15.3	3.3	1.0	2.9	2.3
SICC	77.4	15.4	3.4	0.5	3.4	2.8
SIBSHOPS	76.6	16.7	3.8	0.0	2.9	2.3
LBPAO	73.7	13.4	7.7	1.0	4.3	2.3
LOUISIANA PLANNING COUNCIL ON DD	73.6	15.4	4.3	2.4	4.3	2.8
RESIDENTAL OPTIONS WAIVER	75.6	13.4	3.8	1.4	5.7	2.3
BCSS	70.2	10.6	13.5	1.9	3.8	2.8
SUPPORTS WAIVER	71.6	13.5	7.7	1.4	5.8	2.8
NEW OPPORTUNITIES WAIVER	69.2	12.0	12.0	1.4	5.3	2.8
COMMUNITY SUPPORT TEAMS	68.1	16.9	8.2	1.4	5.3	3.3
TH&SC INJURY TRUST	67.8	21.2	3.8	1.4	5.8	2.8
EXTENDED FAMILY LIVING	66.3	17.8	8.2	1.0	6.7	2.8
INTERMEDIATE CARE DD	64.6	21.5	6.7	1.4	5.7	2.3
LA PARENT TRAINING INFORMATION CENTERS	68.0	18.9	8.7	0.5	3.9	3.7
PEER PARENT TRAINING	68.8	23.6	3.4	0.0	4.3	2.8
COMMISION FOR THE DEAF	70.7	18.8	2.9	1.0	6.7	2.8
BIRTH DEFECTS MONITORING NETWORK	67.5	21.5	4.8	0.5	5.7	2.3
RESOURCE CENTERS	66.0	12.9	15.8	1.4	3.8	2.3
CHILDREN'S CHOICE WAIVER	63.5	12.5	16.8	0.5	6.7	2.8
CSHS CARE COORDINATION & TRANSITION	61.2	17.2	15.8	0.5	5.3	2.3
SUPPORTED LIVING	61.5	19.2	9.6	1.4	8.2	2.8
CRISIS MANAGEMENT SERVICES	61.7	29.7	2.4	2.4	3.8	2.3
VOCATIONAL REHABILITATION	58.4	22.5	7.7	3.8	7.7	2.3
PEER SUPPORT GROUP	57.7	25.5	12.5	1.0	3.4	2.8
LONG TERM PERSONAL CARE SERVICES	56.3	25.5	9.1	0.5	8.7	2.8
MENTAL HEALTH REHABILITATION SERVICES	58.8	24.6	8.5	2.4	5.7	1.4
INDEPENDENT LIVING PROGRAM	56.0	28.2	6.7	0.0	9.1	2.3
ADULT DAY HEALTH CARE WAIVER	56.0	30.1	3.8	2.4	7.7	2.3
CASH SUBSIDY	51.7	12.1	24.2	2.9	9.2	3.3
ELDERLY & DISABLED ADULTS WAIVER	54.3	32.7	5.3	0.0	7.7	2.8
INDEPENDENT LIVING	55.0	30.6	6.2	1.0	7.2	2.3
SUPPORT SERVICES	52.9	20.7	16.3	1.0	9.1	2.8
BLIND SERVICES	54.3	30.0	4.3	1.0	10.5	1.9
INDIVIDUAL AND FAMILY SUPPORT	52.2	18.2	20.1	1.9	7.7	2.3
EARLY CHILDHOOD SUPPORT SERVICES	51.2	23.9	14.4	1.4	9.1	2.3
RESPIRE CARE/SERVICES	47.1	24.0	22.3	2.5	4.1	43.5
ASSISTIVE TRANSPORTATION	52.4	25.5	13.0	1.9	7.2	2.8
DURABLE MEDICAL EQUIPMENT	53.4	20.2	17.8	2.4	6.3	2.8
CSHS SUBSPECIALITY CLINICS	50.7	13.4	29.2	1.0	5.7	2.3
HEARING, SPEECH & VISION	48.8	16.7	28.2	0.5	5.7	2.3
FOSTER CARE SERVICES	44.7	40.9	4.8	0.5	9.1	2.8
CHILD CARE ASSISTANCE PROGRAM	34.4	27.8	21.1	2.4	14.4	2.3
EARLY STEPS	39.1	22.7	27.5	2.4	8.2	3.3
DISABILITIES DETERMINATION SERVICES/SSI	21.9	10.0	53.8	2.4	11.9	1.9
HEAD START	21.6	33.2	28.8	2.4	13.9	2.8
WIC NUTRITIONAL ASSISTANCE PROGRAM	23.0	24.4	43.1	2.4	7.2	2.3
MEDICAID	15.0	8.7	70.0	2.4	3.9	3.3
FOOD STAMPS	10.5	11.4	58.1	4.3	15.7	1.9

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
<u>WHITE: COMMUNITY-BASED RESOURCES</u>						
F2FHIC	74.3	20.4	3.9	0.0	1.3	3.2
SICC	71.7	23.7	1.3	0.7	2.6	3.2
SIBSHOPS	71.7	23.7	2.0	0.0	2.6	3.2
LBPAO	74.3	19.1	4.6	0.7	1.3	3.2
LOUISIANA PLANNING COUNCIL ON DD	72.4	19.1	4.6	2.0	2.0	3.2
RESIDENTAL OPTIONS WAIVER	65.8	21.7	2.0	0.0	10.5	3.2
BCSS	72.4	17.1	7.2	1.3	2.0	3.2
SUPPORTS WAIVER	65.8	17.8	5.9	0.0	10.5	3.2
NEW OPPORTUNITIES WAIVER	63.8	15.8	9.2	0.0	11.2	3.2
COMMUNITY SUPPORT TEAMS	65.6	18.5	8.6	0.7	6.6	3.8
TH&SC INJURY TRUST	60.5	32.9	2.0	0.0	4.6	3.2
EXTENDED FAMILY LIVING	66.4	23.0	3.9	0.7	5.9	3.2
INTERMEDIATE CARE DD	65.8	27.6	2.0	0.7	3.9	3.2
LA PARENT TRAINING INFORMATION CENTERS	60.5	27.0	9.9	0.0	2.6	3.2
PEER PARENT TRAINING	58.6	33.6	2.6	0.0	5.3	3.2
COMMISSION FOR THE DEAF	54.6	36.8	2.6	0.7	5.3	3.2
BIRTH DEFECTS MONITORING NETWORK	55.9	36.8	2.0	0.7	4.6	3.2
RESOURCE CENTERS	56.6	22.4	16.4	0.7	3.9	3.2
CHILDREN'S CHOICE WAIVER	59.2	15.8	13.8	0.0	11.2	3.2
CSHS CARE COORDINATION & TRANSITION	61.2	21.1	15.1	0.7	2.0	3.2
SUPPORTED LIVING	59.9	27.6	3.9	0.7	7.9	3.2
CRISIS MANAGEMENT SERVICES	58.6	32.9	2.6	1.3	4.6	3.2
VOCATIONAL REHABILITATION	54.6	31.6	8.6	1.3	3.9	3.2
PEER SUPPORT GROUP	53.3	32.9	8.6	0.7	4.6	3.2
LONG TERM PERSONAL CARE SERVICES	58.6	30.9	3.9	0.0	6.6	3.2
MENTAL HEALTH REHABILITATION SERVICES	50.7	36.8	6.6	1.3	4.6	3.2
INDEPENDENT LIVING PROGRAM	54.6	35.5	2.0	0.0	7.9	3.2
ADULT DAY HEALTH CARE WAIVER	54.6	38.2	1.3	0.0	5.9	3.2
CASH SUBSIDY	59.2	15.1	13.2	0.7	11.8	3.2
ELDERLY & DISABLED ADULTS WAIVER	52.6	38.8	2.0	0.7	5.9	3.2
INDEPENDENT LIVING	52.0	34.9	2.6	0.7	9.9	3.2
SUPPORT SERVICES	51.3	27.6	13.8	2.6	4.6	3.2
BLIND SERVICES	46.7	44.1	2.6	0.0	6.6	3.2
INDIVIDUAL AND FAMILY SUPPORT	52.0	21.1	18.4	2.6	5.9	3.2
EARLY CHILDHOOD SUPPORT SERVICES	48.0	34.9	9.2	1.3	6.6	3.2
RESPIRE CARE/SERVICES	61.4	18.6	15.7	0.0	4.3	55.4
ASSISTIVE TRANSPORTATION	48.0	38.2	6.6	1.3	5.9	3.2
DURABLE MEDICAL EQUIPMENT	44.1	29.6	21.1	1.3	3.9	3.2
CSHS SUBSPECIALITY CLINICS	44.7	20.4	30.9	1.3	2.6	3.2
HEARING, SPEECH & VISION	40.1	30.3	25.7	0.7	3.3	3.2
FOSTER CARE SERVICES	38.8	50.7	3.3	1.3	5.9	3.2
CHILD CARE ASSISTANCE PROGRAM	37.3	42.5	9.8	1.3	9.2	2.5
EARLY STEPS	33.3	34.0	25.5	0.0	7.2	2.5
DISABILITIES DETERMINATION SERVICES/SSI	30.3	17.8	36.2	2.6	13.2	3.2
HEAD START	25.7	57.2	11.2	0.7	5.3	3.2
WIC NUTRITIONAL ASSISTANCE PROGRAM	18.4	35.5	36.8	0.0	9.2	3.2
MEDICAID	12.4	11.8	69.9	0.7	5.2	2.5
FOOD STAMPS	13.8	29.6	30.9	2.0	23.7	3.2

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
REGION 1: COMMUNITY-BASED RESOURCES						
F2FHIC	80.6	12.9	3.2	0.0	3.2	6.1
SICC	83.3	13.3	0.0	0.0	3.3	9.1
SIBSHOPS	74.2	16.1	0.0	0.0	9.7	6.1
LBPAO	77.4	12.9	6.5	3.2	0.0	6.1
LOUISIANA PLANNING COUNCIL ON DD	73.3	13.3	3.3	3.3	6.7	9.1
RESIDENTAL OPTIONS WAIVER	80.6	12.9	0.0	3.2	3.2	6.1
BCSS	60.0	16.7	16.7	3.3	3.3	9.1
SUPPORTS WAIVER	63.3	10.0	16.7	0.0	10.0	9.1
NEW OPPORTUNITIES WAIVER	58.1	9.7	19.4	3.2	9.7	6.1
COMMUNITY SUPPORT TEAMS	63.3	6.7	16.7	3.3	10.0	9.1
TH&SC INJURY TRUST	64.5	19.4	6.5	3.2	6.5	6.1
EXTENDED FAMILY LIVING	51.6	16.1	19.4	3.2	9.7	6.1
INTERMEDIATE CARE DD	51.6	29.0	3.2	3.2	12.9	6.1
LA PARENT TRAINING INFORMATION CENTERS	50.0	20.0	26.7	0.0	3.3	9.1
PEER PARENT TRAINING	63.3	26.7	3.3	6.7	0.0	9.1
COMMISSION FOR THE DEAF	60.0	36.7	0.0	3.3	0.0	9.1
BIRTH DEFECTS MONITORING NETWORK	71.0	25.8	0.0	0.0	3.2	6.1
RESOURCE CENTERS	58.1	9.7	25.8	3.2	3.2	6.1
CHILDREN'S CHOICE WAIVER	45.2	16.1	29.0	0.0	9.7	6.1
CSHS CARE COORDINATION & TRANSITION	35.5	22.6	32.3	0.0	9.7	6.1
SUPPORTED LIVING	35.5	22.6	22.6	6.5	12.9	6.1
CRISIS MANAGEMENT SERVICES	51.6	38.7	0.0	3.2	6.5	6.1
VOCATIONAL REHABILITATION	48.4	35.5	3.2	3.2	9.7	6.1
PEER SUPPORT GROUP	53.3	30.0	13.3	3.3	0.0	9.1
LONG TERM PERSONAL CARE SERVICES	51.6	25.8	3.2	3.2	16.1	6.1
MENTAL HEALTH REHABILITATION SERVICES	64.5	29.0	0.0	0.0	6.5	6.1
INDEPENDENT LIVING PROGRAM	48.4	32.3	3.2	0.0	16.1	6.1
ADULT DAY HEALTH CARE WAIVER	48.4	35.5	3.3	3.3	9.7	6.1
CASH SUBSIDY	38.7	6.5	35.5	3.2	16.1	6.1
ELDERLY & DISABLED ADULTS WAIVER	50.0	33.3	3.3	0.0	13.3	9.1
INDEPENDENT LIVING	35.5	45.2	3.2	3.2	12.9	6.1
SUPPORT SERVICES	50.0	16.7	20.0	0.0	13.3	9.1
BLIND SERVICES	48.4	32.3	0.0	3.2	16.1	6.1
INDIVIDUAL AND FAMILY SUPPORT	41.9	16.1	32.3	3.2	6.5	6.1
EARLY CHILDHOOD SUPPORT SERVICES	41.9	35.5	3.2	3.2	16.1	6.1
RESPIRE CARE/SERVICES	25.0	21.1	46.4	3.6	3.6	15.2
ASSISTIVE TRANSPORTATION	43.3	36.7	10.0	0.0	10.0	6.1
DURABLE MEDICAL EQUIPMENT	35.5	16.1	38.7	3.2	6.5	6.1
CSHS SUBSPECIALTY CLINICS	25.8	16.1	48.4	3.2	6.5	6.1
HEARING, SPEECH & VISION	32.3	25.8	38.7	3.2	0.0	6.1
FOSTER CARE SERVICES	26.7	56.7	3.3	0.0	13.3	9.1
CHILD CARE ASSISTANCE PROGRAM	41.9	25.8	16.1	0.0	16.1	6.1
EARLY STEPS	12.9	38.7	29.0	6.5	12.9	6.1
DISABILITIES DETERMINATION SERVICES/SSI	12.9	19.4	61.3	3.2	3.2	6.1
HEAD START	9.7	51.6	19.4	6.5	12.9	6.1
WIC NUTRITIONAL ASSISTANCE PROGRAM	16.1	25.8	41.9	6.5	9.7	6.1
MEDICAID	16.1	16.1	64.5	0.0	3.2	6.1
FOOD STAMPS	13.3	26.7	40.0	3.3	16.7	9.1

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
<b>REGION 2: COMMUNITY-BASED RESOURCES</b>						
F2FHIC	76.5	23.5	0.0	0.0	0.0	5.6
SICC	74.5	25.5	0.0	0.0	0.0	5.6
SIBSHOPS	74.5	23.5	2.0	0.0	0.0	5.6
LBPAO	70.6	19.6	7.8	0.0	2.0	5.6
LOUISIANA PLANNING COUNCIL ON DD	74.5	17.6	7.8	0.0	0.0	5.6
RESIDENTAL OPTIONS WAIVER	70.6	25.5	2.0	0.0	2.0	5.6
BCSS	68.6	19.6	9.8	2.0	0.0	5.6
SUPPORTS WAIVER	68.6	19.6	9.8	0.0	2.0	5.6
NEW OPPORTUNITIES WAIVER	68.6	17.6	11.8	0.0	2.0	5.6
COMMUNITY SUPPORT TEAMS	68.6	21.6	3.9	0.0	5.9	5.6
TH&SC INJURY TRUST	70.6	27.5	0.0	0.0	2.0	5.6
EXTENDED FAMILY LIVING	68.6	21.6	3.9	0.0	5.9	5.6
INTERMEDIATE CARE DD	68.6	25.5	3.9	0.0	2.0	5.6
LA PARENT TRAINING INFORMATION CENTERS	64.7	25.5	9.8	0.0	0.0	5.6
PEER PARENT TRAINING	60.8	31.4	5.9	0.0	2.0	5.6
COMMISSION FOR THE DEAF	64.7	31.4	0.0	0.0	3.9	5.6
BIRTH DEFECTS MONITORING NETWORK	68.6	27.5	2.0	0.0	2.0	5.6
RESOURCE CENTERS	66.7	19.6	9.8	0.0	3.9	5.6
CHILDREN'S CHOICE WAIVER	60.8	19.6	15.7	0.0	3.9	5.6
CSHS CARE COORDINATION & TRANSITION	52.9	19.6	25.5	0.0	2.0	5.6
SUPPORTED LIVING	60.8	25.5	5.9	2.0	5.9	5.6
CRISIS MANAGEMENT SERVICES	64.7	31.4	2.0	0.0	2.0	5.6
VOCATIONAL REHABILITATION	60.8	23.5	9.8	3.9	2.2	5.6
PEER SUPPORT GROUP	52.9	33.3	9.8	0.0	3.9	5.6
LONG TERM PERSONAL CARE SERVICES	54.9	31.4	9.8	0.0	3.9	5.6
MENTAL HEALTH REHABILITATION SERVICES	61.5	25.0	9.6	1.9	1.9	3.7
INDEPENDENT LIVING PROGRAM	58.8	31.4	3.9	0.0	5.9	5.6
ADULT DAY HEALTH CARE WAIVER	58.8	37.3	0.0	0.0	3.9	5.6
CASH SUBSIDY	47.1	13.7	31.4	3.9	3.9	5.6
ELDERLY & DISABLED ADULTS WAIVER	51.0	47.1	0.0	0.0	2.0	5.6
INDEPENDENT LIVING	58.8	33.3	5.9	0.0	2.0	5.6
SUPPORT SERVICES	60.8	19.6	13.7	2.0	3.9	5.6
BLIND SERVICES	54.9	33.3	3.9	0.0	7.8	5.6
INDIVIDUAL AND FAMILY SUPPORT	60.8	17.6	15.7	0.0	5.9	5.6
EARLY CHILDHOOD SUPPORT SERVICES	52.9	31.4	9.8	2.0	3.9	5.6
RESPIRE CARE/SERVICES	50.0	30.4	17.4	0.0	2.2	14.8
ASSISTIVE TRANSPORTATION	52.9	25.5	13.7	2.0	5.9	5.6
DURABLE MEDICAL EQUIPMENT	45.1	27.5	21.6	2.0	3.9	5.6
CSHS SUBSPECIALITY CLINICS	37.3	17.6	43.1	0.0	2.2	5.6
HEARING, SPEECH & VISION	41.2	21.6	35.3	0.0	2.0	5.6
FOSTER CARE SERVICES	45.1	49.0	2.0	0.0	3.9	5.6
CHILD CARE ASSISTANCE PROGRAM	37.3	33.3	17.6	2.0	9.8	5.6
EARLY STEPS	29.4	29.4	33.3	2.0	5.9	5.6
DISABILITIES DETERMINATION SERVICES/SSI	5.9	7.8	72.5	2.0	11.8	5.6
HEAD START	19.6	43.1	25.5	2.0	9.8	5.6
WIC NUTRITIONAL ASSISTANCE PROGRAM	19.6	29.4	41.2	0.0	9.8	5.6
MEDICAID	11.8	9.8	72.5	2.0	3.9	5.6
FOOD STAMPS	7.7	17.3	59.6	0.0	15.4	3.7

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
REGION 3: COMMUNITY-BASED RESOURCES						
F2FHIC	73.8	14.0	8.4	0.0	3.7	0.9
SICC	69.2	20.6	3.7	0.9	5.6	0.9
SIBSHOPS	72.9	20.6	2.8	0.0	3.7	0.9
LBPAO	72.0	16.8	8.4	0.9	1.9	0.9
LOUISIANA PLANNING COUNCIL ON DD	68.2	21.5	4.7	2.8	2.8	0.9
RESIDENTAL OPTIONS WAIVER	61.7	21.5	2.8	1.9	12.1	0.9
BCSS	69.2	16.8	10.3	0.9	2.8	0.9
SUPPORTS WAIVER	60.7	19.6	4.7	0.9	14.0	0.9
NEW OPPORTUNITIES WAIVER	57.0	19.6	9.3	0.9	13.1	0.9
COMMUNITY SUPPORT TEAMS	60.7	20.6	10.3	0.0	8.4	0.9
TH&SC INJURY TRUST	59.8	27.1	5.6	0.0	7.5	0.9
EXTENDED FAMILY LIVING	66.4	19.6	6.5	0.9	6.5	0.9
INTERMEDIATE CARE DD	64.5	25.2	6.5	0.0	3.7	0.9
LA PARENT TRAINING INFORMATION CENTERS	62.3	21.7	9.4	0.9	5.7	1.9
PEER PARENT TRAINING	58.9	31.8	4.7	0.0	4.7	0.9
COMMISSION FOR THE DEAF	59.8	30.8	2.8	0.9	5.6	0.9
BIRTH DEFECTS MONITORING NETWORK	60.7	29.0	2.8	0.0	7.5	0.9
RESOURCE CENTERS	54.2	19.6	20.6	1.9	3.7	0.9
CHILDREN'S CHOICE WAIVER	52.3	17.8	15.0	0.9	14.0	0.9
CSHS CARE COORDINATION & TRANSITION	58.9	22.4	13.1	1.9	3.7	0.9
SUPPORTED LIVING	59.8	23.4	6.5	0.9	9.3	0.9
CRISIS MANAGEMENT SERVICES	55.1	35.5	4.7	0.9	3.7	0.9
VOCATIONAL REHABILITATION	50.5	30.8	9.3	0.9	8.4	0.9
PEER SUPPORT GROUP	50.5	30.8	13.1	0.0	5.6	0.9
LONG TERM PERSONAL CARE SERVICES	57.9	29.9	5.6	0.9	5.6	0.9
MENTAL HEALTH REHABILITATION SERVICES	47.2	34.3	10.2	1.9	6.5	0.0
INDEPENDENT LIVING PROGRAM	55.1	29.9	4.7	0.0	10.3	0.9
ADULT DAY HEALTH CARE WAIVER	54.2	35.5	2.8	0.9	6.5	0.9
CASH SUBSIDY	55.1	14.0	16.8	0.9	13.1	0.9
ELDERLY & DISABLED ADULTS WAIVER	51.4	36.4	3.7	0.9	7.5	0.9
INDEPENDENT LIVING	49.5	33.6	5.6	0.9	10.3	0.9
SUPPORT SERVICES	40.2	29.0	18.7	2.8	9.3	0.9
BLIND SERVICES	50.0	36.1	1.9	0.9	11.1	0.0
INDIVIDUAL AND FAMILY SUPPORT	44.4	25.9	19.4	0.0	10.2	0.0
EARLY CHILDHOOD SUPPORT SERVICES	46.7	29.0	14.0	0.0	10.3	0.9
RESPIRE CARE/SERVICES	69.6	14.3	12.5	1.8	1.8	48.1
ASSISTIVE TRANSPORTATION	46.7	35.5	7.5	3.7	6.5	0.9
DURABLE MEDICAL EQUIPMENT	43.0	26.2	20.6	1.9	8.4	0.9
CSHS SUBSPECIALTY CLINICS	46.7	21.5	26.2	0.9	4.7	0.9
HEARING, SPEECH & VISION	41.1	27.1	26.2	0.0	5.6	0.9
FOSTER CARE SERVICES	40.2	44.9	5.6	0.9	8.4	0.9
CHILD CARE ASSISTANCE PROGRAM	29.9	39.3	15.0	0.9	15.0	0.9
EARLY STEPS	33.0	25.5	33.0	1.9	6.6	1.9
DISABILITIES DETERMINATION SERVICES/SSI	25.0	13.9	45.4	0.9	14.8	0.0
HEAD START	20.8	47.2	18.9	1.9	11.3	1.9
WIC NUTRITIONAL ASSISTANCE PROGRAM	15.0	36.4	40.2	0.0	8.4	0.9
MEDICAID	8.3	12.0	73.1	1.9	4.6	0.0
FOOD STAMPS	9.3	23.1	42.6	1.9	23.1	0.0

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
<b>REGION 4: COMMUNITY-BASED RESOURCES</b>						
F2FHIC	68.2	18.2	13.6	0.0	0.0	0.0
SICC	90.9	9.1	0.0	0.0	0.0	0.0
SIBSHOPS	72.7	13.6	13.6	0.0	0.0	0.0
LBPAO	77.3	13.6	4.5	0.0	4.5	0.0
LOUISIANA PLANNING COUNCIL ON DD	81.8	18.2	0.0	0.0	0.0	0.0
RESIDENTAL OPTIONS WAIVER	86.4	9.1	0.0	0.0	4.5	0.0
BCSS	81.8	9.1	9.1	0.0	0.0	0.0
SUPPORTS WAIVER	81.8	9.1	4.5	0.0	4.5	0.0
NEW OPPORTUNITIES WAIVER	86.4	4.5	0.0	0.0	9.1	0.0
COMMUNITY SUPPORT TEAMS	77.3	13.6	4.5	0.0	4.5	0.0
TH&SC INJURY TRUST	77.3	22.7	0.0	0.0	0.0	0.0
EXTENDED FAMILY LIVING	68.2	18.2	0.0	0.0	13.6	0.0
INTERMEDIATE CARE DD	77.3	13.6	4.5	0.0	4.5	0.0
LA PARENT TRAINING INFORMATION CENTERS	68.2	22.7	9.1	0.0	0.0	0.0
PEER PARENT TRAINING	81.8	13.6	4.5	0.0	0.0	0.0
COMMISSION FOR THE DEAF	77.3	18.2	4.5	0.0	0.0	0.0
BIRTH DEFECTS MONITORING NETWORK	72.7	22.7	4.5	0.0	0.0	0.0
RESOURCE CENTERS	81.8	9.1	0.0	0.0	9.1	0.0
CHILDREN'S CHOICE WAIVER	72.7	4.5	13.6	0.0	9.1	0.0
CSHS CARE COORDINATION & TRANSITION	68.2	13.6	13.6	4.5	0.0	0.0
SUPPORTED LIVING	63.6	22.7	0.0	0.0	13.6	0.0
CRISIS MANAGEMENT SERVICES	77.3	13.6	9.1	0.0	0.0	0.0
VOCATIONAL REHABILITATION	68.2	18.2	13.6	0.0	0.0	0.0
PEER SUPPORT GROUP	68.2	18.2	13.6	0.0	0.0	0.0
LONG TERM PERSONAL CARE SERVICES	63.6	13.6	18.2	0.0	4.5	0.0
MENTAL HEALTH REHABILITATION SERVICES	68.2	27.3	4.5	0.0	0.0	0.0
INDEPENDENT LIVING PROGRAM	68.2	22.7	4.5	0.0	4.5	0.0
ADULT DAY HEALTH CARE WAIVER	77.3	22.7	0.0	0.0	0.0	0.0
CASH SUBSIDY	54.5	18.2	9.1	4.5	13.6	0.0
ELDERLY & DISABLED ADULTS WAIVER	81.8	13.6	0.0	0.0	4.5	0.0
INDEPENDENT LIVING	81.8	13.6	0.0	0.0	4.5	0.0
SUPPORT SERVICES	68.2	18.2	13.6	0.0	0.0	0.0
BLIND SERVICES	54.5	36.4	9.1	0.0	0.0	0.0
INDIVIDUAL AND FAMILY SUPPORT	59.1	4.5	22.7	4.5	9.1	0.0
EARLY CHILDHOOD SUPPORT SERVICES	68.2	13.6	18.2	0.0	0.0	0.0
RESPIRE CARE/SERVICES	4.5	0.0	0.0	0.0	0.0	95.5
ASSISTIVE TRANSPORTATION	68.2	18.2	13.6	0.0	0.0	0.0
DURABLE MEDICAL EQUIPMENT	45.5	22.7	31.8	0.0	0.0	0.0
CSHS SUBSPECIALTY CLINICS	45.5	9.1	40.9	4.5	0.0	0.0
HEARING, SPEECH & VISION	31.8	18.2	50.0	0.0	0.0	0.0
FOSTER CARE SERVICES	50.0	50.0	0.0	0.0	0.0	0.0
CHILD CARE ASSISTANCE PROGRAM	45.5	27.3	18.2	0.0	9.1	0.0
EARLY STEPS	27.3	31.8	36.4	0.0	4.5	0.0
DISABILITIES DETERMINATION SERVICES/SSI	27.3	45.5	13.6	0.0	13.6	0.0
HEAD START	31.8	27.3	27.3	0.0	13.6	0.0
WIC NUTRITIONAL ASSISTANCE PROGRAM	22.7	13.6	59.1	0.0	4.5	0.0
MEDICAID	4.5	13.6	72.7	0.0	9.1	0.0
FOOD STAMPS	4.5	4.5	59.1	9.4	22.7	0.0





	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
REGION 5: COMMUNITY-BASED RESOURCES						
F2FHIC	75.0	25.0	0.0	0.0	0.0	0.0
SICC	70.0	30.0	0.0	0.0	0.0	0.0
SIBSHOPS	70.0	25.0	5.0	0.0	0.0	0.0
LBPAO	60.0	25.0	15.0	0.0	0.0	0.0
LOUISIANA PLANNING COUNCIL ON DD	70.0	30.0	0.0	0.0	0.0	0.0
RESIDENTAL OPTIONS WAIVER	60.0	25.0	10.0	0.0	5.0	0.0
BCSS	80.0	10.0	10.0	0.0	0.0	0.0
SUPPORTS WAIVER	65.0	15.0	15.0	0.0	5.0	0.0
NEW OPPORTUNITIES WAIVER	70.0	20.0	10.0	0.0	0.0	0.0
COMMUNITY SUPPORT TEAMS	60.0	30.0	5.0	0.0	5.0	0.0
TH&SC INJURY TRUST	60.0	40.0	0.0	0.0	0.0	0.0
EXTENDED FAMILY LIVING	60.0	20.0	10.0	5.0	5.0	0.0
INTERMEDIATE CARE DD	65.0	30.0	5.0	0.0	0.0	0.0
LA PARENT TRAINING INFORMATION CENTERS	65.0	25.0	10.0	0.0	0.0	0.0
PEER PARENT TRAINING	60.0	40.0	0.0	0.0	0.0	0.0
COMMISSION FOR THE DEAF	65.0	25.0	5.0	0.0	5.0	0.0
BIRTH DEFECTS MONITORING NETWORK	55.0	30.0	15.0	0.0	0.0	0.0
RESOURCE CENTERS	50.0	35.0	5.0	5.0	5.0	0.0
CHILDREN'S CHOICE WAIVER	60.0	20.0	20.0	0.0	0.0	0.0
CSHS CARE COORDINATION & TRANSITION	70.0	15.0	15.0	0.0	0.0	0.0
SUPPORTED LIVING	60.0	25.0	10.0	0.0	5.0	0.0
CRISIS MANAGEMENT SERVICES	55.0	45.0	0.0	0.0	0.0	0.0
VOCATIONAL REHABILITATION	55.0	25.0	10.0	5.0	5.0	0.0
PEER SUPPORT GROUP	55.0	35.0	5.0	5.0	0.0	0.0
LONG TERM PERSONAL CARE SERVICES	65.0	30.0	5.0	0.0	0.0	0.0
MENTAL HEALTH REHABILITATION SERVICES	50.0	40.0	0.0	5.0	5.0	0.0
INDEPENDENT LIVING PROGRAM	55.0	30.0	10.0	0.0	5.0	0.0
ADULT DAY HEALTH CARE WAIVER	65.0	30.0	0.0	5.0	0.0	0.0
CASH SUBSIDY	50.0	20.0	15.0	5.0	10.0	0.0
ELDERLY & DISABLED ADULTS WAIVER	60.0	35.0	5.0	0.0	0.0	0.0
INDEPENDENT LIVING	55.0	30.0	5.0	5.0	5.0	0.0
SUPPORT SERVICES	55.0	40.0	5.0	0.0	0.0	0.0
BLIND SERVICES	35.0	45.0	15.0	0.0	5.0	0.0
INDIVIDUAL AND FAMILY SUPPORT	40.0	30.0	20.0	5.0	5.0	0.0
EARLY CHILDHOOD SUPPORT SERVICES	50.0	35.0	10.0	0.0	5.0	0.0
RESPIRE CARE/SERVICES	0.0	100.0	0.0	0.0	0.0	95.0
ASSISTIVE TRANSPORTATION	50.0	30.0	15.0	0.0	5.0	0.0
DURABLE MEDICAL EQUIPMENT	52.6	26.3	15.8	0.0	5.3	0.0
CSHS SUBSPECIALTY CLINICS	50.0	20.0	30.0	0.0	0.0	0.0
HEARING, SPEECH & VISION	50.0	25.0	25.0	0.0	0.0	0.0
FOSTER CARE SERVICES	50.0	45.0	5.0	0.0	0.0	0.0
CHILD CARE ASSISTANCE PROGRAM	45.0	35.0	15.0	0.0	5.0	0.0
EARLY STEPS	40.0	35.0	20.0	0.0	5.0	0.0
DISABILITIES DETERMINATION SERVICES/SSI	25.0	20.0	45.0	0.0	10.0	0.0
HEAD START	40.0	40.0	15.0	0.0	0.0	0.0
WIC NUTRITIONAL ASSISTANCE PROGRAM	35.0	25.0	40.0	0.0	0.0	0.0
MEDICAID	30.0	15.0	55.0	0.0	0.0	0.0
FOOD STAMPS	15.0	20.0	50.0	0.0	15.0	0.0

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
REGION 6: COMMUNITY-BASED RESOURCES						
F2FHIC	65.5	24.1	10.3	0.0	0.0	3.3
SICC	62.1	34.5	0.0	0.0	3.4	3.3
SIBSHOPS	69.0	27.6	3.4	0.0	0.0	3.3
LBPAO	75.9	10.3	10.3	3.4	0.0	3.3
LOUISIANA PLANNING COUNCIL ON DD	65.5	31.0	0.0	3.4	0.0	3.3
RESIDENTAL OPTIONS WAIVER	69.0	20.7	3.4	0.0	6.9	3.3
BCSS	75.9	6.9	17.2	0.0	0.0	3.3
SUPPORTS WAIVER	65.5	20.7	6.9	0.0	6.9	3.3
NEW OPPORTUNITIES WAIVER	69.0	17.2	10.3	0.0	3.4	3.3
COMMUNITY SUPPORT TEAMS	67.9	17.9	10.7	0.0	3.6	6.7
TH&SC INJURY TRUST	58.6	31.0	3.4	0.0	6.9	3.3
EXTENDED FAMILY LIVING	69.0	27.6	0.0	0.0	3.4	3.3
INTERMEDIATE CARE DD	51.7	37.9	3.4	3.4	3.4	0.0
LA PARENT TRAINING INFORMATION CENTERS	65.5	20.7	10.3	0.0	3.4	3.3
PEER PARENT TRAINING	55.2	34.5	3.4	0.0	6.9	3.3
COMMISION FOR THE DEAF	55.2	27.6	6.9	3.4	6.9	3.3
BIRTH DEFECTS MONITORING NETWORK	58.6	27.6	6.9	3.4	3.4	3.3
RESOURCE CENTERS	51.7	17.2	24.1	0.0	6.9	3.3
CHILDREN'S CHOICE WAIVER	58.6	13.8	20.7	0.0	6.9	3.3
CSHS CARE COORDINATION & TRANSITION	69.0	20.7	10.3	0.0	0.0	3.3
SUPPORTED LIVING	62.1	20.7	10.3	0.0	6.9	0.0
CRISIS MANAGEMENT SERVICES	58.6	27.6	3.4	3.4	6.9	3.3
VOCATIONAL REHABILITATION	65.5	20.7	6.9	6.9	0.0	3.3
PEER SUPPORT GROUP	51.7	31.0	10.3	0.0	6.9	3.3
LONG TERM PERSONAL CARE SERVICES	44.8	27.6	10.3	3.4	13.8	3.3
MENTAL HEALTH REHABILITATION SERVICES	37.9	44.8	10.3	0.0	6.9	3.3
INDEPENDENT LIVING PROGRAM	55.2	44.8	0.0	0.0	0.0	3.3
ADULT DAY HEALTH CARE WAIVER	41.4	44.8	0.0	0.0	13.8	3.3
CASH SUBSIDY	55.2	17.2	17.2	3.4	6.9	3.3
ELDERLY & DISABLED ADULTS WAIVER	41.4	48.3	0.0	0.0	10.3	3.3
INDEPENDENT LIVING	51.7	31.0	3.4	0.0	13.8	3.3
SUPPORT SERVICES	55.2	20.7	17.2	3.4	3.4	3.3
BLIND SERVICES	48.3	41.4	3.4	0.0	6.9	3.3
INDIVIDUAL AND FAMILY SUPPORT	55.2	20.7	13.8	10.3	0.0	3.3
EARLY CHILDHOOD SUPPORT SERVICES	44.8	37.9	10.3	3.4	3.4	3.3
RESPIRE CARE/SERVICES	66.7	33.3	0.0	0.0	0.0	90.0
ASSISTIVE TRANSPORTATION	48.3	27.6	13.8	3.4	6.9	3.3
DURABLE MEDICAL EQUIPMENT	65.5	17.2	10.3	3.4	3.4	3.3
CSHS SUBSPECIALITY CLINICS	62.1	10.3	27.6	0.0	0.0	3.3
HEARING, SPEECH & VISION	55.2	27.6	10.3	3.4	3.4	3.3
FOSTER CARE SERVICES	31.0	44.8	6.9	3.4	13.8	3.3
CHILD CARE ASSISTANCE PROGRAM	40.0	30.0	20.0	6.7	3.3	0.0
EARLY STEPS	41.4	27.6	27.6	0.0	3.4	3.3
DISABILITIES DETERMINATION SERVICES/SSI	37.9	13.8	41.4	0.0	6.9	
HEAD START	27.6	48.3	10.0	0.0	13.8	3.3
WIC NUTRITIONAL ASSISTANCE PROGRAM	13.8	27.6	51.7	0.0	6.9	3.3
MEDICAID	27.6	10.3	55.2	0.0	6.9	3.3
FOOD STAMPS	13.8	34.5	41.4	3.4	6.9	3.3

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
REGION 7: COMMUNITY-BASED RESOURCES						
F2FHIC	58.3	33.3	8.3	0.0	0.0	0.0
SICC	66.7	16.7	8.3	0.0	8.3	0.0
SIBSHOPS	75.0	16.7	8.3	0.0	0.0	0.0
LBPAO	75.0	16.7	0.0	0.0	8.3	0.0
LOUISIANA PLANNING COUNCIL ON DD	58.3	16.7	0.0	8.3	16.7	0.0
RESIDENTAL OPTIONS WAIVER	58.3	8.3	0.0	8.3	25.0	0.0
BCSS	58.3	8.3	34.7	0.0	16.7	0.0
SUPPORTS WAIVER	66.7	16.7	0.0	0.0	16.7	0.0
NEW OPPORTUNITIES WAIVER	58.3	16.7	0.0	8.3	16.7	0.0
COMMUNITY SUPPORT TEAMS	50.0	41.7	8.3	0.0	0.0	0.0
TH&SC INJURY TRUST	50.0	33.3	0.0	8.3	8.3	0.0
EXTENDED FAMILY LIVING	33.3	41.7	16.7	0.0	8.3	0.0
INTERMEDIATE CARE DD	58.3	25.0	8.3	0.0	8.3	0.0
LA PARENT TRAINING INFORMATION CENTERS	50.0	33.3	16.7	0.0	0.0	0.0
PEER PARENT TRAINING	75.0	25.0	0.0	0.0	0.0	0.0
COMMISION FOR THE DEAF	50.0	25.0	0.0	8.3	16.7	0.0
BIRTH DEFECTS MONITORING NETWORK	41.7	33.3	0.0	8.3	16.7	0.0
RESOURCE CENTERS	50.0	33.3	16.7	0.0	0.0	0.0
CHILDREN'S CHOICE WAIVER	58.3	16.7	0.0	8.3	16.7	0.0
CSHS CARE COORDINATION & TRANSITION	41.7	16.7	33.3	0.0	8.3	0.0
SUPPORTED LIVING	50.0	41.7	0.0	0.0	8.3	0.0
CRISIS MANAGEMENT SERVICES	50.0	33.3	0.0	16.7	0.0	0.0
VOCATIONAL REHABILITATION	50.0	33.3	0.0	8.3	8.3	0.0
PEER SUPPORT GROUP	58.3	25.0	8.3	8.3	0.0	0.0
LONG TERM PERSONAL CARE SERVICES	66.7	25.0	0.0	0.0	8.3	0.0
MENTAL HEALTH REHABILITATION SERVICES	50.0	25.0	8.3	0.0	16.7	0.0
INDEPENDENT LIVING PROGRAM	58.3	33.3	8.3	0.0	0.0	0.0
ADULT DAY HEALTH CARE WAIVER	41.7	25.0	8.3	16.7	8.3	0.0
CASH SUBSIDY	58.3	25.0	16.7	0.0	0.0	0.0
ELDERLY & DISABLED ADULTS WAIVER	41.7	41.7	8.3	0.0	8.3	0.0
INDEPENDENT LIVING	50.0	16.7	8.3	0.0	25.0	0.0
SUPPORT SERVICES	50.0	33.3	8.3	0.0	8.3	0.0
BLIND SERVICES	66.7	16.7	16.7	0.0	0.0	0.0
INDIVIDUAL AND FAMILY SUPPORT	25.0	41.7	25.0	0.0	8.3	0.0
EARLY CHILDHOOD SUPPORT SERVICES	58.3	16.7	16.7	0.0	8.3	0.0
RESPIRE CARE/SERVICES	12.5	25.0	12.5	25.0	25.0	33.3
ASSISTIVE TRANSPORTATION	33.3	50.0	0.0	8.3	8.3	0.0
DURABLE MEDICAL EQUIPMENT	41.7	33.3	8.3	8.3	8.3	0.0
CSHS SUBSPECIALITY CLINICS	25.0	8.3	50.0	8.3	8.3	0.0
HEARING, SPEECH & VISION	41.7	25.0	16.7	0.0	16.7	0.0
FOSTER CARE SERVICES	33.3	33.3	0.0	8.3	25.0	0.0
CHILD CARE ASSISTANCE PROGRAM	16.7	58.3	16.7	0.0	8.3	0.0
EARLY STEPS	33.3	33.3	25.0	0.0	8.3	0.0
DISABILITIES DETERMINATION SERVICES/SSI	41.7	16.7	33.3	0.0	8.3	0.0
HEAD START	25.0	58.3	16.7	0.0	0.0	0.0
WIC NUTRITIONAL ASSISTANCE PROGRAM	33.3	25.0	25.0	0.0	16.7	0.0
MEDICAID	16.7	16.7	41.7	0.0	25.0	0.0
FOOD STAMPS	33.3	41.7	25.0	0.0	0.0	0.0

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
REGION 8: COMMUNITY-BASED RESOURCES						
F2FHIC	76.9	15.7	1.7	0.8	5.0	2.4
SICC	75.2	14.9	5.0	0.8	4.1	2.4
SIBSHOPS	75.2	16.5	3.3	0.0	5.0	2.4
LBPAO	71.9	16.5	5.0	1.7	5.0	2.4
LOUISIANA PLANNING COUNCIL ON DD	74.4	14.0	5.8	1.7	4.1	2.4
RESIDENTAL OPTIONS WAIVER	79.3	9.1	3.3	0.0	8.3	2.4
BCSS	69.4	14.0	9.1	2.5	5.0	2.4
SUPPORTS WAIVER	74.4	12.4	5.0	2.5	5.8	2.4
NEW OPPORTUNITIES WAIVER	71.9	9.9	10.7	0.8	6.6	2.4
COMMUNITY SUPPORT TEAMS	68.3	15.0	10.0	2.5	4.2	3.2
TH&SC INJURY TRUST	71.1	20.7	3.3	0.8	4.1	2.4
EXTENDED FAMILY LIVING	68.3	18.3	6.7	0.0	6.7	3.2
INTERMEDIATE CARE DD	67.8	19.0	5.8	0.8	6.6	2.4
LA PARENT TRAINING INFORMATION CENTERS	70.0	19.2	5.0	0.0	5.8	3.2
PEER PARENT TRAINING	67.8	21.5	3.3	0.8	6.6	2.4
COMMISSION FOR THE DEAF	67.8	19.0	3.3	0.0	9.9	2.4
BIRTH DEFECTS MONITORING NETWORK	62.8	26.4	3.3	0.8	6.6	2.4
RESOURCE CENTERS	66.9	12.4	14.0	0.8	5.8	2.4
CHILDREN'S CHOICE WAIVER	71.1	9.1	13.2	0.0	6.6	2.4
CSHS CARE COORDINATION & TRANSITION	70.2	14.0	10.7	0.8	4.1	2.4
SUPPORTED LIVING	68.3	19.2	6.7	0.0	5.8	3.2
CRISIS MANAGEMENT SERVICES	62.8	24.8	4.1	2.5	5.8	2.4
VOCATIONAL REHABILITATION	62.8	21.5	6.6	2.5	6.6	2.4
PEER SUPPORT GROUP	61.2	24.0	7.4	0.8	6.6	2.4
LONG TERM PERSONAL CARE SERVICES	59.2	24.2	7.5	0.8	8.3	3.2
MENTAL HEALTH REHABILITATION SERVICES	61.2	22.3	7.4	2.5	6.6	2.4
INDEPENDENT LIVING PROGRAM	57.9	26.4	6.6	0.0	9.1	2.4
ADULT DAY HEALTH CARE WAIVER	57.0	27.3	6.6	0.8	8.3	2.4
CASH SUBSIDY	60.8	13.3	16.7	1.7	7.5	3.2
ELDERLY & DISABLED ADULTS WAIVER	57.9	27.3	6.6	0.0	8.3	2.4
INDEPENDENT LIVING	53.7	33.1	6.6	0.0	6.6	2.4
SUPPORT SERVICES	64.5	21.5	14.9	1.7	7.4	2.4
BLIND SERVICES	58.7	33.1	1.7	0.0	6.6	2.4
INDIVIDUAL AND FAMILY SUPPORT	55.0	20.0	17.5	3.3	4.2	3.2
EARLY CHILDHOOD SUPPORT SERVICES	52.9	22.3	15.7	1.7	7.4	2.4
RESPIRE CARE/SERVICES	53.1	26.6	14.1	1.6	4.7	48.4
ASSISTIVE TRANSPORTATION	53.7	26.4	13.2	0.8	5.8	2.4
DURABLE MEDICAL EQUIPMENT	53.7	22.3	16.5	2.5	5.0	2.4
CSHS SUBSPECIALTY CLINICS	60.3	12.4	21.5	0.8	5.0	2.4
HEARING, SPEECH & VISION	53.7	18.2	21.5	0.8	5.8	2.4
FOSTER CARE SERVICES	47.9	38.0	6.6	0.0	7.4	2.4
CHILD CARE ASSISTANCE PROGRAM	36.4	28.9	18.2	2.5	14.0	2.4
EARLY STEPS	43.8	24.8	22.3	0.8	8.3	2.4
DISABILITIES DETERMINATION SERVICES/SSI	32.2	14.9	37.2	3.3	12.4	2.4
HEAD START	25.6	34.7	28.1	0.8	10.7	2.4
WIC NUTRITIONAL ASSISTANCE PROGRAM	25.6	24.8	41.3	2.5	5.8	2.4
MEDICAID	15.1	7.6	71.4	4.2	1.7	4.0
FOOD STAMPS	12.5	16.7	50.0	5.0	15.8	3.2

	DO NOT KNOW ABOUT	KNOW & DO NOT NEED	USED IN PAST YEAR & HELPFUL	USED IN PAST YEAR & NOT HELPFUL	KNOW, NEED, BUT UNABLE TO GET	MISSING
REGION 9: COMMUNITY-BASED RESOURCES						
F2FHIC	87.5	8.3	4.2	0.0	0.0	4.0
SICC	91.7	4.2	4.2	0.0	0.0	4.0
SIBSHOPS	8.3	12.5	4.2	0.0	0.0	4.0
LBPAO	95.8	4.2	0.0	0.0	0.0	4.0
LOUISIANA PLANNING COUNCIL ON DD	87.5	8.3	4.2	0.0	0.0	4.0
RESIDENTAL OPTIONS WAIVER	83.3	12.5	4.2	0.0	0.0	4.0
BCSS	83.3	12.5	0.0	0.0	4.2	4.0
SUPPORTS WAIVER	87.5	4.2	4.2	0.0	4.2	4.0
NEW OPPORTUNITIES WAIVER	87.0	4.3	0.0	0.0	8.7	8.0
COMMUNITY SUPPORT TEAMS	91.7	4.2	4.2	0.0	0.0	4.0
TH&SC INJURY TRUST	69.6	17.4	0.0	0.0	13.0	8.0
EXTENDED FAMILY LIVING	79.2	20.8	0.0	0.0	0.0	4.0
INTERMEDIATE CARE DD	79.2	16.7	0.0	0.0	4.2	4.0
LA PARENT TRAINING INFORMATION CENTERS	70.8	16.7	12.5	0.0	0.0	4.0
PEER PARENT TRAINING	79.2	12.5	0.0	0.0	8.3	4.0
COMMISSION FOR THE DEAF	75.0	20.8	0.0	0.0	4.2	4.0
BIRTH DEFECTS MONITORING NETWORK	75.0	20.8	0.0	0.0	4.2	4.0
RESOURCE CENTERS	79.2	8.3	12.5	0.0	0.0	4.0
CHILDREN'S CHOICE WAIVER	78.3	4.3	13.0	0.00	4.3	8.0
CSHS CARE COORDINATION & TRANSITION	70.8	20.8	8.3	0.0	0.0	4.0
SUPPORTED LIVING	75.0	20.8	0.0	0.0	4.2	4.0
CRISIS MANAGEMENT SERVICES	79.2	20.8	0.0	0.0	0.0	4.0
VOCATIONAL REHABILITATION	70.8	16.7	8.3	0.0	4.2	4.0
PEER SUPPORT GROUP	79.2	8.3	12.5	0.0	0.0	4.0
LONG TERM PERSONAL CARE SERVICES	54.2	29.2	8.3	0.0	8.3	4.0
MENTAL HEALTH REHABILITATION SERVICES	79.2	20.8	0.0	0.0	0.0	4.0
INDEPENDENT LIVING PROGRAM	54.2	37.5	0.0	0.0	8.3	4.0
ADULT DAY HEALTH CARE WAIVER	66.7	33.3	0.0	0.0	0.0	4.0
CASH SUBSIDY	74.0	0.0	13.0	0.0	13.0	8.0
ELDERLY & DISABLED ADULTS WAIVER	66.7	29.2	0.0	0.0	4.2	4.0
INDEPENDENT LIVING	70.8	25.0	4.2	0.0	0.0	4.0
SUPPORT SERVICES	75.0	8.3	16.7	0.0	0.0	4.0
BLIND SERVICES	50.0	33.3	0.0	0.0	16.7	4.0
INDIVIDUAL AND FAMILY SUPPORT	87.5	0.0	12.5	0.0	0.0	4.0
EARLY CHILDHOOD SUPPORT SERVICES	66.7	16.7	8.3	0.0	8.3	4.0
RESPIRE CARE/SERVICES	38.5	23.1	23.1	0.0	15.4	48.0
ASSISTIVE TRANSPORTATION	58.3	16.7	8.3	4.2	12.5	4.0
DURABLE MEDICAL EQUIPMENT	62.5	16.7	16.7	0.0	4.2	4.0
CSHS SUBSPECIALTY CLINICS	54.2	12.5	25.0	0.0	8.3	4.0
HEARING, SPEECH & VISION	54.2	8.3	29.2	4.2	4.2	4.0
FOSTER CARE SERVICES	50.0	45.8	0.0	0.0	4.2	4.0
CHILD CARE ASSISTANCE PROGRAM	62.5	25.0	12.5	0.0	0.0	4.0
EARLY STEPS	54.2	20.8	25.0	0.0	0.0	4.0
DISABILITIES DETERMINATION SERVICES/SSI	45.8	16.7	33.3	0.0	4.2	4.0
HEAD START	33.3	33.3	20.8	0.0	12.5	4.0
WIC NUTRITIONAL ASSISTANCE PROGRAM	37.5	20.8	37.5	0.0	4.2	4.0
MEDICAID	33.3	62.5	0.0	0.0	4.2	4.0
FOOD STAMPS	16.7	8.3	45.8	0.0	29.2	4.0

## **Appendix I. Final Report of the Family Survey**

### **Needs Assessment Overview**

The Louisiana Office of Public Health Children's Special Health Services (CSHS) program is required, as a recipient of the Maternal and Child Health Bureau (MCHB) Title V grant, to conduct every five years a statewide Needs Assessment (NA). It is through the NA process that CSHS will identify both the consistent and new emerging needs for their target population, Children and Youth with Special Health Care Needs (CYSHCN) and their families. Additionally, the NA process involves identifying the appropriate the state and federal initiatives that relate to the priority area needs, and integrating them within the established Maternal and Child Health Pyramid of services. The 2010 CSHS NA has multiple components, of which one will be detailed in this publication. This report describes the background, methods, results, and conclusions for the statewide assessment of the knowledge, use, and need for community based resources among Louisiana's CYSHCN and their families.

### **Background**

CYSHCN in Louisiana are a dynamic group, who by definition require a multitude of medical, educational, and social/behavioral health services. Gaps in service use, need, and satisfaction have been noted according to race, ethnicity, household income, and primary guardian(s) educational level attainment. The Maternal and Child Health Bureau has established six national and state outcomes measures, which also reflect the American Academy of Pediatrics (AAP) defined characteristics of a Medical Home. Through the National Survey of Children with Special Health Care Needs (NS-CSHCN), each state able to confidently estimate the proportion of children and youth who meet special health care need criteria, service use, need, and satisfaction, and the proportion who meet each MCHB outcome measure. The CSHS epidemiologist conducted multiple analyses using the recent 2005-06 NSCHSN to determine Louisiana specific steady and emerging needs in order to identify factors the CSHS program needed to further investigate. It was decided to compare outcomes by Medicaid eligibility status since health care insurance coverage reflects access, system use, satisfaction of use, needs, and health outcomes. This analysis was also done using the 2007 National Survey of Children's Health. The information gleaned from these analyses were compared to supplemental data from the CSHS patient care coordination database (PCCD) data, the Families Helping Families (FHF) organizations' yearly activity summary reports from each of their ten regional offices, and the Louisiana Department of Education, Special Education section report in order to concur and provide further insight into the statistical picture. Based on all the information obtained it was determined that obstacles from attaining better health outcomes for

Louisiana's CYSHCN population were the product of the complexity of the service system, and dependency on the family by service providers to translate critical health/educational information. Consequently, many of Louisiana's families with CYSHCN experience redundant services, incomplete care, and both time and financial constraints.

## **Methods**

In the Fall of 2009, the CSHS epidemiologist presented the analysis findings to the program director, manager, statewide nurse consultant, statewide social work consultant, statewide parent liaison consultant, and statewide care coordinator supervisor. Based on the results of the analyses it was agreed that more specific information was needed to supplement the statistics generated. The needed information was the knowledge, use, satisfaction, and needs for community based resources for Louisiana's CYSHCN and their families. It was noted however, that capturing a comprehensive list of all CSYCHN and their families was logistically and financially unfeasible. Through discussions, it was decided that the best source to gather the data on the family perspective was from collaboration with each of the 10 FHF regional offices, and therefore obtain feedback from a convenience sample. In September 2009 the statewide nurse consultant and epidemiologist collaboratively developed a brief 3-paged survey that covered the content areas of access to services, knowledge, use, and satisfaction with services, and transition benchmark measures. People eligible to answer the survey were families with CYSHCN, or YSHCN. They must have at least 1 CYSHCN living in the household. The CSHS statewide parent liaison consultant and statewide parent training coordinator reviewed the survey for clarity and content prior to disseminating to the public. Both the statewide parent liaison consultant and statewide parent training coordinator contacted each FHF regional office and briefly explained the CSHS 2010 Needs Assessment process and the Family Survey, in order to garner collaboration with disseminating and promoting the survey. The survey was published in the Winter publication of the quarterly newsletter, Family Matters. This publication is spearheaded by the CSHS statewide parent training coordinator, but is produced in collaboration with a diverse group of parents with CYSHCN, physicians, nurses, social workers, and CSHS Central Office Staff. Distribution of the publication is through many means. The editor mails approximately 60 hard copies to each regional FHF parent liaisons, who then copy the newsletter and display these at each of the nine CSHS statewide subspecialty clinics, in each FHF regional office, as well as community outreach events. The editor also has a subscriber list of 100 persons and groups who receive the edition by email. The publication was posted on the CSHS program website beginning on October 7, 2009, and remained until January 14, 2010. The newsletter was posted on the family section of the program

website. The survey was also posted, by a hyperlink on the CSHS home page listed under the current highlights section. Each FHF regional staff members promoted the survey at outreach events, within the office, community meetings, conferences, and parent groups. The respondent could complete the survey on their own, or with help from any FHF staff member, another parent, or anyone they requested. The surveys were mailed to the CSHS epidemiologist. Parents could mail them to CSHS themselves, or if they wished to save on postage cost, could request the parent liaison in their respective regional office to mail their completed survey. Results were inputted into an Excel 2007 database, where data cleaning was also conducted. Data was transferred to SPSS (v. 15) for all analyses. Simple descriptive and stratified frequency counts were conducted for respondent characteristics, community resource variables, and transition outcomes. Means were calculated for resource priority rankings.

## Results

There were 429 respondents. The survey was initially published with an error; a result from pasting the document in MS Publisher. Therefore, one community resource, respite care, was removed from the list of assessed resources. The mistake was quickly (within 2 weeks) corrected, and the complete survey was pasted in the newsletter. Staff in each of the 10 FHF offices were alerted of this mistake and asked to ensure the proper survey was disseminated to parents. Of the respondents, roughly half were families with Youth with Special Health Care Needs (YSHCN). The majority were African-American. Most had only one child in the household who had a special health care need. Finally, most responses originated from regions 3 and 8.

	TOTAL RESPONDENTS (n=429)	FAMILIES WITH CSHCN (n=210)	FAMILIES WITH YSHCN (n=219)
<b>RACE</b>			
AFRICAN-AMERICAN/BLACK	53.4	49.0	57.9
CAUCASIAN/WHITE	39.2	41.7	36.5
ASIAN	0.2	0.0	0.5
NATIVE AMERICAN/ALASKAN NATIVE	2.0	2.9	1.0
NATIVE HAWAIIAN/PACIFIC ISLANDER	0.0	0.0	0.0
MULTIPLE RACE	3.5	3.9	3.0
OTHER	1.7	2.5	1.0
<b>ETHNICITY</b>			
HISPANIC	5.0	5.3	4.6
NON-HISPANIC	95.0	94.7	95.4
<b># CYSHCN IN HOUSEHOLD</b>			
1	84.1	85.7	83.0



2	13.5	11.9	14.7
3	1.6	1.9	1.4
4	0.5	0.5	0.5
5	0.2	0.0	0.5
AGE			
BIRTH-9 YEARS	46.5	86.5	0.0
10-14 YEARS	23.1	13.5	34.8
15-18 YEARS	20.8	0.0	44.5
19+ YEARS	9.6	0.0	20.6
REGION OF RESIDENCE			
1	7.7	8.6	6.9
2	12.6	12.4	12.8
3	25.2	28.6	22.0
4	5.1	5.2	5.0
5	4.7	3.3	6.0
6	7.0	9.0	5.0
7	2.8	2.9	2.8
8	29.0	23.8	33.9
9	5.8	6.2	5.5

### Priority Needs

Respondents were asked to rank ten listed resources from 1 to 10, where 1 is the most important, and 10 was the least. Unfortunately, a lot of respondents had difficulty with this question; for example, they would record 1 for all ten. This resulted in approximately 37% of responses missing. For the remaining responses, the mean for each resource was calculated and ranked from lowest to highest value. This was done for all respondents, and then by age, race, and region. The top four priorities centered around access to medical providers who accepted Medicaid. With a few exceptions, this was consistently the case even in stratified analyses.

Resource Priority Rankings (n=267)	
Rank (mean score)	Priority
1 (4.08)	Pediatricians who accept Medicaid
2 (4.25)	Subspecialists who accept Medicaid
3 (4.32)	OT/PT who accept CYSHCN with Medicaid
4 (4.60)	Dentists who accept CYSHCN with Medicaid
5 (5.41)	Expanded Prescription Coverage
6 (5.51)	Transition for YSHCN
7 (6.10)	Accessible Transportation
8 (6.17)	Mental Health Services
9 (6.19)	Care Coordination by Primary Care Physician
10 (8.08)	Translators in Pediatric Practices

Resource Priority Rankings among Families with CSHCN (n=135)

Rank (mean score)	Priority
1 (3.78)	Pediatricians who accept Medicaid
2 (4.12)	OT/PT who accept CYSHCN with Medicaid
3 (4.33)	Dentists who accept CYSHCN with Medicaid
4 (4.36)	Subspecialists who accept Medicaid
5 (5.47)	Expanded Prescription Coverage
6 (5.53)	Transition for YSHCN
7 (6.11)	Mental Health Services
8 (6.28)	Care Coordination by Primary Care Physician
9 (6.30)	Accessible Transportation
10 (8.32)	Translators in Pediatric Practices

Resource Priority Rankings among Families with YSHCN (n=132)

Rank (mean score)	Priority
1 (4.14)	Subspecialists who accept Medicaid
2 (4.39)	Pediatricians who accept Medicaid
3 (4.54)	OT/PT who accept CYSHCN with Medicaid
4 (4.88)	Dentists who accept CYSHCN with Medicaid
5 (5.35)	Expanded Prescription Coverage
6 (5.50)	Transition for YSHCN
7 (5.89)	Accessible Transportation
8 (6.10)	Care Coordination by Primary Care Physician
9 (6.24)	Mental Health Services
10 (7.83)	Translators in Pediatric Practices

African American/Black Respondents (n=127)

Rank (mean score)	Priority
1 (4.40)	Pediatricians who accept Medicaid
2 (4.43)	Subspecialists who accept Medicaid
3 (4.67)	OT/PT who accept CYSHCN with Medicaid
4 (4.77)	Dentists who accept CYSHCN with Medicaid
5 (5.01)	Transition for YSHCN
6 (5.46)	Expanded Prescription Coverage
7 (5.53)	Accessible Transportation
8 (6.03)	Mental Health Services
9 (6.35)	Care Coordination by Primary Care Physician
10 (7.98)	Translators in Pediatric Practices

White Respondents (n=99)

Rank (mean score)	Priority
1 (3.59)	Pediatricians who accept Medicaid
2 (3.98)	OT/PT who accept CYSHCN with Medicaid
3 (4.04)	Subspecialists who accept Medicaid
4 (4.38)	Dentists who accept CYSHCN with Medicaid
5 (5.21)	Expanded Prescription Coverage
6 (6.00)	Transition for YSHCN
7 (6.02)	Care Coordination by Primary Care Physician
8 (6.28)	Mental Health Services
9 (6.98)	Accessible Transportation
10 (8.42)	Translators in Pediatric Practices

Native American/Alaskan Native Respondents (n=5)

Rank (mean score)	Priority
1 (3.20)	Subspecialists who accept Medicaid
2 (3.60)	Pediatricians who accept Medicaid
3 (4.00)	Dentists who accept CYSHCN with Medicaid
4 (4.40)	OT/PT who accept CYSHCN with Medicaid
5 (5.00)	Care Coordination by Primary Care Physician
6 (5.80)	Expanded Prescription Coverage
7 (6.00)	Accessible Transportation
8 (7.40)	Translators in Pediatric Practices
9 (7.80)	Mental Health Services
10 (8.00)	Transition for YSHCN

Multiple Race Respondents (n=11)

Rank (mean score)	Priority
1 (4.08)	Pediatricians who accept Medicaid
2 (4.25)	Subspecialists who accept Medicaid
3 (4.32)	OT/PT who accept CYSHCN with Medicaid
4 (4.60)	Dentists who accept CYSHCN with Medicaid
5 (5.41)	Expanded Prescription Coverage
6 (5.51)	Transition for YSHCN
7 (6.10)	Accessible Transportation
8 (6.17)	Mental Health Services
9 (6.19)	Care Coordination by Primary Care Physician
10 (8.08)	Translators in Pediatric Practices

Other Race Respondents (n=7)

Rank (mean score)	Priority
1 (2.43)	Dentists who accept CYSHCN with Medicaid
2 (2.57)	Pediatricians who accept Medicaid
3 (3.71)	Subspecialists who accept Medicaid
4 (3.86)	OT/PT who accept CYSHCN with Medicaid
5 (6.00)	Translators in Pediatric Practices
6 (6.57)	Care Coordination by Primary Care Physician
7 (7.00)	Accessible Transportation
8 (7.43)	Mental Health Services
9 (7.71)	Transition for YSHCN
10 (7.71)	Expanded Prescription Coverage

Region 1 Respondents (n=25)

Rank (mean score)	Priority
1 (4.04)	Subspecialists who accept Medicaid
2 (4.20)	OT/PT who accept CYSHCN with Medicaid
3 (4.24)	Pediatricians who accept Medicaid
4 (4.80)	Dentists who accept CYSHCN with Medicaid
5 (5.24)	Accessible Transportation
6 (5.68)	Transition for YSHCN
7 (5.85)	Expanded Prescription Coverage
8 (6.04)	Care Coordination by Primary Care Physician
9 (6.35)	Mental Health Services
10 (8.32)	Translators in Pediatric Practices

Region 2 Respondents (n=26)

Rank (mean score)	Priority
1 (3.58)	Subspecialists who accept Medicaid
2 (4.33)	Pediatricians who accept Medicaid
3 (4.42)	OT/PT who accept CYSHCN with Medicaid
4 (4.81)	Dentists who accept CYSHCN with Medicaid
5 (4.92)	Transition for YSHCN
6 (5.62)	Care Coordination by Primary Care Physician
7 (5.93)	Expanded Prescription Coverage
8 (6.08)	Accessible Transportation
9 (6.52)	Mental Health Services
10 (8.27)	Translators in Pediatric Practices

Region 3 Respondents (n=68)

Rank (mean score)	Priority
1 (3.97)	Pediatricians who accept Medicaid
2 (4.14)	OT/PT who accept CYSHCN with Medicaid
3 (4.34)	Dentists who accept CYSHCN with Medicaid
4 (4.74)	Expanded Prescription Coverage
5 (4.86)	Subspecialists who accept Medicaid
6 (5.71)	Mental Health Services
7 (5.713)	Transition for YSHCN
8 (6.36)	Accessible Transportation
9 (6.50)	Care Coordination by Primary Care Physician
10 (8.46)	Translators in Pediatric Practices

Region 4 Respondents (n=12)

Rank (mean score)	Priority
1 (3.58)	Subspecialists who accept Medicaid
2 (4.33)	Dentists who accept CYSHCN with Medicaid
3 (4.42)	Pediatricians who accept Medicaid
4 (4.81)	Transition for YSHCN
5 (4.92)	OT/PT who accept CYSHCN with Medicaid
6 (5.62)	Expanded Prescription Coverage
7 (5.93)	Care Coordination by Primary Care Physician
8 (6.08)	Mental Health Services
9 (6.52)	Accessible Transportation
10 (8.27)	Translators in Pediatric Practices

Region 5 Respondents (n=7)

Rank (mean score)	Priority
1 (3.13)	Pediatricians who accept Medicaid
2 (4.13)	OT/PT who accept CYSHCN with Medicaid
3 (4.29)	Care Coordination by Primary Care Physician
4 (4.43)	Dentists who accept CYSHCN with Medicaid
5 (4.43)	Subspecialists who accept Medicaid
6 (6.29)	Expanded Prescription Coverage
7 (6.57)	Transition for YSHCN
8 (6.57)	Accessible Transportation
9 (6.88)	Mental Health Services
10 (8.00)	Translators in Pediatric Practices

Region 6 Respondents (n=20)

Rank (mean score)	Priority
1 (3.71)	Pediatricians who accept Medicaid
2 (4.00)	Subspecialists who accept Medicaid
3 (5.00)	Care Coordination by Primary Care Physician
4 (5.10)	Dentists who accept CYSHCN with Medicaid
5 (5.48)	OT/PT who accept CYSHCN with Medicaid
6 (5.75)	Accessible Transportation
7 (5.86)	Transition for YSHCN
8 (6.71)	Translators in Pediatric Practices
9 (6.38)	Expanded Prescription Coverage
10 (7.00)	Mental Health Services

Region 7 Respondents (n=2)

Rank (mean score)	Priority
1 (2.67)	Subspecialists who accept Medicaid
2 (3.30)	Transition for YSHCN
3 (4.00)	OT/PT who accept CYSHCN with Medicaid
4 (4.50)	Pediatricians who accept Medicaid
5 (5.33)	Accessible Transportation
6 (5.50)	Dentists who accept CYSHCN with Medicaid
7 (5.67)	Expanded Prescription Coverage
8 (5.67)	Care Coordination by Primary Care Physician
9 (7.75)	Mental Health Services
10 (9.00)	Translators in Pediatric Practices

Region 8 Respondents (n=88)

Rank (mean score)	Priority
1 (4.16)	OT/PT who accept CYSHCN with Medicaid
2 (4.30)	Pediatricians who accept Medicaid
3 (4.51)	Subspecialists who accept Medicaid
4 (4.47)	Dentists who accept CYSHCN with Medicaid
5 (5.10)	Expanded Prescription Coverage
6 (5.43)	Transition for YSHCN
7 (6.07)	Accessible Transportation
8 (6.22)	Mental Health Services
9 (6.63)	Care Coordination by Primary Care Physician
10 (7.96)	Translators in Pediatric Practices

Region 9 Respondents (n=18)	
Rank (mean score)	Priority
1 (3.45)	Subspecialists who accept Medicaid
2 (3.58)	Pediatricians who accept Medicaid
3 (4.11)	OT/PT who accept CYSHCN with Medicaid
4 (5.00)	Dentists who accept CYSHCN with Medicaid
5 (5.06)	Mental Health Services
6 (5.89)	Transition for YSHCN
7 (6.10)	Care Coordination by Primary Care Physician
8 (6.26)	Accessible Transportation
9 (6.56)	Expanded Prescription Coverage
10 (8.16)	Translators in Pediatric Practices

### Access to community resources/supports

Challenges related to accessing community resources and/or supports were assessed with seven questions. The obstacles centered around location, provider knowledge of resources, and resource capacity, as well as an option where the respondent could input a specific challenge they faced that was otherwise not captured in the available list. Lastly, the respondent could cite there was no problem with access. The majority of respondents answered that they did not have any problems accessing services. Among those experiencing problems, most stated the reason was because there were no resources nearby, or that the nearby resource was not taking on new clients.

### Accessing Community Resources/Supports among all respondents (n=429)

	YES	NO	MISSING
Location is hard to get to	21.7%	78.3%	11.0%
MD/Staff do not know about any resources nearby	17.0%	83.0%	11.0%
MD/Staff do not know eligibility requirements for resources	17.8%	82.2%	11.0%
There are not many resources nearby	25.7%	74.3%	11.0%
The resources nearby are not taking on new clients	26.2%	73.8%	11.0%
Other	7.3%	92.7%	11.0%
None-I have no problems accessing resources	47.2%	52.8%	11.2%

### Accessing Community Resources/Supports among Families with CSHCN (n=210)

	YES	NO	MISSING
Location is hard to get to	21.8%	78.2%	8.1%
MD/Staff do not know about any resources nearby	18.1%	81.9%	8.1%
MD/Staff do not know eligibility requirements for resources	20.2%	79.8%	8.1%
There are not many resources nearby	29.0%	71.0%	8.1%
The resources nearby are not taking on new clients	26.4%	73.6%	8.1%
Other	8.8%	91.2%	8.1%
None-I have no problems accessing resources	45.8%	54.2%	8.6%

**Accessing Community Resources/Supports among Families with YSHCN (n=219)**

	YES	NO	MISSING
Location is hard to get to	21.7%	78.3%	13.7%
MD/Staff do not know about any resources nearby	15.9%	84.1%	13.7%
MD/Staff do not know eligibility requirements for resources	15.3%	84.7%	13.7%
There are not many resources nearby	22.2%	77.8%	13.7%
The resources nearby are not taking on new clients	25.9%	74.1%	13.7%
Other	5.8%	94.2%	13.7%
None-I have no problems accessing resources	48.7%	51.3%	13.7%

**Accessing Community Resources/Supports among Missing Race Respondents (n=28)**

	YES	NO	MISSING
Location is hard to get to	50.0%	50.0%	35.7%
MD/Staff do not know about any resources nearby	44.4%	55.6%	35.7%
MD/Staff do not know eligibility requirements for resources	27.8%	72.2%	35.7%
There are not many resources nearby	44.4%	55.6%	35.7%
The resources nearby are not taking on new clients	38.9%	61.1%	35.7%
Other	5.6%	94.4%	35.7%
None-I have no problems accessing resources	38.9%	61.1%	35.7%

**Accessing Community Resources/Supports among African American /Black Respondents (n=214)**

	YES	NO	MISSING
Location is hard to get to	19.6%	80.4%	9.3%
MD/Staff do not know about any resources nearby	13.4%	86.6%	9.3%
MD/Staff do not know eligibility requirements for resources	17.5%	82.5%	9.3%
There are not many resources nearby	23.7%	76.3%	9.3%
The resources nearby are not taking on new clients	21.6%	78.4%	9.3%
Other	8.8%	91.2%	9.3%
None-I have no problems accessing resources	51.3%	48.7%	9.8%

**Accessing Community Resources/Supports among White Respondents (n=157)**

	YES	NO	MISSING
Location is hard to get to	22.0%	78.0%	10.2%
MD/Staff do not know about any resources nearby	18.4%	81.6%	10.2%
MD/Staff do not know eligibility requirements for resources	18.4%	81.6%	10.2%
There are not many resources nearby	24.8%	75.2%	10.2%
The resources nearby are not taking on new clients	31.2%	68.8%	10.2%
Other	4.3%	95.7%	10.2%
None-I have no problems accessing resources	44.0%	56.0%	10.2%



**Accessing Community Resources/Supports among Native American/Alaskan Native Respondents (n=8)**

	YES	NO	MISSING
Location is hard to get to	0.0%	100.0%	0.0%
MD/Staff do not know about any resources nearby	12.5%	87.5%	0.0%
MD/Staff do not know eligibility requirements for resources	12.5%	87.5%	0.0%
There are not many resources nearby	25.0%	75.0%	0.0%
The resources nearby are not taking on new clients	25.0%	75.0%	0.0%
Other	12.5%	87.5%	0.0%
None-I have no problems accessing resources	50.0%	50.0%	0.0%

**Accessing Community Resources/Supports among Multiple Race Respondents (n=14)**

	YES	NO	MISSING
Location is hard to get to	23.1%	76.9%	7.1%
MD/Staff do not know about any resources nearby	15.4%	84.6%	7.1%
MD/Staff do not know eligibility requirements for resources	7.7%	92.3%	7.1%
There are not many resources nearby	30.8%	69.2%	7.1%
The resources nearby are not taking on new clients	30.8%	69.2%	7.1%
Other	15.4%	84.6%	7.1%
None-I have no problems accessing resources	23.1%	76.9%	7.1%

**Accessing Community Resources/Supports among Other Race Respondents (n=7)**

	YES	NO	MISSING
Location is hard to get to	28.6%	71.4%	0.0%
MD/Staff do not know about any resources nearby	28.6%	71.4%	0.0%
MD/Staff do not know eligibility requirements for resources	14.3%	85.7%	0.0%
There are not many resources nearby	42.9%	57.1%	0.0%
The resources nearby are not taking on new clients	14.3%	85.7%	0.0%
Other	14.3%	85.7%	0.0%
None-I have no problems accessing resources	57.1%	42.9%	0.0%

**Accessing Community Resources/Supports Region 1 (n=33)**

	YES	NO	MISSING
Location is hard to get to	32.3%	67.7%	6.1%
MD/Staff do not know about any resources nearby	16.1%	83.9%	6.1%
MD/Staff do not know eligibility requirements for resources	22.6%	77.4%	6.1%
There are not many resources nearby	35.5%	64.5%	6.1%
The resources nearby are not taking on new clients	12.9%	87.1%	6.1%
Other	16.1%	83.9%	6.1%
None-I have no problems accessing resources	46.7%	53.3%	9.1%

**Accessing Community Resources/Supports Region 2 (n=54)**

	YES	NO	MISSING
Location is hard to get to	22.7%	77.3%	18.5%
MD/Staff do not know about any resources nearby	20.5%	79.5%	18.5%
MD/Staff do not know eligibility requirements for resources	18.2%	81.8%	18.5%
There are not many resources nearby	25.0%	75.0%	18.5%
The resources nearby are not taking on new clients	34.1%	65.9%	18.5%
Other	4.5%	95.5%	18.5%
None-I have no problems accessing resources	34.1%	65.9%	18.5%

**Accessing Community Resources/Supports Region 3 (n=108)**

	YES	NO	MISSING
Location is hard to get to	27.2%	72.8%	4.6%
MD/Staff do not know about any resources nearby	20.4%	79.6%	4.6%
MD/Staff do not know eligibility requirements for resources	21.4%	78.6%	4.6%
There are not many resources nearby	28.2%	71.8%	4.6%
The resources nearby are not taking on new clients	65.0%	35.0%	4.6%
Other	10.7%	89.3%	4.6%
None-I have no problems accessing resources	42.7%	57.3%	4.6%

**Accessing Community Resources/Supports Region 4 (n=22)**

	YES	NO	MISSING
Location is hard to get to	23.8%	76.2%	4.5%
MD/Staff do not know about any resources nearby	28.6%	71.4%	4.5%
MD/Staff do not know eligibility requirements for resources	28.6%	71.4%	4.5%
There are not many resources nearby	38.1%	61.9%	4.5%
The resources nearby are not taking on new clients	23.8%	76.2%	4.5%
Other	4.8%	95.2%	4.5%
None-I have no problems accessing resources	38.1%	61.9%	4.5%

**Accessing Community Resources/Supports Region 5 (n=20)**

	YES	NO	MISSING
Location is hard to get to	21.4%	78.6%	30.0%
MD/Staff do not know about any resources nearby	7.1%	92.9%	30.0%
MD/Staff do not know eligibility requirements for resources	7.1%	92.9%	30.0%
There are not many resources nearby	14.3%	85.7%	30.0%
The resources nearby are not taking on new clients	7.1%	92.9%	30.0%
Other	0.0%	100.0%	30.0%
None-I have no problems accessing resources	71.4%	28.6%	30.0%

**Accessing Community Resources/Supports Region 6 (n=30)**

	YES	NO	MISSING
Location is hard to get to	16.0%	84.0%	16.7%
MD/Staff do not know about any resources nearby	8.0%	92.0%	16.7%
MD/Staff do not know eligibility requirements for resources	20.0%	80.0%	16.7%
There are not many resources nearby	16.0%	84.0%	16.7%
The resources nearby are not taking on new clients	28.0%	72.0%	16.7%
Other	8.0%	92.0%	16.7%
None-I have no problems accessing resources	65.0%	44.0%	16.7%

**Accessing Community Resources/Supports Region 7 (n=12)**

	YES	NO	MISSING
Location is hard to get to	11.1%	88.9%	25.0%
MD/Staff do not know about any resources nearby	22.2%	77.8%	25.0%
MD/Staff do not know eligibility requirements for resources	22.2%	77.8%	25.0%
There are not many resources nearby	22.2%	77.8%	25.0%
The resources nearby are not taking on new clients	11.1%	88.9%	25.0%
Other	11.1%	88.9%	25.0%
None-I have no problems accessing resources	55.6%	44.4%	25.0%

**Accessing Community Resources/Supports Region 8 (n=124)**

	YES	NO	MISSING
Location is hard to get to	13.4%	86.6%	9.7%
MD/Staff do not know about any resources nearby	11.6%	88.4%	9.7%
MD/Staff do not know eligibility requirements for resources	11.6%	88.4%	9.7%
There are not many resources nearby	21.4%	78.6%	9.7%
The resources nearby are not taking on new clients	17.9%	82.1%	9.7%
Other	3.6%	96.4%	9.7%
None-I have no problems accessing resources	58.0%	42.0%	9.7%

**Accessing Community Resources/Supports Region 9 (n=25)**

	YES	NO	MISSING
Location is hard to get to	30.4%	69.6%	8.0%
MD/Staff do not know about any resources nearby	26.1%	73.9%	8.0%
MD/Staff do not know eligibility requirements for resources	17.4%	82.6%	8.0%
There are not many resources nearby	30.4%	69.6%	8.0%
The resources nearby are not taking on new clients	47.8%	52.2%	8.0%
Other	8.7%	91.3%	8.0%
None-I have no problems accessing resources	21.7%	78.3%	8.0%

The next question listed 48 community resources and/or supports. The respondent was asked to circle a number next to the resource that captured either their knowledge or their experience of using a community resource/support in the past 12 months. The answers to this question were analyzed for the entire respondent group, then by age, race (black, white), and region. Because there were so many respondents who did not know about a community resource and/or support, the results were ranked from the highest to lowest proportion for that answer choice (Appendices a-n).

### Subspecialty Care

CSHS provides direct subspecialty care for Louisiana’s CYSHCN population in nine regional parish health units. Under the state statutes, CSHS is limited in this capacity by only providing care for those children and youth who meet both medical and financial eligibility. However, this curve cutting intervention approach is effective in improving access to care in health care sector deprived areas, mostly rural parishes, and locations where the type of subspecialist availability is limited. With the expansion Medicaid eligibility requirements, Louisiana has seen improvements in the proportion of CYSHCN who have adequate health insurance (NSCSHCN 2001: 51.9% vs. NSCSHCN 2006/05: 65.5%). However, as the results of priority analyses discussed above, many families would like more providers who accept Medicaid for service reimbursement. Thus, although Medicaid enables affordability of medical care, access to providers remains a challenge as physicians chose to not be a Louisiana Medicaid provider. Based on this information, it was important for CSHS to assess the ease or challenges families face when accessing subspecialists. The information gleamed, although not representative of all Louisiana families with CYSHCN, will indicate the degree to which subspecialty direct medical care remains a consistent need, and the role in which CSHS will remain a gap filling entity. The access to subspecialty care was assessed based on location, transportation, and health financing. Results were analyzed overall, then by age, race, and region.

#### **Subspecialty Care (n=429)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	24.0%	76.0%	6.8%
I am able to travel outside area to see the Subspecialist	68.5%	31.5%	7.5%
Type of Subspecialist I need is not in my area	37.9%	62.1%	13.3%
Type of Subspecialist I need is in my area but doesn’t take my insurance	22.0%	78.0%	14.0%

**Subspecialty Care among families with YSHCN (n=219)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	26.8%	73.2%	9.6%
I am able to travel outside area to see the Subspecialist	63.5%	36.5%	8.7%
Type of Subspecialist I need is not in my area	35.1%	64.9%	15.5%
Type of Subspecialist I need is in my area but doesn't take my insurance	22.8%	77.2%	16.0%

**Subspecialty Care among families with CSHCN (n=210)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	21.3%	78.7%	3.8%
I am able to travel outside area to see the Subspecialist	73.6%	26.4%	6.2%
Type of Subspecialist I need is not in my area	40.6%	59.4%	11.0%
Type of Subspecialist I need is in my area but doesn't take my insurance	21.1%	78.9%	11.9%

**Subspecialty Care among Missing Race Respondents (n=28)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	30.0%	70.0%	28.6%
I am able to travel outside area to see the Subspecialist	50.0%	50.0%	28.6%
Type of Subspecialist I need is not in my area	50.0%	50.0%	35.7%
Type of Subspecialist I need is in my area but doesn't take my insurance	22.2%	77.8%	35.7%

**Subspecialty Care among African American/Black Respondents (n=214)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	21.0%	79.0%	4.2%
I am able to travel outside area to see the Subspecialist	65.7%	34.3%	6.1%
Type of Subspecialist I need is not in my area	38.4%	61.6%	13.6%
Type of Subspecialist I need is in my area but doesn't take my insurance	21.6%	78.4%	13.6%

**Subspecialty Care among White Respondents (n=157)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	27.9%	72.1%	6.4%
I am able to travel outside area to see the Subspecialist	77.0%	23.0%	5.7%
Type of Subspecialist I need is not in my area	37.9%	62.1%	10.8%
Type of Subspecialist I need is in my area but doesn't take my insurance	22.3%	77.7%	11.5%

**Subspecialty Care among Native American/Alaskan Native Respondents (n=8)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	12.5%	87.5%	0.0%
I am able to travel outside area to see the Subspecialist	50.0%	50.0%	0.0%
Type of Subspecialist I need is not in my area	12.5%	87.5%	0.0%
Type of Subspecialist I need is in my area but doesn't take my insurance	25.0%	75.0%	0.0%

**Subspecialty Care among Multiple Race Respondents (n=14)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	16.7%	83.3%	14.3%
I am able to travel outside area to see the Subspecialist	61.5%	38.5%	7.1%
Type of Subspecialist I need is not in my area	30.8%	69.2%	7.1%
Type of Subspecialist I need is in my area but doesn't take my insurance	16.7%	83.3%	14.3%

**Subspecialty Care among Other Race Respondents (n=7)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	42.9%	57.1%	0.0%
I am able to travel outside area to see the Subspecialist	50.0%	50.0%	14.3%
Type of Subspecialist I need is not in my area	42.9%	57.1%	0.0%
Type of Subspecialist I need is in my area but doesn't take my insurance	33.3%	66.7%	14.3%

**Subspecialty Care Region 1 (n=33)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	12.9%	87.1%	6.1%
I am able to travel outside area to see the Subspecialist	53.1%	46.9%	3.0%
Type of Subspecialist I need is not in my area	27.6%	72.4%	12.1%
Type of Subspecialist I need is in my area but doesn't take my insurance	14.3%	85.7%	15.2%

**Subspecialty Care Region 2 (n=54)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	32.7%	67.3%	9.3%
I am able to travel outside area to see the Subspecialist	62.5%	37.5%	11.1%
Type of Subspecialist I need is not in my area	51.1%	48.9%	16.7%
Type of Subspecialist I need is in my area but doesn't take my insurance	22.7%	77.3%	18.5%

**Subspecialty Care Region 3 (n=108)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	19.4%	80.6%	4.6%
I am able to travel outside area to see the Subspecialist	74.0%	26.0%	7.4%
Type of Subspecialist I need is not in my area	35.1%	64.9%	10.2%
Type of Subspecialist I need is in my area but doesn't take my insurance	21.4%	78.6%	9.3%

**Subspecialty Care Region 4 (n=22)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	28.6%	71.4%	4.5%
I am able to travel outside area to see the Subspecialist	70.0%	30.0%	9.1%
Type of Subspecialist I need is not in my area	40.0%	60.0%	9.1%
Type of Subspecialist I need is in my area but doesn't take my insurance	15.8%	84.2%	13.6%

**Subspecialty Care Region 5 (n=20)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	16.7%	83.3%	10.0%
I am able to travel outside area to see the Subspecialist	52.9%	47.1%	15.0%
Type of Subspecialist I need is not in my area	19.4%	70.6%	15.0%
Type of Subspecialist I need is in my area but doesn't take my insurance	22.2%	77.8%	10.0%

**Subspecialty Care Region 6 (n=30)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	33.3%	66.7%	10.0%
I am able to travel outside area to see the Subspecialist	92.9%	7.1%	6.7%
Type of Subspecialist I need is not in my area	35.0%	65.0%	33.3%
Type of Subspecialist I need is in my area but doesn't take my insurance	25.9%	74.1%	10.0%

**Subspecialty Care Region 7 (n=12)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	30.0%	70.0%	16.7%
I am able to travel outside area to see the Subspecialist	63.6%	36.4%	8.3%
Type of Subspecialist I need is not in my area	50.0%	50.0%	16.7%
Type of Subspecialist I need is in my area but doesn't take my insurance	42.9%	57.1%	41.7%

**Subspecialty Care Region 8 (n=124)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	22.4%	77.6%	6.5%
I am able to travel outside area to see the Subspecialist	66.1%	33.9%	7.3%
Type of Subspecialist I need is not in my area	36.0%	64.0%	10.5%
Type of Subspecialist I need is in my area but doesn't take my insurance	22.0%	78.0%	12.1%

**Subspecialty Care Region 9 (n=25)**

	YES	NO	MISSING
Problems getting Subspecialist Care in my area	37.5%	62.5%	4.0%
I am able to travel outside area to see the Subspecialist	72.0%	28.0%	0.0%
Type of Subspecialist I need is not in my area	50.0%	50.0%	12.0%
Type of Subspecialist I need is in my area but doesn't take my insurance	27.8%	72.2%	28.0%

Transition

CYSHCN are experiencing extended life expectancies as advances in medical technologies, diagnostics, and care have evolved. With the benefits of these changes, also come challenges as the youth ages and enters the adult medical model of care. Differences in health insurance coverage eligibility and benefits, degree of expertise and treatment experience among adult providers for otherwise childhood known health conditions, and the role the young adult with a special health care need plays in his/her health

care management are factors that influence successful transition from the pediatric physician to the adult provider. Based on data from the 2005/06 NS-CSHCN, approximately 40.9% of youth with special health care needs are considered to have received the services necessary to make appropriate transition to adult health care, work, and independence. Since health care financing is an important component to access, CSHS continues to provide needed subspecialty medical care in each of the nine parish health units for CYSHCN up to age 22. This extension of care into young adulthood minimizes disruption of insurance coverage related to LaCHIP eligibility. Furthermore, this time frame allows CSHS to remain an important contributor to the young adults care as staff assist the youth to establish an adult primary care provider, and to also find an adult specialist who has the expertise to address the young adult's unique health condition needs. Therefore, based on the need to increase receipt of transition services and ensure a smooth process, it was decided that the family survey would also include questions related to the components of transition. Most respondents reported that they had a primary care physician (86.7% (170)). Frequencies were run overall, as well as by race, and region, and results were limited to reflect transition components among respondents who stated they had a primary care physician.

<b>Transition Components among families with YSHCN (n=170)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	46.9	53.1	5.9
<i>The PCP has talked about finding an adult primary care provider</i>	34.0	66.0	8.2
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	28.9	71.1	6.5
<i>The PCP has talked about work and/or education choices for the future</i>	30.8	69.2	8.2
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	42.1	57.9	10.6

African American/Black respondents: 79.8% (91) YSHCN had a primary care physician

<b>Transition Components among African American/Black Respondents (n=91)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	49.4	50.6	8.8
<i>The PCP has talked about finding an adult primary care provider</i>	35.8	64.2	11.0
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	31.3	68.7	8.8
<i>The PCP has talked about work and/or education choices for the future</i>	35.3	64.7	6.6
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	42.9	57.1	7.7



White respondents: 86.1% (62) YSHCN had a primary care physician

<b>Transition Components among White Respondents (n=62)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	43.3	56.7	3.2
<i>The PCP has talked about finding an adult primary care provider</i>	33.9	66.1	4.8
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	23.3	76.7	3.2
<i>The PCP has talked about work and/or education choices for the future</i>	23.6	76.4	11.3
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	39.6	60.4	14.5

Region 1 respondents: 80.0% (12) YSHCN had a primary care physician

<b>Transition Components among Region 1 Respondents (n=12)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	66.7	33.3	0.0
<i>The PCP has talked about finding an adult primary care provider</i>	41.7	58.3	0.0
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	27.3	72.7	8.3
<i>The PCP has talked about work and/or education choices for the future</i>	20.0	80.0	16.7
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	30.0	70.0	16.7

Region 2 respondents: 82.1% (23) YSHCN had a primary care physician

<b>Transition Components among Region 2 Respondents (n=23)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	52.4	47.6	8.7
<i>The PCP has talked about finding an adult primary care provider</i>	45.5	54.5	4.3
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	45.5	54.5	4.3
<i>The PCP has talked about work and/or education choices for the future</i>	42.9	57.1	8.7
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	60.0	40.0	13.0

Region 3 respondents: 85.4% (41) YSHCN had a primary care physician

<b>Transition Components among Region 3 Respondents (n=41)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	35.1	64.9	9.8
<i>The PCP has talked about finding an adult primary care provider</i>	38.9	61.1	12.2
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	34.2	65.8	7.3
<i>The PCP has talked about work and/or education choices for the future</i>	40.5	59.5	9.8
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	47.1	52.9	17.1

Region 4 respondents: 72.7% (8) YSHCN had a primary care physicians

<b>Transition Components among Region 4 Respondents (n=8)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	28.6	71.4	12.5
<i>The PCP has talked about finding an adult primary care provider</i>	42.9	57.1	12.5
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	37.5	62.5	0.0
<i>The PCP has talked about work and/or education choices for the future</i>	25.0	75.0	0.0
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	37.5	62.5	0.0

Region 5 respondents: 61.5% (8) YSHCN had a primary care physician

<b>Transition Components among Region 5 Respondents (n=8)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	12.5	87.5	0.0
<i>The PCP has talked about finding an adult primary care provider</i>	12.5	87.5	0.0
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	12.5	87.5	0.0
<i>The PCP has talked about work and/or education choices for the future</i>	12.5	87.5	0.0
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	12.5	87.5	0.0

Region 6 respondents: 72.7% (8) YSHCN had a primary care physician

<b>Transition Components among Region 6 Respondents (n=8)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	62.5	37.5	0.0
<i>The PCP has talked about finding an adult primary care provider</i>	14.3	85.7	12.5
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	12.5	87.5	0.0
<i>The PCP has talked about work and/or education choices for the future</i>	42.9	57.1	12.5
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	42.9	57.1	12.5

Region 7 respondents: 100.0% (7) YSHCN had a primary care physician

<b>Transition Components among Region 7 Respondents (n=7)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	16.7	83.3	0.0
<i>The PCP has talked about finding an adult primary care provider</i>	33.3	66.7	0.0
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	0.0	100.0	0.0
<i>The PCP has talked about work and/or education choices for the future</i>	0.0	100.0	0.0
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	16.7	83.3	0.0

Region 8 respondents: 71.6% (53) YSHCN had a primary care physician

<b>Transition Components among Region 8 Respondents (n=53)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	60.8	39.2	3.8
<i>The PCP has talked about finding an adult primary care provider</i>	31.3	68.8	9.4
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	29.2	70.8	9.4
<i>The PCP has talked about work and/or education choices for the future</i>	28.0	72.0	5.7
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	43.1	56.9	3.8

Region 9 respondents: 83.3% (10) YSHCN had a primary care physician

<b>Transition Components among Region 9 Respondents (n=10)</b>	<b>Yes</b>	<b>No</b>	<b>Missing</b>
<i>The PCP has talked about Health/Dental Insurance options</i>	33.3	66.7	10.0
<i>The PCP has talked about finding an adult primary care provider</i>	22.2	77.8	10.0
<i>The PCP has talked about the type &amp; eligibility requirements for community resources</i>	11.1	88.9	10.0
<i>The PCP has talked about work and/or education choices for the future</i>	25.0	75.0	20.0
<i>The PCP has talked about the Youth's role with managing the health care routine</i>	42.9	57.1	30.0



### **Children's Special Health Services (CSHS) Needs Your Help!!**



- ✓ If you are a parent/primary guardian of a child with a special health care need, we need to hear from you!

**OR**

- ✓ If you are a teen (14 years of age and older) and have a special health care need, we need to hear from you!

*In order to serve you better, Children's Special Health Services is conducting a brief survey to determine what your most important concerns are about getting medical care. The first step toward making great programs that help meet families' need is to understand what those needs are! Your input is important. Thank you for your help!*

#### **What to do**

- Please take 5 minutes and fill out the survey below.
- If you would like someone in Families Helping Families to review with you, please don't hesitate to ask.
- When you are finished, mail it to this address: **P.O. BOX 60630 New Orleans, LA 70160**

#### **What you may want to know**

- Your answers are strictly confidential; we only want to know your answers to the survey and the region you live in.
- The information you provide will be sent to Louisiana's Children's Special Health Services (CSHS) Program.
- The results of the survey will be available for public review and feedback.
- The results will be posted on the CSHS Program website: <http://www.dhh.louisiana.gov/offices/?ID=256>.
- If you have questions or concerns, please call CSHS at (504) 568-5055 and ask for Nicole, or submit an inquiry on the website.

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#### **Please order each need by level of importance where 1 is most important and 10 is least important.**

- \_\_\_\_\_ Handicap/universally accessible public transportation
- \_\_\_\_\_ Transition services for youth with special health care needs
- \_\_\_\_\_ Pediatric dental providers who accept children/youth with special health care needs covered by Medicaid
- \_\_\_\_\_ Occupational/Physical Therapists who accept children/youth with special health care needs covered by Medicaid
- \_\_\_\_\_ Mental health services
- \_\_\_\_\_ Expanded prescription coverage by health insurer (Private, Military, Medicaid, etc)
- \_\_\_\_\_ Pediatricians who accept Medicaid
- \_\_\_\_\_ Subspecialists who accept Medicaid
- \_\_\_\_\_ Translators in pediatric practices
- \_\_\_\_\_ Care Coordination by primary care provider/primary pediatric practice

#### **What are some problems you have had when trying to get community resources/supports? (check all that apply)**

- \_\_\_\_\_ The location is hard to get to; it is not close to where I work and/or live.
- \_\_\_\_\_ The doctor/staff do not know about any resources that are near where I live.
- \_\_\_\_\_ The doctor/staff cannot really tell me what makes someone eligible for the resource.
- \_\_\_\_\_ There are not that many available resources near where I live.
- \_\_\_\_\_ The resources nearby are not available because they are not taking on new clients or the waiting list is too long.
- \_\_\_\_\_ Other: (please specify) \_\_\_\_\_
- \_\_\_\_\_ None. I have not had any problems getting care.

**The following is a list of resources that are of interest to children/youth with special health care needs and their families. For each resource, please circle only one number based on the information below.**

**Circle 1:** I do not know anything about it or I have not heard about it.

**Circle 2:** I know about it and I do NOT need it.

**Circle 3:** I have used it in the past 12 months & it was helpful.

**Circle 4:** I have used it in the past 12 months & it was NOT helpful.

**Circle 5:** I know about it, and want to use it but I cannot because of cost, hours of operation, time, etc.

|                                            | Don't know | Know, don't need | Used & helpful | Used & not helpful | Know, but can't use |                                               | Don't know | Know, don't need | Used & helpful | Used & not helpful | Know, but can't use |
|--------------------------------------------|------------|------------------|----------------|--------------------|---------------------|-----------------------------------------------|------------|------------------|----------------|--------------------|---------------------|
| Respite care/services                      | 1          | 2                | 3              | 4                  | 5                   | Head Start                                    | 1          | 2                | 3              | 4                  | 5                   |
| Bureau of Community Supports & Services    | 1          | 2                | 3              | 4                  | 5                   | Food Stamps                                   | 1          | 2                | 3              | 4                  | 5                   |
| Louisiana's Planning Council on DD         | 1          | 2                | 3              | 4                  | 5                   | Disabilities Determination Services/SSI       | 1          | 2                | 3              | 4                  | 5                   |
| La Benefits Planning Assistance & Outreach | 1          | 2                | 3              | 4                  | 5                   | Blind Services                                | 1          | 2                | 3              | 4                  | 5                   |
| Early Steps                                | 1          | 2                | 3              | 4                  | 5                   | Independent Living Program                    | 1          | 2                | 3              | 4                  | 5                   |
| Cash Subsidy                               | 1          | 2                | 3              | 4                  | 5                   | Early Childhood Support Services (ECSS)       | 1          | 2                | 3              | 4                  | 5                   |
| Individual and Family Support              | 1          | 2                | 3              | 4                  | 5                   | Intermediate Care Facilities for People w/ DD | 1          | 2                | 3              | 4                  | 5                   |
| Extended Family Living                     | 1          | 2                | 3              | 4                  | 5                   | CSHS Subspecialty Medical Clinics             | 1          | 2                | 3              | 4                  | 5                   |
| Supported Living                           | 1          | 2                | 3              | 4                  | 5                   | CSHS Care Coordination & Transition           | 1          | 2                | 3              | 4                  | 5                   |
| Community Support Teams                    | 1          | 2                | 3              | 4                  | 5                   | Durable medical equipment                     | 1          | 2                | 3              | 4                  | 5                   |
| Resource Centers                           | 1          | 2                | 3              | 4                  | 5                   | Assistive transportation                      | 1          | 2                | 3              | 4                  | 5                   |
| Children's Choice Waiver                   | 1          | 2                | 3              | 4                  | 5                   | Louisiana Medicaid/LaCHIP                     | 1          | 2                | 3              | 4                  | 5                   |
| New Opportunities Waiver                   | 1          | 2                | 3              | 4                  | 5                   | Traumatic Head & Spinal Cord Injury Trust     | 1          | 2                | 3              | 4                  | 5                   |
| Supports Waiver                            | 1          | 2                | 3              | 4                  | 5                   | Vocational Rehabilitation                     | 1          | 2                | 3              | 4                  | 5                   |
| Residential Options Waiver                 | 1          | 2                | 3              | 4                  | 5                   | Hearing Speech & Vision                       | 1          | 2                | 3              | 4                  | 5                   |
| Commission for Deaf                        | 1          | 2                | 3              | 4                  | 5                   | Birth Defects Monitoring Network              | 1          | 2                | 3              | 4                  | 5                   |
| Independent Living                         | 1          | 2                | 3              | 4                  | 5                   | WIC Nutritional assistance program            | 1          | 2                | 3              | 4                  | 5                   |
| Foster Care Services                       | 1          | 2                | 3              | 4                  | 5                   | Parent Support Group                          | 1          | 2                | 3              | 4                  | 5                   |
| Elderly & Disabled Adults Waiver           | 1          | 2                | 3              | 4                  | 5                   | Peer Parent Training                          | 1          | 2                | 3              | 4                  | 5                   |
| Adult Day Health Care Waiver               | 1          | 2                | 3              | 4                  | 5                   | SIBSHOPS                                      | 1          | 2                | 3              | 4                  | 5                   |
| Long Term Personal Care Services           | 1          | 2                | 3              | 4                  | 5                   | F2FHIC                                        | 1          | 2                | 3              | 4                  | 5                   |
| Crisis Management Services                 | 1          | 2                | 3              | 4                  | 5                   | Louisiana Parent Training Information Center  | 1          | 2                | 3              | 4                  | 5                   |
| Support Services                           | 1          | 2                | 3              | 4                  | 5                   | State Interagency Coordinating Council (SICC) | 1          | 2                | 3              | 4                  | 5                   |
| Child Care Assistance Program              | 1          | 2                | 3              | 4                  | 5                   | Mental Health Rehabilitation Services         | 1          | 2                | 3              | 4                  | 5                   |

**These questions are about getting subspecialty medical care** (neurology, orthopedics, cardiology, genetics, audiology, etc.).

|              |                                                                                                                                                                                        |
|--------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ___Yes ___No | I have problems getting subspecialty medical care in my area.                                                                                                                          |
| ___Yes ___No | I can travel outside my area to get the subspecialty medical care.                                                                                                                     |
| ___Yes ___No | The type of subspecialist that I/my child need(s) is not available where I live.                                                                                                       |
| ___Yes ___No | The type of subspecialist that I/my child need(s) is available but does not take my insurance (Private insurance, Louisiana Medicaid/LaCHIP, Military Health Insurance: TriCare, etc). |

**If you are:**

**14 years or older OR the parent of a teen with a special healthcare need, please answer the following:**

|                                                          |                                                                                                                                                      |
|----------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> Yes <input type="checkbox"/> No | I have a primary care provider (PCP-pediatrician, family doctor)                                                                                     |
| <input type="checkbox"/> Yes <input type="checkbox"/> No | The PCP has talked with us about health/dental insurance options                                                                                     |
| <input type="checkbox"/> Yes <input type="checkbox"/> No | The PCP has talked with us about finding an adult primary care provider                                                                              |
| <input type="checkbox"/> Yes <input type="checkbox"/> No | The PCP has talked with us about the type & eligibility requirements for community based resources such as: Waivers, Trusts, Independent Living etc. |
| <input type="checkbox"/> Yes <input type="checkbox"/> No | The PCP has talked with us about work and/or education choices for the future                                                                        |
| <input type="checkbox"/> Yes <input type="checkbox"/> No | The PCP has talked about the teen's role with managing the health care routine, such as: prescriptions, equipment, scheduling appointments, etc.     |

**What region do you currently live in? (Please mark a check on the line)**

- ☐ **Region 1:** Orleans, Jefferson, Plaquemines, St. Bernard Parishes
- ☐ **Region 2:** East, West Feliciana, East, West Baton Rouge, Pointe Coupee, Iberville, Ascension Parishes
- ☐ **Region 3:** St. Mary, Assumption, St. James, St. Charles, Lafourche, Terrebonne Parishes
- ☐ **Region 4:** St. Landry, St. Martin, Iberia, Lafayette, Vermillion, Acadia, Evangeline Parishes
- ☐ **Region 5:** Cameron, Calcasieu, Beauregard, Allen, Jefferson Davis Parishes
- ☐ **Region 6:** Vernon, Rapides, Avoyelles, Concordia, Catahoula, La Salle, Grant, Winn Parishes
- ☐ **Region 7:** Caddo, De Soto, Sabine, Bossier, Red River, Natchitoches, Webster, Bienville, Claiborne Parishes
- ☐ **Region 8:** Lincoln, Jackson, Union, Ouachita, Caldwell, Morehouse, Richland, Franklin, East, West Carroll, Madison, Tensas Parishes
- ☐ **Region 9:** St. Helena, St. Tammany, Livingston, Tangipahoa, Washington

**How many children/youth with special health care needs are in your household? \_\_\_\_\_**

**What age group(s) does your child/youth with special health care needs fall into?**

- ☐ Birth to 9 years
- ☐ 10 to 14 years
- ☐ 15 to 18 years
- ☐ 19 years and older

**Please choose one category below that best describes your (respondent) race:**

- ☐ African American/Black
- ☐ Caucasian/White
- ☐ Asian
- ☐ Native American/Alaskan Native
- ☐ Native Hawaiian/Pacific Islander
- ☐ Multiple race
- ☐ Other

**Please choose one category below that best describes your (respondent) ethnicity:**

- ☐ Hispanic
- ☐ Non-Hispanic

# Final Report – Physician Survey

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Louisiana Department of Health and Hospitals  
Office of Public Health – Children’s Special Health Services

March 2010

The Policy & Research Group  
8434 Oak Street  
New Orleans, LA 70118  
[www.policyandresearch.com](http://www.policyandresearch.com)  
504.865.1545



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## Needs Assessment Overview

The Louisiana Office of Public Health Children's Special Health Services (CSHS) program is required to carry out a needs assessment every five years. CSHS contracted with The Policy & Research Group (PRG) to help conduct the 2010 Statewide Needs Assessment. As part of the needs assessment, a survey of pediatricians and family practitioners was administered from November 23, 2009, through January 15, 2010. The survey aimed to assess the state of health care services for children and youth related to the medical home that are currently being provided by pediatricians and family practitioners around the state.

## Methods

In this section we present the instrument, data collection procedures, analysis methods, and the goals, objectives, and indicators used in this instrument of the needs assessment.

### Instrument

The *Physician Survey* consists of 26 closed-ended questions. The questions address certain criteria under five of the seven domains of a medical home as outlined by the American Academy of Pediatrics (AAP).<sup>1</sup> The process by which the survey questions were developed is explained in detail in the Goals, Objectives, and Indicators section of the report. After the survey was created, four pediatricians identified by CSHS were invited to pretest the survey and provide feedback on the clarity and content of the questions and answer choices. Minor adjustments were made to the survey based on feedback from the physicians. According to the pre-testers, the survey takes between ten and 15 minutes to complete. The full survey can be found in Appendix A.

### Data Collection Procedures

Respondents for the survey were selected based on member lists provided to PRG by the AAP (Louisiana members only) and the Louisiana Academy of Family Physicians (LAFP). The sample was divided into those who had valid email addresses and those who did not. All practitioners with email addresses received an invitation via email to complete the online survey; those who did not were sent a paper survey. The packet for the paper survey contained a cover letter, the survey, a self-addressed stamped return envelope, and a postcard with which the respondent could request information about having their practice become a medical home.

The paper version of the survey was printed, packaged, and sent out by PRG on the same day that the email invitations were sent out for the online survey. The survey was scheduled for administration from November 23 through December 18, 2009. Invitations to complete the survey came from the medical director of CSHS. Four reminder emails were sent out to respondents over the course of the survey. With the last reminder, respondents were given an incentive of being entered in a drawing for a \$100 American Express gift card if they completed the survey. The closing date for the survey was extended twice, each time by two weeks, to increase the response rate; the survey closed on January 15, 2010. PRG recommended that a subset of physicians receive a follow-up phone call to try and increase the response rate. CSHS decided against this in order to preserve respondents' confidentiality and also to abide by LAFP's terms of releasing member contact information, which included no phone contact.

As paper surveys were returned, responses were entered into a single dataset shared with online responses. Online data were downloaded weekly from the web server for backup purposes.

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<sup>1</sup> American Academy of Pediatrics Policy Statement, "The Medical home." PEDIATRICS. Vol. 110, No. 1, July 2002.

In total, 1,432 physicians were initially invited to complete the survey; 1,262 online and 170 on paper. Of those physicians invited by email, 1,135 had valid email addresses; 194 of these respondents completed the online survey for a response rate of 17.0%.<sup>2</sup> Six paper surveys were unable to be delivered to the address provided, leaving 164 respondents eligible for the paper survey. Thirty-two respondents returned the paper surveys for a response rate of 19.5%. A total of 226 surveys were submitted for an overall response rate of 17.4%.

## **Data Analysis**

Data were converted to Excel for cleaning and then converted to Stata 10 for analysis. In order to maintain a consistent number of respondents for each variable, data missing due to respondent omission and data missing due to a skip pattern (where the respondent does not have to answer a question based on a previous answer) were coded and included as categories in the results.

The purpose of the survey is to assess the extent to which pediatricians and family practitioners in Louisiana are offering care coordination services and transitional services to children and youth with special health care needs. To this end, we use descriptive statistics (i.e., distributions or frequencies/percents of responses) to depict the current status of care coordination and transitional services as measured by physician responses to each indicator.

In addition, CSHS expressed interest in whether significant differences of reported services exist between pediatrician and family practitioner respondents. Secondary analysis was conducted to assess if these differences are present in the survey results.

## **Respondents**

Respondents to the survey are pediatricians and family practitioners who are registered with either the Louisiana branch of the American Academy of Pediatrics or the Louisiana Academy of Family Physicians. PRG received contact lists directly from the academies; any member with a valid email or physical address was invited to complete the survey either online or on paper.

Eligibility for the survey is determined by two screening questions on the survey. Respondents are first asked if they provide primary care to children and/or adolescents at least three days per week. CSHS determined that they are interested in the current state of health care services only for those practices that operate full time; therefore, if a respondent answers no to the question, they are not eligible to complete the survey. The second screening question asks whether the respondent provides primary care to children and youth with special health care needs (CYSHCN). Much of the information that CSHS is interested in gathering is specific to services provided to this population; therefore, those respondents who do not work with CYSHCN are not eligible to complete the survey. Table 1 presents eligibility of the 226 physicians that responded to the survey.

---

<sup>2</sup> A total of 1,135 respondents had valid email addresses that did not bounce and therefore received at least one email invitation or reminder to complete the survey. We are unable to determine the number of respondents that received all five emails regarding the survey.

**Table 1.** Eligibility

|                                                                        | <b>N</b>   | <b>Percent</b> |
|------------------------------------------------------------------------|------------|----------------|
| Ineligible (does not provide primary care three or more days per week) | 77         | 34.1%          |
| Ineligible (does not provide primary care to CYSHCN)                   | 37         | 16.4%          |
| Eligible: completed survey                                             | 112        | 49.6%          |
| <b>Total</b>                                                           | <b>226</b> | <b>100.0%</b>  |

Several general information questions were asked to respondents that passed the first screening question before being asked about provision of primary care to CYSHCN. Table 2 presents general information on the 149 respondents who proceeded with the survey after the first screening question (full-time providers) and the 112 respondents who were eligible to complete the full survey (full-time providers and care for CYSHCN).

**Table 2.** General Respondent Information

| <b>Indicator</b>             | <b>Full-Time Providers</b> | <b>Full-Time Providers (%)</b> | <b>Eligible Respondents</b> | <b>Eligible Respondents (%)</b> |
|------------------------------|----------------------------|--------------------------------|-----------------------------|---------------------------------|
| <b>Specialty</b>             |                            |                                |                             |                                 |
| Family practice physician    | 67                         | 45.0%                          | 36                          | 32.1%                           |
| Pediatrician                 | 81                         | 54.4%                          | 75                          | 67.0%                           |
| Missing, blank <sup>3</sup>  | 1                          | 0.6%                           | 1                           | 0.9%                            |
| <b>Total</b>                 | <b>149</b>                 | <b>100.0%</b>                  | <b>112</b>                  | <b>100%</b>                     |
| <b>Medicaid provider</b>     |                            |                                |                             |                                 |
| Yes                          | 128                        | 85.9%                          | 104                         | 92.9%                           |
| No                           | 21                         | 14.1%                          | 8                           | 7.1%                            |
| <b>Total</b>                 | <b>149</b>                 | <b>100.0%</b>                  | <b>112</b>                  | <b>100.0%</b>                   |
| <b>Public health region:</b> |                            |                                |                             |                                 |
| 1                            | 36                         | 24.2%                          | 29                          | 25.9%                           |
| 2                            | 29                         | 19.4%                          | 24                          | 21.5%                           |
| 3                            | 15                         | 10.1%                          | 12                          | 10.7%                           |
| 4                            | 18                         | 12.1%                          | 11                          | 9.8%                            |
| 5                            | 12                         | 8.0%                           | 10                          | 8.9%                            |
| 6                            | 6                          | 4.0%                           | 4                           | 3.6%                            |
| 7                            | 10                         | 6.7%                           | 8                           | 7.1%                            |
| 8                            | 8                          | 5.4%                           | 5                           | 4.5%                            |
| 9                            | 14                         | 9.4%                           | 8                           | 7.1%                            |
| Missing, blank               | 1                          | 0.7%                           | 1                           | 0.9%                            |
| <b>Total</b>                 | <b>149</b>                 | <b>100.0%</b>                  | <b>112</b>                  | <b>100.0%</b>                   |

<sup>3</sup> "Missing, blank" indicates that the answer to the question was left blank despite the respondent being eligible to respond to the question.

## Goals, Objectives, and Indicators

CSHS and PRG worked together to develop the scope and specific criteria that would be measured by the *Physician Survey*. The process involved three principal stages – definition of goals, specification of objectives, and development of individual indicators. PRG assisted CSHS with the first two stages. Because CSHS intends to use the survey data for strategic planning and setting long-term programming goals, CSHS was primarily responsible for developing specific indicators (survey items).

### Goals

The initial stage in the development of the instrument was to establish the intent of the survey. CSHS in consultation with PRG agreed on two basic goals, which set the parameters for the survey. The goals are too general to be measured themselves, but they identify for CSHS and PRG the basic components of pediatric and family medicine practices that are to be investigated in the final instrument.

CSHS indicated that the principal aim for the survey is to identify gaps in care coordination (a medical home domain) using perceptions and services provided as reported by physicians who serve children and youth with special health care needs (CYSHCN) in Louisiana. Empirical findings from the survey will help CSHS plan programs and technical assistance to expand and improve care coordination around the state. To that end, PRG and CSHS specified that the primary purpose of the survey was to measure the degree to which an individual pediatric or family physician's practice offers care coordination services to children and youth.<sup>4</sup> The American Academy of Pediatrics (AAP) provides guidance on the components for providing comprehensive care coordination services.

#### **Goal 1. To measure the extent to which pediatric practices across the state offer care coordination services as identified by the American Academy of Pediatricians in their medical home criteria.**

Another aim of CSHS was to assess progress on transition services for youth. Every five years, states participate in the *National Survey of Children with Special Health Care Needs*, which measures the health of the state's CYSHCN. In the 2005 survey, Louisiana showed improvement in all domains, including transition services for youth with special health care needs, though provision of transition services still lags behind other indicators. For this survey, CSHS wanted to assess the current status of transition services and identify opportunities for further improvement.

#### **Goal 2. To measure the extent to which pediatric practices across the state provide transitional services for children and youth with special health care needs.**

### Objectives

With the goals agreed upon, PRG and CSHS worked to identify the specific set of concepts – or objectives – that would be assessed by the instrument. These objectives are specific components within: (1) care coordination services; and (2) transitional services that will be assessed. Under the first goal, CSHS and PRG identified the seven criteria in the AAP policy statement for the care coordination domain of the medical home as the objectives to be measured. They are:

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<sup>4</sup> CSHS provided PRG with a policy statement from the American Academy of Pediatrics that details the care coordination domain of the medical home. American Academy of Pediatrics Policy Statement, "Care Coordination in the Medical home: Integrating Health and Related Systems of Care for Children with Health Needs." PEDIATRICS. Vol. 116, No. 5. November 5, 2005.

1. A plan of care developed by the physician, practice care coordinator, child, and family in collaboration with other providers, agencies, and organizations involved with the care of the patient.
2. A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.
3. The medical home physician shares information among the child, family, and consultant and provides a specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.
4. Families are linked to family resources, including family support groups and parent-to-parent groups.
5. When a child is referred for a consultation or additional care, the medical home physician assists the child and family in understanding clinical issues.
6. The medical home physician evaluates and interprets the consultants' recommendations for the child and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.
7. The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

For the second goal, objectives were determined by CSHS as the specific transition services they wish to measure with the needs assessment. These objectives are:

1. Referrals to adult medical providers.
2. Independent living skills, i.e., the ability of the patient to manage his/her care (including prescriptions, equipment, etc.) without caregiver assistance.
3. Assistance with changes in insurance.
4. Developmentally appropriate health assessments and counseling.

Additional objectives were added to include criteria under other AAP medical home domains. They are:

1. Accessible: Practice accessible by public transportation.
2. Accessible: All insurance is accepted.
3. Accessible: Families or youth are able to speak directly to the physician when needed.
4. Continuous: The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

5. Comprehensive: Preventive care is provided that includes immunizations, growth and development assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, safety, nutrition, parenting, and psychosocial issues.
6. Comprehensive: Information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid, the State Children's Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children with Special Health Care Needs.
7. Comprehensive: Extra time for an office visit is scheduled for children with special health care needs, when indicated.
8. Culturally effective: All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of (para)professional translators or interpreters, as needed.
9. Culturally effective: The child's or youth's and family's cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan.

Though CSHS does not intend to fully address them, these nine additional objectives indirectly concern criteria listed under additional AAP domains as defined by the AAP policy statement, "The Medical Home."<sup>5,6</sup>

### Indicators

Indicators are empirical measures of the concepts articulated in each of the objectives. In this survey of physicians, individual questions serve this purpose. CSHS developed the questions with some feedback from PRG. In a typical situation, each item or scale in the questionnaire would be developed for the sole purpose of operationalizing the concept detailed in each of the objectives. In this case, however, because CSHS intends to use the empirical results for purposes outside of this assessment, the measurement criterion was sometimes relaxed. The result is that the relationship between the indicator (question) and the concept (objective) may not be equivalent. PRG and CSHS are aware of these gaps.

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<sup>5</sup> American Academy of Pediatrics Policy Statement, "The Medical home." PEDIATRICS. Vol. 110, No. 1, July 2002.

<sup>6</sup> The criteria are: Accessible, Continuous, Comprehensive, and Culturally Effective. The survey does not address any criteria under the remaining medical home domains: Family Centered and Compassionate.

## Results

This section presents results from the *Physician Survey*. An overview of the results by goal and indicator is first presented, followed by a detailed account and interpretation of these results. Based on the two eligibility criteria of being a full-time physician and providing care to children and youth with special health care needs, 112 respondents completed the full survey. Of the eligible respondents, 32.1% are family practice physicians and 67.0% are pediatricians (one respondent did not specify). The results below include only the responses of the 112 respondents who met the criteria to complete the entire survey.

Because of the differences that may occur between the survey objectives and their indicators, we are unable to measure fulfillment of all the objectives based on the survey results. In the sections below we depart from the objectives to report and analyze the results of the individual indicators, which will provide information to CSHS for their program planning efforts.

### Overview of Results

The overview of results presents the percent of respondents that report provision of the services specified in the survey questions (indicators). Where appropriate, we have collapsed response categories for those questions that have a four-point *always-never* response scale. For these indicators we consider the selection of “always” or “usually” as a positive response to the question and present those results here.

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**Goal 1: To measure the extent to which pediatric practices across the state offer care coordination services as identified by the American Academy of Pediatricians in their medical home criteria.**

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**Indicator 1.1** *My staff or I provide my patients with a written plan of care that addresses the patients' and families' needs and improves collaboration of care among other providers, agencies, and organizations.* 39.3%

**Indicator 1.2** *Record-keeping characteristics:*

|                                                                      |                                       |       |
|----------------------------------------------------------------------|---------------------------------------|-------|
| <i>Patient medical records contain pertinent medical information</i> | <i>Intra-clinic data</i>              | 97.6% |
|                                                                      | <i>Out of clinic history and data</i> | 70.5% |
|                                                                      | <i>Electronic prescriptions</i>       | 36.6% |
|                                                                      | <i>All pertinent information</i>      | 27.7% |
| <i>Accessibility of patient records</i>                              | <i>Between providers</i>              | 75.9% |
|                                                                      | <i>For patients at no cost</i>        | 58.9% |
|                                                                      | <i>Both accessibility criteria</i>    | 44.6% |
| <i>Confidentiality of patient records</i>                            | <i>Meets HIPAA criteria</i>           | 98.2% |

**Indicator 1.3** *When I refer a patient for specialty care, my staff or I share information with the family and sub-specialist that provides the specific reason for the referral.* 95.5%

**Indicator 1.4** *My staff or I discuss with my CYSHCN patients and/or their families about the need for and acquisition of Families Helping Families or other family/parent support group* 29.5%

**Indicator 1.5** *When I refer a patient for specialty care, my staff or I assist the family with communicating clinical information to the sub-specialist.* 92.0%

|                                                                                                                                                                                                                                                                 |       |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| <b>Indicator 1.6</b> <i>When I refer a patient for specialty care, my staff or I discuss the results and recommendations from the sub-specialist visit with the child/youth and family and integrate the recommendations in the child/youth's plan of care.</i> | 93.5% |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|

|                                                                                                                                                                 |       |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| <b>Indicator 1.7</b> <i>My CYSHCN patients' plans of care involve coordination with the patients' schools so that their special health needs are addressed.</i> | 49.1% |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|

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**Goal 2: To measure the extent to which pediatric practices across the state provide transitional services for children and youth with special health care needs.**

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*The transition process from my care to adult medical care for my adolescent patients with special health care needs (YSHCN) and their families involves the following:*

|                                                                                          |       |
|------------------------------------------------------------------------------------------|-------|
| <b>Indicator 2.1.</b> <i>The patient has established an adult primary care provider.</i> | 79.2% |
|------------------------------------------------------------------------------------------|-------|

**Indicator 2.2** *Discussion of independent living skills*

|                                               |       |
|-----------------------------------------------|-------|
| <i>Patient's role in managing health care</i> | 61.0% |
| <i>Educational/vocation choices</i>           | 45.4% |
| <i>Community-based resources</i>              | 24.7% |
| <i>All independent living skills</i>          | 16.9% |

|                                                                                    |       |
|------------------------------------------------------------------------------------|-------|
| <b>Indicator 2.3</b> <i>My staff or I discuss health/dental insurance options.</i> | 36.4% |
|------------------------------------------------------------------------------------|-------|

|                                                                                                             |       |
|-------------------------------------------------------------------------------------------------------------|-------|
| <b>Indicator 2.4</b> <i>My staff or I provide developmentally appropriate counseling directly to youth.</i> | 64.9% |
|-------------------------------------------------------------------------------------------------------------|-------|

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**Additional indicators pertaining to the medical home**

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|                                                                                 |       |
|---------------------------------------------------------------------------------|-------|
| <b>Indicator 3.1</b> <i>My practice is accessible by public transportation.</i> | 77.7% |
|---------------------------------------------------------------------------------|-------|

|                                                                                                                      |       |
|----------------------------------------------------------------------------------------------------------------------|-------|
| <b>Indicator 3.2</b> <i>I accept CYSHCN patients with most types of insurance, including Medicaid and/or LaCHIP.</i> | 89.3% |
|----------------------------------------------------------------------------------------------------------------------|-------|

|                                                                               |       |
|-------------------------------------------------------------------------------|-------|
| <b>Indicator 3.3</b> <i>My patients can speak directly to me when needed.</i> | 78.5% |
|-------------------------------------------------------------------------------|-------|

|                                                                                                                                                                                                                         |       |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| <b>Indicator 3.4</b> <i>My practice has a system in place to alert me when my patients have been hospitalized so that I can schedule an office visit to review the clinical information with the patients/families.</i> | 50.0% |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|

|                                                                                                                                                                                  |       |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| <b>Indicator 3.5.1</b> <i>I use pediatric growth and developmental screening tools at 9, 18, and 24-30 months, as well as when I and/or my patients' families have concerns.</i> | 85.7% |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|

|                                                                                                                        |       |
|------------------------------------------------------------------------------------------------------------------------|-------|
| <b>Indicator 3.5.2</b> <i>I use pediatric behavioral checklists when I and/or my patients' families have concerns.</i> | 61.6% |
|------------------------------------------------------------------------------------------------------------------------|-------|

**Indicator 3.6** *My staff or I discuss with my CYSHCN patients and/or their families about the need for and acquisition of the following services and resources:*

|                                                     |       |
|-----------------------------------------------------|-------|
| <i>Occupational, physical, and speech therapies</i> | 84.8% |
| <i>WIC nutritional assistance program</i>           | 81.3% |



|                                                                                                                                                                                              |       |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| <i>Durable medical equipment</i>                                                                                                                                                             | 76.8% |
| <i>Early Steps</i>                                                                                                                                                                           | 74.1% |
| <i>Louisiana Medicaid/LaCHIP</i>                                                                                                                                                             | 70.5% |
| <i>Head Start</i>                                                                                                                                                                            | 67.9% |
| <i>Individualized Education Plans (IEP)</i>                                                                                                                                                  | 52.7% |
| <i>504 Accommodations</i>                                                                                                                                                                    | 50.0% |
| <i>Assistive transportation</i>                                                                                                                                                              | 38.4% |
| <i>Title V Programs</i>                                                                                                                                                                      | 36.6% |
| <i>Supplemental Security Income or SSI-Disability</i>                                                                                                                                        | 31.3% |
| <i>Respite care</i>                                                                                                                                                                          | 27.7% |
| <i>Louisiana Rehabilitation Services</i>                                                                                                                                                     | 23.2% |
| <b>Indicator 3.7</b> <i>For my CYSHCN patients, I schedule extra time or extend the time for their office visits when indicated.</i>                                                         | 65.1% |
| <b>Indicator 3.8</b> <i>I provide my patients interpreters/translators in my practice.</i>                                                                                                   | 29.5% |
| <b>Indicator 3.9</b> <i>Characteristics of the patient or family that are incorporated into a patient's plan of care and taken into consideration when communicating health information:</i> |       |
| <i>Education level</i>                                                                                                                                                                       | 93.8% |
| <i>Cultural background: Beliefs, rituals, and customs</i>                                                                                                                                    | 89.3% |
| <i>Socioeconomic status</i>                                                                                                                                                                  | 83.9% |
| <i>Household composition</i>                                                                                                                                                                 | 83.9% |
| <i>Religion, gender roles, ethnicity, language</i>                                                                                                                                           | 83.0% |
| <i>Louisiana resident status</i>                                                                                                                                                             | 31.3% |

## Detailed Results

Below we present detailed results of the indicators measured by the questionnaire. Indicators are listed under the needs assessment goals that they operationalize. Distributions of responses for each of the indicator categories – both number and percent – are used to describe the current status of the care coordination or transitional service indicator.

We also have conducted a secondary analysis of the results to determine if there are significant differences in provision of services as reported by pediatricians and family practitioners. Where we find significant differences, results are noted in the tables and discussed in the interpretation of findings. A full set of cross-tabulations of survey indicators by type of physician can be found in Appendix B.

**Goal 1: To measure the extent to which pediatric practices across the state offer care coordination services as identified by the American Academy of Pediatricians in their medical home criteria.**

**Indicator 1.1** *My staff or I provide my patients with a written plan of care that addresses the patients' and families' needs and improves collaboration of care among other providers, agencies, and organizations.*

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 12                    | 10.7%                  |
| Usually                                           | 32                    | 28.6%                  |
| Sometimes                                         | 49                    | 43.7%                  |
| Never                                             | 13                    | 11.6%                  |
| Not applicable, this is not needed in my practice | 6                     | 5.4%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

Fewer than 40% of responding physicians report “always” or “usually” providing their patients with a written plan of care that addresses their needs and improves collaboration of care, meaning a majority (55%) of providers do not consistently provide these care plans for their patients.

**Indicator 1.2** *My practice has a central record-keeping system with the following characteristics:*

Respondents were asked to select all characteristics of a central record-keeping system that apply to their practice. Below we present the findings from the indicator by component part of the associated objective: contains pertinent medical information, record accessibility, and confidentiality.

*Pertinent Medical Information*

|                                                                                                   | Yes | Percent | No | Percent | Missing | Percent | Total (%)  |
|---------------------------------------------------------------------------------------------------|-----|---------|----|---------|---------|---------|------------|
| Records patient demographics and contact information                                              | 111 | 99.1%   | 1  | 0.9%    | 0       | 0.0%    | 112 (100%) |
| Records patient billing/insurance information                                                     | 111 | 99.1%   | 1  | 0.9%    | 0       | 0.0%    | 112 (100%) |
| Records patient clinical record charting                                                          | 106 | 94.6%   | 4  | 3.6%    | 2       | 1.8%    | 112 (100%) |
| Tracks and records patient referrals, specialists, labs, tests, and hospitalizations/ER histories | 79  | 70.5%   | 33 | 29.5%   | 0       | 0.0%    | 112 (100%) |
| Can produce electronic prescriptions                                                              | 41  | 36.6%   | 68 | 60.7%   | 3       | 2.7%    | 112 (100%) |
| Records contain all five characteristics of pertinent medical information                         | 31  | 27.7%   | 81 | 72.3%   | 0       | 0.0%    | 112 (100%) |

Basic in-clinic patient information appears to be recorded by a majority of responding physicians. Nearly all respondents indicate that they record patient demographics, billing, and clinical record charting.

Patient histories that occur outside of the clinic are less well tracked. Only 70% report that they have systems that record specialist and hospital care. This comparative deficit is noteworthy for its magnitude and because this aspect of record-keeping directly relates to care coordination. Finally, fewer than 40% are able to produce electronic prescriptions indicating an opportunity to improve record-keeping technology. Overall, only 28% of responding physicians report that they currently engage in all five of the pertinent record-keeping characteristics at their practice.

#### *Accessibility*

|                                                                                                     | <b>Yes</b> | <b>Percent</b> | <b>No</b> | <b>Percent</b> | <b>Missing</b> | <b>Percent</b> | <b>Total (%)</b> |
|-----------------------------------------------------------------------------------------------------|------------|----------------|-----------|----------------|----------------|----------------|------------------|
| Allows the transfer of medical records between medical providers                                    | 85         | 75.9%          | 25        | 22.3%          | 2              | 1.8%           | 112 (100%)       |
| Copies of patients' records are made available to patients and their families on request at no cost | 66         | 58.9%          | 43        | 38.4%          | 3              | 2.7%           | 112 (100%)       |
| Records adhere to both <i>accessibility</i> characteristics                                         | 50         | 44.6%          | 62        | 55.4%          | 0              | 0.0%           | 112 (100%)       |

Just over 75% of physicians report that they have records that can be transferred between providers, allowing for easier transition of patient care. Accessibility is also assessed by the extent to which physicians report that patients and families have access to their records at no cost. This is a basic measure of whether records are accessible to CYSHCN client families, regardless of their income. Approximately 60% of responding physicians report that they make records available at no cost. Fifty respondents (45%) report both aspects of accessibility in their record-keeping system.

#### *Confidentiality*

|                                      | <b>Yes</b> | <b>Percent</b> | <b>No</b> | <b>Percent</b> | <b>Missing</b> | <b>Percent</b> | <b>Total (%)</b> |
|--------------------------------------|------------|----------------|-----------|----------------|----------------|----------------|------------------|
| Meets HIPAA confidentiality criteria | 110        | 98.2%          | 1         | 0.9%           | 1              | 0.9%           | 112 (100%)       |

Nearly all of the respondents' record-keeping systems comply with the confidentiality criteria of the objective, indicating that records for patients are kept according to HIPAA regulations.

**Indicator 1.3** *When I refer a patient for specialty care, my staff or I do the following: share information with the family and sub-specialist that provides the specific reason for the referral.*

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 75                    | 66.9%                  |
| Usually                                           | 32                    | 28.6%                  |
| Sometimes                                         | 5                     | 4.5%                   |
| Never                                             | 0                     | 0.0%                   |
| Not applicable, this is not needed in my practice | 0                     | 0.0%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

Nearly all responding physicians report that they or their staff share information with the family and sub-specialist as part of the referral process. Over 95% report “always” or “usually” sharing information with families and subspecialist when a referral is made. As we observe in responses to other questions in the survey, communication between physicians, families, and sub-specialists appears to be consistent.

**Indicator 1.4** *My staff or I discuss with my CYSHCN patients and/or their families about the need for and acquisition of the following services and resources: Families Helping Families or other family/parent support group.*

|              | Number of respondents | Percent of respondents |
|--------------|-----------------------|------------------------|
| Yes*         | 33                    | 29.5%                  |
| No           | 79                    | 70.5%                  |
| <b>Total</b> | <b>112</b>            | <b>100%</b>            |

\* Pediatricians are more likely to discuss family support groups with patients and families than family practitioners. Differences between the two are statistically significant.<sup>7</sup>

Results suggest that at this time a majority of providers do not discuss support resources with families. Less than one third of respondents indicate that they discuss family or parent support groups with CYSHCN patients’ families. This may indicate a general lack of emphasis on the support system for the family in the child’s care plan or a lack of knowledge of available family support resources.

Secondary analysis of the data for Indicator 1.4 suggests that pediatricians are much more active in discussing support group options with patients and their families. Forty percent of pediatricians report that they discuss this resource. Only 8% of family practitioners report the same. The differences are statistically meaningful. Nevertheless, while substantially more pediatricians or their staff are consulting with families about the need for support groups than family practitioners, the majority of both groups still do not discuss these services.

<sup>7</sup> We use the t-test to assess whether differences in mean/proportion scores reported by pediatricians and family practitioners are statistically significant. For dichotomous variables (e.g., yes/no) and ordinal variables (always...never) we assign numeric values to each response item and for each relevant question calculate the mean score/ proportion for pediatricians and family practitioners. We test for statistical difference between these mean scores/proportions using unpaired, two-tailed t-tests; results are deemed significant at the  $p \leq .05$  level. The t-test assumes continuity and a normal distribution. We relax the assumption of continuity, which is conventional for ordered scales such as the ones used here; distributions have been checked for normality in appearance. Since the mean of a dichotomous variable is a proportion, a test on equality of proportions is also used to test for significance. No substantive differences between the two tests were observed.

**Indicator 1.5** *When I refer a patient for specialty care, my staff or I do the following: assist the family with communicating clinical information to the sub-specialist.*

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 63                    | 56.3%                  |
| Usually                                           | 40                    | 35.7%                  |
| Sometimes                                         | 9                     | 8.0%                   |
| Never                                             | 0                     | 0.0%                   |
| Not applicable, this is not needed in my practice | 0                     | 0.0%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

The majority of responding physicians, 92%, report that they “always” or “usually” communicate clinical information to the sub-specialist as a service to patients. These results suggest that nearly all of the responding physicians or their staff are actively engaged in making sure that the requisite clinical information is passed onto a specialist. These results are consistent with Indicator 1.3, which also asks respondents about communicating clinical information to the sub specialist.

**Indicator 1.6** *When I refer a patient for specialty care, my staff or I do the following: discuss the results and recommendations from the sub-specialist, visit with the child/youth and family, and integrate the recommendations in the child/youth’s plan of care.*

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 60                    | 53.5%                  |
| Usually                                           | 45                    | 40.2%                  |
| Sometimes                                         | 3                     | 2.7%                   |
| Never                                             | 1                     | 0.9%                   |
| Not applicable, this is not needed in my practice | 3                     | 2.7%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

Following their referrals to sub-specialists, over 90% of responding physicians report that they or their staff communicate with patients and families about the results. Specifically, 93.7% of family practitioners and pediatricians report “always” or “usually” discussing results from a sub-specialist visit with their patient. Data do not provide any information on the extent to which the family is assisted in understanding the clinical and care issues, but it appears that the vast majority of responding physicians are communicating clinical information and integrating that information into care plans. Additionally, since only 40% of responding physicians report regularly providing a plan of care to CYSHCN families, it remains unclear if there are reliability concerns or if a plan of care is more universally developed but not specifically provided to the families.

**Indicator 1.7** *My CYSHCN patients' plans of care involve coordination with the patients' schools so that their special health needs are addressed.*

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 19                    | 17.0%                  |
| Usually                                           | 36                    | 32.1%                  |
| Sometimes                                         | 50                    | 44.6%                  |
| Never                                             | 3                     | 2.7%                   |
| Not applicable, this is not needed in my practice | 4                     | 3.6%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

Nearly half of all respondents (49%) report “always” or “usually” coordinating care plans with their patients’ schools in order to address health care needs. The comparatively low number of physicians that report providing this service is consistent with care plan results in Indicator 1.1; note, however, that 10% more respondents report that they coordinate plans of care with their patients’ schools than say that they regularly provide these plans of care to their CYSHCN patients and families.

**Goal 2: To measure the extent to which pediatric practices across the state provide transitional services for children and youth with special health care needs.**

Thirty-five of the 112 respondents reported that transition services were not applicable to their practice. Results in the four tables below reflect the remaining 77 providers who provide transition services. As expected, family practitioners are more likely than pediatricians to report that transition services are not applicable to their practices.<sup>8</sup> The differences are statistically significant. Most pediatric practices cease seeing patients after age 18, while family practices may continue to see patients through adulthood.

**Indicator 2.1** *The transition process from my care to adult medical care for my adolescent patients with special health care needs (YSHCN) and their families involves the following: the patient has established an adult primary care provider.*

|                                                             | Yes | Percent | No | Percent | Missing | Percent | Total (%) |
|-------------------------------------------------------------|-----|---------|----|---------|---------|---------|-----------|
| The patient has established an adult primary care provider. | 61  | 79.2%   | 13 | 16.9%   | 3       | 3.9%    | 77 (100%) |

A vast majority of responding physicians that provide transition services report that their patients have established an adult primary care provider when they are transitioned from their (pediatric) care.

<sup>8</sup> Seventy-two percent of family practitioners report that transition services are not applicable because they serve patients from childhood through adulthood, compared to 10.7% of pediatricians.

**Indicator 2.2** *The transition process from my care to adult medical care for my adolescent patients with special health care needs (YSHCN) and their families involves the following:*<sup>9</sup>

|                                                                                                                                               | Yes | Percent | No | Percent | Missing | Percent | Total (%) |
|-----------------------------------------------------------------------------------------------------------------------------------------------|-----|---------|----|---------|---------|---------|-----------|
| My staff or I discuss the patient's role in managing his/her health care routines (prescriptions, equipment, scheduling, appointments, etc.). | 47  | 61.0%   | 24 | 31.2%   | 6       | 7.8%    | 77 (100%) |
| My staff or I discuss vocational and/or education choices.                                                                                    | 35  | 45.4%   | 36 | 46.8%   | 6       | 7.8%    | 77 (100%) |
| My staff or I discuss the type and eligibility requirements for community based resources (waivers, trusts, independent living, etc.).        | 19  | 24.7%   | 51 | 66.2%   | 7       | 9.1%    | 77 (100%) |
| All independent living skills criteria are discussed                                                                                          | 13  | 16.9%   | 64 | 83.1%   | 0       | 0.0%    | 77 (100%) |

The data in the table above suggest that the provision of transition services that help youth establish independent living skills vary by indicator. While over 60% of respondents report discussing a patient's role in managing his or her health, only 45% discuss education choices, and 25% discuss eligibility for community-based resources. Overall, 13 respondents (17%) report discussing all three transition issues with their patients and families. Together, responses show, perhaps unsurprisingly, that physicians report discussing issues directly related to health more than other non-medical aspects of the transition to adult care such as community resource and educational options.

**Indicator 2.3** *The transition process from my care to adult medical care for my adolescent patients with special health care needs (YSHCN) and their families involves the following: my staff or I discuss health/dental insurance options.*

|                                                        | Yes | Percent | No | Percent | Missing | Percent | Total (%) |
|--------------------------------------------------------|-----|---------|----|---------|---------|---------|-----------|
| My staff or I discuss health/dental insurance options. | 28  | 36.4%   | 43 | 55.8%   | 6       | 7.8%    | 77 (100%) |

Just over 36% of physicians report discussing options for the transition of health and dental insurance with their adolescent patients. The data do not provide any insight as to why insurance options are not discussed.

<sup>9</sup> As specified by CSHS, "independent living skills" is operationalized by "yes" responses to questions 19c, 19d, and 19e, which correspond to the items that are presented in the table.

**Indicator 2.4** *The transition process from my care to adult medical care for my adolescent patients with special health care needs (YSHCN) and their families involves the following: my staff or I provide developmentally appropriate counseling directly to youth.*

|                                                                                 | Yes | Percent | No | Percent | Missing | Percent | Total (%) |
|---------------------------------------------------------------------------------|-----|---------|----|---------|---------|---------|-----------|
| My staff or I provide developmentally appropriate counseling directly to youth. | 50  | 64.9%   | 21 | 27.3%   | 6       | 7.8%    | 77 (100%) |

As part of the transition to adult care, nearly 65% of respondents report that they or their staff counsel their adolescent patients directly with developmentally appropriate counseling.

#### Additional Indicators

In addition to the indicators linked to the two goals above, CSHS was also interested in the status of several other aspects of medical care for children and youth as they are currently being provided by pediatricians and family practice providers around the state. The results for these indicators are presented below.

**Indicator 3.1** *My practice is accessible by public transportation.*

|                | Number of Respondents | Percent of Respondents |
|----------------|-----------------------|------------------------|
| Yes            | 87                    | 77.7%                  |
| No             | 23                    | 20.5%                  |
| Missing, blank | 2                     | 1.8%                   |
| <b>Total</b>   | <b>112</b>            | <b>100.0%</b>          |

Over three quarters of respondents indicate that their practice is accessible by public transportation. Still, 20.5% of the responding physicians' offices are not accessible by public transportation. As one measure of accessibility to healthcare, the data indicate that for some CYSHCN clients, transportation presents a barrier to a sizeable proportion of physicians' offices included in this survey.

**Indicator 3.2** *I accept CYSHCN patients with most types of insurance, including Medicaid and/or LaCHIP.*

|                | Number of Respondents | Percent of Respondents |
|----------------|-----------------------|------------------------|
| Yes            | 100                   | 89.3%                  |
| No             | 11                    | 9.8%                   |
| Missing, blank | 1                     | 0.9%                   |
| <b>Total</b>   | <b>112</b>            | <b>100.0%</b>          |

Insurance acceptance is another important indicator of general accessibility of CYSHCN medical provision. If a physician's office does not accept "most" types of insurance, we can infer that some CYSHCN families – particularly the economically disadvantaged – could not access their services. Most respondents, nearly 90%, report accepting CYSHCN with most types of insurance, which includes Medicaid and the Louisiana Children's Health Insurance Plan. Nearly ten percent do not.



**Indicator 3.3** *My patients can speak directly to me when needed.*

|                                                   | <b>Number of Respondents</b> | <b>Percent of Respondents</b> |
|---------------------------------------------------|------------------------------|-------------------------------|
| Always                                            | 39                           | 34.8%                         |
| Usually                                           | 49                           | 43.7%                         |
| Sometimes                                         | 21                           | 18.8%                         |
| Never                                             | 0                            | 0.0%                          |
| Not applicable, this is not needed in my practice | 2                            | 1.8%                          |
| Missing, blank                                    | 1                            | 0.9%                          |
| <b>Total</b>                                      | <b>112</b>                   | <b>100.0%</b>                 |

In a more direct measure of physician accessibility, we ask responding pediatricians and family practitioners to what extent they avail themselves to their patients. Approximately 80% of physician respondents report that patients are “always” or “usually” able to speak directly to them. Nearly 20% report somewhat more limited access – that is, patients may “sometimes” speak directly to them when needed.

**Indicator 3.4** *My practice has a system in place to alert me when my patients have been hospitalized so that I can schedule an office visit to review the clinical information with the patients/families.*

|                                                   | <b>Number of Respondents</b> | <b>Percent of Respondents</b> |
|---------------------------------------------------|------------------------------|-------------------------------|
| Always                                            | 19                           | 17.0%                         |
| Usually                                           | 37                           | 33.0%                         |
| Sometimes                                         | 21                           | 18.8%                         |
| Never                                             | 20                           | 17.8%                         |
| Not applicable, this is not needed in my practice | 15                           | 13.4%                         |
| <b>Total</b>                                      | <b>112</b>                   | <b>100.0%</b>                 |

Half of respondents report that they “always” or “usually” are alerted when a patient is hospitalized and schedule a follow-up visit for the patient. Approximately 40% of the surveyed providers report that they do not have a system in place that regularly keeps clinical information about hospitalizations updated. In fact, nearly 20% report that they never monitor this information. For a sizeable proportion of physicians, then, hospitalizations represent a gap in the continuity of care provided to patients and their families.

**Indicator 3.5.1** *I use pediatric growth and developmental screening tools at 9, 18, and 24-30 months, as well as when I and/or my patients' families have concerns.*

|                                               | Number of Respondents | Percent of Respondents |
|-----------------------------------------------|-----------------------|------------------------|
| Yes                                           | 96                    | 85.7%                  |
| No                                            | 10                    | 8.9%                   |
| N/A - I do not serve patients aged 0-5 years. | 4                     | 3.6%                   |
| Missing, blank                                | 2                     | 1.8%                   |
| <b>Total</b>                                  | <b>112</b>            | <b>100.0%</b>          |

*If yes, please indicate the screening tools you use (select all that apply):*

|                                                                                 | Number of Respondents | Percent of Respondents |
|---------------------------------------------------------------------------------|-----------------------|------------------------|
| Ages and Stages Questionnaire (ASQ)*                                            | 34                    | 35.4%                  |
| Denver-II Developmental Test                                                    | 29                    | 30.2%                  |
| Child Development Chart (CDC)**                                                 | 26                    | 27.1%                  |
| Prescreening Developmental Questionnaire (PDQ-II)*                              | 26                    | 27.1%                  |
| Parents' Evaluation of Developmental Status (PEDS)                              | 16                    | 16.7%                  |
| Parents' Evaluation of Developmental Status Developmental Milestones (PEDS: DM) | 10                    | 10.4%                  |
| Revised Prescreening Developmental Questionnaire (R-PDQ)                        | 7                     | 7.3%                   |
| Other <sup>10</sup>                                                             | 7                     | 7.3%                   |
| Battelle Developmental Inventory Screening Test (BDIST)                         | 0                     | 0.0%                   |
| Brigance Screens                                                                | 0                     | 0.0%                   |
| <b>Total responses (total respondents)</b>                                      | <b>155 (96)</b>       |                        |

Results include the 96 respondents who answered yes to question 16 above.

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

\*Pediatricians are more likely than family practitioners to report use of these screening tools. Differences are statistically significant.

\*\*Family practitioners are more likely than pediatricians to report use of these screening tools. Differences are statistically significant.

Most physicians (86%) report using growth and development screenings when required and when indicated by parental or physician concern. Nearly 10% do not – even when parental or physician concerns indicate it might be appropriate. Data do not indicate why.

Four screening tools appear to be the most popular by a fairly sizeable margin. The *ASQ*, *Denver-II*, *CDC*, and *PDQ-II* are each used by roughly one-third of the 96 respondents who say that they conduct developmental screening assessments. The next most popular are the PEDS instruments. Two instruments are not used at all. Additional analysis shows that pediatricians and family practitioners tend to rely on different instruments for developmental screening. Significantly more pediatricians report using the *ASQ*

<sup>10</sup> Other responses include: MCHAT, verbal screening, in-house formulated questionnaire, Kidmed developmental screen, growth charts, and don't recall name.

and *PDQ-11* screening tools than family practitioners, while significantly more family practitioners report using the *CDC* tool.<sup>11</sup>

**Indicator 3.5.2** *I use pediatric behavioral checklists when I and/or my patients' families have concerns.*

|              | Number of Respondents | Percent of Respondents |
|--------------|-----------------------|------------------------|
| Yes*         | 69                    | 61.6%                  |
| No           | 43                    | 38.7%                  |
| <b>Total</b> | <b>112</b>            | <b>100.0%</b>          |

\*Pediatricians are more likely than family practitioners to report use of checklists. Differences are statistically significant.

*If yes, please indicate the checklists you use (select all that apply):*

|                                                            | Number of Respondents | Percent of Respondents |
|------------------------------------------------------------|-----------------------|------------------------|
| NICHQ Vanderbilt Assessment Scales*                        | 38                    | 55.1%                  |
| Pediatric Symptom Checklist                                | 20                    | 29.0%                  |
| Child Behavior Checklist**                                 | 13                    | 18.9%                  |
| Other <sup>12</sup>                                        | 13                    | 18.9%                  |
| Eyberg Child Behavior Inventory (ECBI)                     | 0                     | 0.0%                   |
| Sutter Eyberg Student Behavior Inventory Revised (SESBI-R) | 0                     | 0.0%                   |
| <b>Total responses (total respondents)</b>                 | <b>84 (69)</b>        |                        |

Results include the 69 respondents who answered yes to question 17.

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

\*Pediatricians are more likely than family practitioners to report use of the checklist. Differences are statistically significant.

\*\*Family practitioners are more likely than pediatricians to report use of the checklist. Differences are statistically significant.

Behavioral assessments, which fit more clearly in the domain of psychological growth, are used by fewer responding physicians than developmental screens. Sixty-two percent of respondents report using a behavior assessment when they or the family have concerns about the child. Nearly 40% of responding physicians report that they do not – even when they or the child's parents have concerns. Again, data do not provide any insight as to why this is the case, except to indicate that significantly more pediatricians (70.7%) than family practitioners (44.4%) report using behavioral assessment instruments.

More than half of those who use a checklist report using the *NHCQ Vanderbilt Assessment Scales*. Pediatricians report that they use this tool more often than family practitioners (64.2% vs. 25.0%, respectively). Family practitioners, in turn, reported significantly more use of the *Child Behavior Checklist* – the third most popular instrument overall – than pediatricians (43.8% vs. 11.3%, respectively).

<sup>11</sup> For the ASQ, 40.6% of pediatricians report use compared to 19.2% of family practitioners; 33.3% of pediatricians report use of the PDQ-11 compared to 7.7% of family practitioners; and for the CDC, 53.8% of family practitioners compared to 15.9% of pediatricians report use.

<sup>12</sup> Other responses include: hybrid of several tools; Kid Med form; Owens scales; MCHAT; ADHD evaluation; AAP; Connors; DSM-IV based questionnaire for ADHD; DSM-IV diagnostic criteria; mental health review of symptoms; my own.

**Indicator 3.6** *My staff or I discuss with my CYSHCN patients and/or their families about the need for and acquisition of the following services and resources (select all that apply):*

|                                                                                                                                                               | Number of Respondents | Percent of Respondents |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|------------------------|
| Occupational, physical, and speech therapies*                                                                                                                 | 95                    | 84.8%                  |
| Women, Infants, and Children (WIC) nutritional assistance program*                                                                                            | 91                    | 81.3%                  |
| Durable medical equipment (DME)                                                                                                                               | 86                    | 76.8%                  |
| Early Steps*                                                                                                                                                  | 83                    | 74.1%                  |
| Louisiana Medicaid/LaCHIP**                                                                                                                                   | 79                    | 70.5%                  |
| Head Start*                                                                                                                                                   | 76                    | 67.9%                  |
| Individualized Education Plans (IEP)*                                                                                                                         | 59                    | 52.7%                  |
| 504 Accommodations*                                                                                                                                           | 56                    | 50.0%                  |
| Assistive transportation                                                                                                                                      | 43                    | 38.4%                  |
| Title V Programs: Children's Special Health Services; Child Health; Partners for Health Babies; Hearing, Speech, and Vision; Birth Defects Monitoring Network | 41                    | 36.6%                  |
| Supplemental Security Income (SSI) or SSI-Disability                                                                                                          | 35                    | 31.3%                  |
| Respite care                                                                                                                                                  | 31                    | 27.7%                  |
| Department of Social Services: Louisiana Rehabilitation Services (LRS)                                                                                        | 26                    | 23.2%                  |
| Office for Citizens with Developmental Disabilities: waivers, Family Support and Services                                                                     | 18                    | 16.1%                  |
| Other                                                                                                                                                         | 4                     | 3.6%                   |
| None of the above                                                                                                                                             | 1                     | 0.9%                   |
| <b>Total responses (total respondents)</b>                                                                                                                    | <b>824 (112)</b>      |                        |

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

\*Pediatricians are significantly more likely than family practitioners to report discussion of the resource ( $p \leq .05$ .)

\*\*Family practitioners are more likely than pediatricians to report discussion of the resource. Differences are statistically significant.

Responding physicians are asked to select which services and resources they discuss with their patients and their families. Responses indicate that this discussion varies a great deal by type of resource. Therapy, equipment, education, and nutritional services tend to be discussed by most responding physicians. Over 70% of respondents report discussing occupational, physical, and speech therapies, WIC, durable medical equipment, Early Steps, and/or Louisiana Medicaid/LaCHIP; 68% report discussing Head Start. Social and support resources are less discussed with clients. Though the data do not indicate why, the difference may be explained by needs of the client. Whereas a majority of clients could be expected to benefit from therapeutic and nutritional services, some clients may not be in need of social support services.

Further analysis shows that pediatricians tend to discuss certain services and resources more than family practitioners. Pediatricians are significantly more likely than family practitioners to report discussing

Early Steps (93% vs. 33%), Head Start (79% vs. 44%), individualized education plans (71% vs. 14%), 504 Accommodations (68% vs. 14%), occupational, physical, and speech therapies (93% vs. 67%), and WIC (91% vs. 61%) with their patients and families.

**Indicator 3.7** *For my CYSHCN patients, I schedule extra time or extend the time for their office visits when indicated.*

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 33                    | 29.4%                  |
| Usually                                           | 40                    | 35.7%                  |
| Sometimes                                         | 28                    | 25.0%                  |
| Never                                             | 5                     | 4.5%                   |
| Not applicable, this is not needed in my practice | 5                     | 4.5%                   |
| Missing, blank                                    | 1                     | 0.9%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

Pediatricians are more likely to schedule extra time for CYSHCN patients than family practitioners. Differences are statistically significant.

Overall, 65% of respondents report that they “always” or “usually” schedule more time for CYSHCN when indicated. Again, pediatricians tend to schedule extra time for CYSHCN patients more frequently than family practitioners. This difference is statistically significant.<sup>13</sup>

**Indicator 3.8** *I provide my patients interpreters/translators in my practice.*

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 15                    | 13.4%                  |
| Usually                                           | 18                    | 16.1%                  |
| Sometimes                                         | 29                    | 25.9%                  |
| Never                                             | 30                    | 26.8%                  |
| Not applicable, this is not needed in my practice | 19                    | 16.9%                  |
| Missing, blank                                    | 1                     | 0.9%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

Less than 30% of responding physicians report “always” or “usually” providing interpreters for their patients. Though one could expect that interpretation services may not be required on a regular basis for many practitioners, the fact that the most frequently selected category for this indicator is “never,” with 26.8% of the responses, suggests that patients in need of translation services may have difficulty accessing them at a sizeable proportion of physicians’ offices.

<sup>13</sup> On a scale of one to four, where one is “always” and four is “never,” pediatricians report a mean frequency of scheduling extra time for CYSHCN of 1.9 and family practitioners a mean of 2.4.

**Indicator 3.9** Which of the following characteristics of the patient or family do you incorporate into a patient's plan of care and take into consideration when communicating health information? (select all that apply)

|                                                                                   | Number of Respondents | Percent of Respondents |
|-----------------------------------------------------------------------------------|-----------------------|------------------------|
| Education level                                                                   | 105                   | 93.8%                  |
| Cultural background: Beliefs, rituals, and customs                                | 100                   | 89.3%                  |
| Socioeconomic status                                                              | 94                    | 83.9%                  |
| Household composition: single, teen, or step parent; adoptive/foster; gay/lesbian | 94                    | 83.9%                  |
| Religion, gender roles, ethnicity, language                                       | 93                    | 83.0%                  |
| Louisiana resident status                                                         | 35                    | 31.3%                  |
| <b>Total responses (total respondents)</b>                                        | <b>521 (112)</b>      |                        |

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

Responding physicians largely report that they are sensitive to differences in their patients' and families' backgrounds when it comes to the discussion and planning of health issues. Over 80% of respondents report that they consider a patient's background and cultural beliefs when planning care and communicating with the patient and family. Over 80% also report considering education level, socioeconomic status, and household composition of their patients. Louisiana resident status, however, appears to be of little concern to most responding physicians; less than one third of respondents reported taking it into consideration.

The following three indicators were included on the survey by CSHS to inform them on the state of pediatric medical care. These indicators will also be used by CSHS for planning programs and technical assistance opportunities for care providers.

**Indicator** I have difficulty locating pediatric medical sub-specialists in my geographic area for patient referrals.

|                                                   | Number of Respondents | Percent of Respondents |
|---------------------------------------------------|-----------------------|------------------------|
| Always                                            | 11                    | 9.8%                   |
| Usually                                           | 22                    | 19.6%                  |
| Sometimes                                         | 59                    | 52.7%                  |
| Never                                             | 20                    | 17.9%                  |
| Not applicable, this is not needed in my practice | 0                     | 0.0%                   |
| <b>Total</b>                                      | <b>112</b>            | <b>100.0%</b>          |

Nearly 30% of respondents report "always" or "usually" having trouble finding pediatric sub-specialists in their area. Respondents who answered anything other than "never" and "not applicable" were asked to identify which sub-specialties they have had difficulty accessing. Responses are presented below for those 92 respondents.

*If yes, which of the following sub-specialties do you have difficulty accessing? (select all that apply)*

|                                            | Number of<br>Respondents | Percent of<br>Respondents |
|--------------------------------------------|--------------------------|---------------------------|
| Psychiatry                                 | 69                       | 75.0%                     |
| Developmental/Behavioral pediatrician      | 62                       | 67.4%                     |
| Neurology                                  | 58                       | 63.0%                     |
| Orthopedic                                 | 49                       | 53.3%                     |
| Dermatology                                | 42                       | 45.7%                     |
| Endocrinology                              | 38                       | 41.3%                     |
| Rheumatology                               | 36                       | 39.1%                     |
| Pulmonology                                | 27                       | 29.4%                     |
| Neurosurgery                               | 23                       | 25.0%                     |
| Gastroenterology                           | 20                       | 21.7%                     |
| Infectious Disease                         | 20                       | 21.7%                     |
| Urology                                    | 20                       | 21.7%                     |
| Genetics                                   | 16                       | 17.4%                     |
| General Surgery                            | 13                       | 14.1%                     |
| Hematology/Oncology                        | 13                       | 14.1%                     |
| Ophthalmology                              | 12                       | 13.4%                     |
| Allergy/Immunology                         | 10                       | 10.9%                     |
| Otolaryngology                             | 7                        | 7.6%                      |
| Cardiology                                 | 6                        | 6.5%                      |
| Other                                      | 4                        | 4.4%                      |
| Neonatology                                | 2                        | 2.2%                      |
| <b>Total responses (total respondents)</b> | <b>510 (92)</b>          |                           |

Results include all respondents who responded “always,” “usually,” or “sometimes” to question 23. Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

Mental and developmental health top the list of specialties that physicians find difficult for referrals. Psychiatry (75.0%) and developmental/behavioral pediatricians (67.4%) are most identified by pediatricians and family practitioners as sub-specializations that are difficult to access. Most physicians also report that they have difficulty referring patients to neurologists (63.0%) and orthopedic specialists (53.3%).

**Indicator** *Barriers that limit my ability to provide public health/community-based referrals for my CYSHCN patients include (select all that apply):*

|                                                             | <b>Number of Respondents</b> | <b>Percent of Respondents</b> |
|-------------------------------------------------------------|------------------------------|-------------------------------|
| Limited number of available resources in my geographic area | 62                           | 68.1%                         |
| Lack of knowledge about resources available in our area     | 55                           | 60.4%                         |
| Lack of knowledge of resource eligibility criteria          | 46                           | 50.5%                         |
| Lack of time                                                | 33                           | 36.3%                         |
| Other                                                       | 7                            | 7.7%                          |
| <b>Total responses (total respondents)</b>                  | <b>203 (91)</b>              |                               |

Respondents were allowed to select all the responses that apply; consequently, the percentage of respondents replying to all categories may not equal 100.

Twenty-one of the 112 respondents indicate that they have not experienced any barriers to providing referrals for public health or community-based services. The remaining 91 providers have been asked to identify where they experience these barriers.

Physicians who report experiencing barriers in community and public-health-based referrals most often identify availability of resources in their geographic area as the reason for that difficulty. Knowledge of resources in the area is the second-most identified barrier (60.4%). A slim majority also report lack of knowledge of eligibility criteria for community and public-health-based referrals (50.4%).

Though these data are only descriptive, these results – that resources are hard to find and physicians lack knowledge of those resources – may provide some insight as to why responding physicians report comparatively low provision of:

- Family support services (Indicator 1.4);
- Transitional support services (Indicator 2.2);
- Social support services (Indicator 3.6).

The responses here suggest that knowledge and access may in part explain the provision of support services. Further focus group investigation, survey research, or theory-based inferential statistics could provide support for this hypothesis.



**Indicator** The following is a list of the top 10 needs identified by Louisiana's CYSHCN and their families. Please rank the needs you believe are most important for the patients and families you care for in your practices by level of importance where 1 is the most important and 10 is the least important.

| Need                                                                                 | Mean | Rank |   |   |   |   |   |   |   |   |    |
|--------------------------------------------------------------------------------------|------|------|---|---|---|---|---|---|---|---|----|
|                                                                                      |      | 1    | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Mental health services                                                               | 2.7  |      |   | * |   |   |   |   |   |   |    |
| Sub-specialists who accept Medicaid                                                  | 3.2  |      |   | * |   |   |   |   |   |   |    |
| Occupational/Physical therapists who accept CYSHCN patients covered by Medicaid      | 5.3  |      |   |   |   | * |   |   |   |   |    |
| Pediatric dental providers who accept CYSHCN patients covered by Medicaid            | 5.4  |      |   |   |   | * |   |   |   |   |    |
| Care coordination by primary care provider/primary pediatric practice                | 5.4  |      |   |   |   | * |   |   |   |   |    |
| Pediatricians who accept Medicaid                                                    | 5.5  |      |   |   |   |   | * |   |   |   |    |
| Transition services for YSHCN                                                        | 6.2  |      |   |   |   |   | * |   |   |   |    |
| Handicap/universally accessible public transportation                                | 6.4  |      |   |   |   |   | * |   |   |   |    |
| Expanded prescription coverage by health insurer (private, military, Medicaid, etc.) | 6.6  |      |   |   |   |   |   | * |   |   |    |
| Translators in pediatric practices                                                   | 7.9  |      |   |   |   |   |   |   | * |   |    |

\*Asterisks represent the approximation of the mean for each ranked need.

Physicians were asked to rank in terms of priority the needs faced by their CYSHCN clients. The list of needs was specified as part of an earlier survey distributed to CYSHCN families. The table above presents mean physician responses for each need identified in the questionnaire and ranks the needs based on this descriptive statistic. Lower mean numbers reflect higher physician-perceived priority of need; lower numbers reflect the opposite.

Presented this way, the statistics suggest that, according responding physicians, “mental health services” and “sub-specialists who accept Medicaid” are the most important needs for Louisiana’s CYSHCN population. As is illustrated in the table above, these perceived needs appear categorically greater than the remaining needs in the list. Mean scores for these two are a full two points lower than the next identified need. By comparison, the following seven needs are only separated by 1.3 points. What this suggests is there is broad general agreement about the top two needs, but that the remaining items are viewed more amorphously by physicians.

## Appendix A: Physician Survey

### Children's Special Health Services Program: 2010 Statewide Needs Assessment

*The Louisiana Office of Public Health Maternal and Child Health Program and Children's Special Health Services (CSHS) Program are conducting a statewide needs assessment to learn more about the key components of medical care that Louisiana physicians provide for children and adolescents. All answers to the questions are STRICTLY confidential and anonymous. Results will be analyzed by region, and key findings will be published in the American Academy of Pediatrics and Louisiana Academy of Family Physicians newsletters. If you are interested in learning about the results of this survey, please feel free to contact CSHS at (504) 568-5055.*

**Instructions:** To indicate your answer, please fill in the appropriate bubble completely.

**1. Are you a physician who currently provides primary care for children and/or adolescents at least three days each week in an outpatient setting?**

- ☐ Yes  
☐ No

*If you answered YES, please continue.*

*If you answered NO, you are not eligible to complete this survey. Thank you for your time.*

---

**2. Are you a family practice physician or a pediatrician? (choose one)**

- ☐ Family practice physician  
☐ Pediatrician

**3. Are you a Louisiana Medicaid provider?**

- ☐ Yes  
☐ No

**4. What is the ZIP code(s) for your practice(s)?** \_\_\_\_\_

**5. In which parish is your practice?** \_\_\_\_\_

Children and Youth with Special Health Care Needs (CYSHCN) are defined by the Maternal and Child Health Bureau as: *Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*

**6. Do you provide primary care for CYSHCN in your practice?**

- ☐ Yes  
☐ No

*If you answered YES to question 6, please continue with the survey.*

*If you answered NO to question 6, you are not eligible to complete the survey. However, the answers that you have already given can provide us with important information for the needs assessment. Please assist us by returning your survey in the return envelope provided. Thank you very much for your time.*

---

**Instructions:**

Below are statements that describe ways in which a medical practice is managed. Statements using the first person “I” or “my” will prompt you to refer to your perspective as the physician; other statements will prompt you to refer to the practice. For statements concerning patients, you should consider all child/adolescent patients in the practice, unless explicitly stated to reference only the CYSHCN group. After reading each statement, select the answer choice(s) that best captures your opinions.

**7. In my practice I serve the following age groups (*select all that apply*):**

- ☐ All children 0-18 years old
- ☐ Adolescents only (12-18)
- ☐ YSHCN 19 years and older
- ☐ Other (please specify) \_\_\_\_\_

**8. My practice is accessible by public transportation.**

- ☐ Yes
- ☐ No

**9. I accept CYSHCN patients with most types of insurance, including Medicaid and/or LaCHIP.**

- ☐ Yes
- ☐ No

**10. My patients can speak directly to me when needed.**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

**11. My staff or I provide my patients with a written plan of care that addresses the patients’ and families’ needs and improves collaboration of care among other providers, agencies, and organizations.**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

**12. My CYSHCN patients' plans of care involve coordination with the patients' schools so that their special health needs are addressed.**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

**13. My practice has a system in place to alert me when my patients have been hospitalized so that I can schedule an office visit to review the clinical information with the patients/families.**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

**14. When I refer a patient for specialty care, my staff or I do the following:**

a) Assist the family with communicating clinical information to the sub-specialist.

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

b) Share information with the family and sub-specialist that provides the specific reason for the referral.

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

c) Discuss the results and recommendations from the sub-specialist visit with the child/youth and family, and integrate the recommendations in the child/youth's plan of care.

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

**15. My practice has a central record-keeping system with the following characteristics:**

|                                                                                                        | Yes                   | No                    |
|--------------------------------------------------------------------------------------------------------|-----------------------|-----------------------|
| a) Meets HIPAA confidentiality criteria                                                                | <input type="radio"/> | <input type="radio"/> |
| b) Records patient demographics and contact information                                                | <input type="radio"/> | <input type="radio"/> |
| c) Records patient billing/insurance information                                                       | <input type="radio"/> | <input type="radio"/> |
| d) Records patient clinical record charting                                                            | <input type="radio"/> | <input type="radio"/> |
| e) Can produce electronic prescriptions                                                                | <input type="radio"/> | <input type="radio"/> |
| f) Tracks and records patient referrals, specialists, labs, tests, and hospitalizations/ER histories   | <input type="radio"/> | <input type="radio"/> |
| g) Allows the transfer of medical records between medical providers                                    | <input type="radio"/> | <input type="radio"/> |
| h) Copies of patients' records are made available to patients and their families on request at no cost | <input type="radio"/> | <input type="radio"/> |
| i) Identification of special health-care needs status on patients' medical records                     | <input type="radio"/> | <input type="radio"/> |

**16. I use pediatric growth and developmental screening tools at 9, 18, and 24-30 months, as well as when I and/or my patients' families have concerns.**

- ☐ Yes  
☐ No (*skip to question 17*)  
☐ N/A – I do not serve patients aged 0-5 years. (*skip to question 17*)

**If yes, please indicate the screening tools you use (*select all that apply*):**

- ☐ Ages and Stages Questionnaire (ASQ)  
☐ Child Development Chart (CDC)  
☐ Parents' Evaluation of Developmental Status (PEDS)  
☐ Parents' Evaluation of Developmental Status Developmental Milestones (PEDS:DM)  
☐ Battelle Developmental Inventory Screening Test (BDIST)  
☐ Brigance Screens  
☐ Denver-II Developmental Test  
☐ Prescreening Developmental Questionnaire (PDQ-II)  
☐ Revised Prescreening Developmental Questionnaire (R-PDQ)  
☐ Other (specify) \_\_\_\_\_  
☐ N/A – I do not serve patients aged 0-5 years.

**17. I use pediatric behavioral checklists when I and/or my patients' families have concerns.**

- ☐ Yes
- ☐ No (*skip to question 18*)

**If yes, please indicate the checklists you use (*select all that apply*):**

- ☐ Pediatric Symptom Checklist
- ☐ Child Behavior Checklist
- ☐ NICHQ Vanderbilt Assessment Scales
- ☐ Eyberg Child Behavior Inventory (ECBI)
- ☐ Sutter Eyberg Student Behavior Inventory Revised (SESBI-R)
- ☐ Other (specify) \_\_\_\_\_

**18. My staff or I discuss with my CYSHCN patients and/or their families about the need for and acquisition of the following services and resources (*select all that apply*):**

- ☐ Respite care
- ☐ Durable medical equipment (DME)
- ☐ Assistive transportation
- ☐ Louisiana Medicaid/LaCHIP
- ☐ Supplemental Security Income (SSI) or SSI – Disability
- ☐ Department of Social Services: Louisiana Rehabilitation Services (LRS)
- ☐ Title V Programs: Children's Special Health Services; Child Health; Partners for Healthy Babies; Hearing, Speech, and Vision; Birth Defects Monitoring Network
- ☐ Office for Citizens with Developmental Disabilities: waivers, Family Support and Services
- ☐ Early Steps
- ☐ Head Start
- ☐ Individualized Education Plans (IEP)
- ☐ 504 Accommodations
- ☐ Occupational, physical, and speech therapies
- ☐ Women, Infants, and Children (WIC) nutritional assistance program
- ☐ Families Helping Families or other family/parent support groups
- ☐ Other (specify) \_\_\_\_\_
  
- ☐ None of the above

**19. The transition process from my care to adult medical care for my adolescent patients with special health care needs (YSHCN) and their families involves the following:**

|                                                                                                                                                 | <b>Yes</b>            | <b>No</b>             |
|-------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|-----------------------|
| a) The patient has established an adult primary care provider.                                                                                  | <input type="radio"/> | <input type="radio"/> |
| b) My staff or I discuss health/dental insurance options.                                                                                       | <input type="radio"/> | <input type="radio"/> |
| c) My staff or I discuss the type and eligibility requirements for community based resources (waivers, trusts, independent living, etc.).       | <input type="radio"/> | <input type="radio"/> |
| d) My staff or I discuss vocational and/or education choices.                                                                                   | <input type="radio"/> | <input type="radio"/> |
| e) My staff or I discuss the patient's role in managing his/her health care routines (prescriptions, equipment, scheduling appointments, etc.). | <input type="radio"/> | <input type="radio"/> |
| f) My staff or I provide developmentally appropriate counseling directly to youth.                                                              | <input type="radio"/> | <input type="radio"/> |
| <i>Transition services are not applicable to my practice- I care for YSHCN from childhood through adulthood.</i>                                | <input type="radio"/> | <input type="radio"/> |

**20. For my CYSHCN patients, I schedule extra time or extend the time for their office visits when indicated.**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

**21. I provide my patients interpreters/translators in my practice.**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Not applicable, this is not needed in my practice.

**22. Which of the following characteristics of the patient or family do you incorporate into a patient's plan of care and take into consideration when communicating health information (*select all that apply*):**

- ☐ Educational level
- ☐ Cultural background: Beliefs, rituals, and customs
- ☐ Religion, gender roles, ethnicity, language
- ☐ Socioeconomic status
- ☐ Household composition: single, teen, or step parent; adoptive/foster, gay/lesbian
- ☐ Louisiana resident status

**23. I have difficulty locating pediatric medical sub-specialists in my geographic area for patient referrals.**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never (*skip to question 24*)
- ☐ Not applicable, this is not needed in my practice. (*skip to question 24*)

**If yes, which of the following sub-specialties do you have difficulty accessing? (*select all that apply*)**

- ☐ Allergy/Immunology
  - ☐ Cardiology
  - ☐ Dermatology
  - ☐ Developmental/Behavioral Pediatrician
  - ☐ Endocrinology
  - ☐ Gastroenterology
  - ☐ General Surgery
  - ☐ Genetics
  - ☐ Hematology/Oncology
  - ☐ Infectious Disease
  - ☐ Neonatology
  - ☐ Neurology
  - ☐ Neurosurgery
  - ☐ Ophthalmology
  - ☐ Orthopedic
  - ☐ Otolaryngology
  - ☐ Psychiatry
  - ☐ Pulmonology
  - ☐ Rheumatology
  - ☐ Urology
  - ☐ Other (please specify):
-



**24. Barriers that limit my ability to provide public health/community-based referrals for my CYSHCN patients include (*select all that apply*):**

- ☐ Lack of time
- ☐ Lack of knowledge about resources available in our area
- ☐ Lack of knowledge of resource eligibility criteria
- ☐ Limited number of available resources in my geographic area
- ☐ Other (please specify) \_\_\_\_\_
- ☐ None - I have not experienced any barriers to providing referrals.

**25. The following is a list of the top 10 needs identified by Louisiana's CYSHCN and their families. Please rank the needs you believe are most important for the patients and families you care for in your practices by level of importance where 1 is *most important* and 10 is *least important*.**

***PLEASE WRITE IN EACH NUMBER 1 THROUGH 10 ONLY ONCE.***

- \_\_\_\_\_ Handicap/universally accessible public transportation
- \_\_\_\_\_ Transition services for YSHCN
- \_\_\_\_\_ Pediatric dental providers who accept CYSHCN patients covered by Medicaid
- \_\_\_\_\_ Occupational/Physical therapists who accept CYSHCN patients covered by Medicaid
- \_\_\_\_\_ Mental health services
- \_\_\_\_\_ Expanded prescription coverage by health insurer (private, military, Medicaid, etc.)
- \_\_\_\_\_ Pediatricians who accept Medicaid
- \_\_\_\_\_ Sub-specialists who accept Medicaid
- \_\_\_\_\_ Translators in pediatric practices
- \_\_\_\_\_ Care coordination by primary care provider/primary pediatric practice

**26. Please choose one category that best captures the medical home status of your practice:**

- ☐ My practice applied to be a NCQA-certified medical home in the past 12 months.
- ☐ My practice is a NCQA-certified medical home.
- ☐ My practice is not interested in applying to be a NCQA-certified medical home at this time.
- ☐ My practice is interested in the process and application for NCQA-certification as a medical home.

**Thank you very much for participating in the 2010 statewide needs assessment.  
Please return your survey using the stamped return envelope provided.**

## Appendix B: Crosstabs

7. In my practice I serve the following age groups (select all that apply):

| practice<br>serves all<br>children | Pediatrixian or FP |              |             | Total         |
|------------------------------------|--------------------|--------------|-------------|---------------|
|                                    | family pr          | pediatric    | missing     |               |
| No                                 | 3<br>8.33          | 2<br>2.67    | 0<br>0.00   | 5<br>4.46     |
| Yes                                | 33<br>91.67        | 73<br>97.33  | 1<br>100.00 | 107<br>95.54  |
| Total                              | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| practice<br>serves<br>adolescent<br>s | Pediatrixian or FP |              |             | Total         |
|---------------------------------------|--------------------|--------------|-------------|---------------|
|                                       | family pr          | pediatric    | missing     |               |
| No                                    | 26<br>72.22        | 70<br>93.33  | 1<br>100.00 | 97<br>86.61   |
| Yes                                   | 10<br>27.78        | 5<br>6.67    | 0<br>0.00   | 15<br>13.39   |
| Total                                 | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| practice<br>serves 19<br>yrs and<br>older | Pediatrixian or FP |              |             | Total         |
|-------------------------------------------|--------------------|--------------|-------------|---------------|
|                                           | family pr          | pediatric    | missing     |               |
| No                                        | 17<br>47.22        | 55<br>73.33  | 1<br>100.00 | 73<br>65.18   |
| Yes                                       | 19<br>52.78        | 20<br>26.67  | 0<br>0.00   | 39<br>34.82   |
| Total                                     | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| practice<br>serves<br>other | Pediatrician or FP |              |             | Total         |
|-----------------------------|--------------------|--------------|-------------|---------------|
|                             | family pr          | pediatric    | missing     |               |
| No                          | 32<br>88.89        | 67<br>89.33  | 1<br>100.00 | 100<br>89.29  |
| Yes                         | 4<br>11.11         | 8<br>10.67   | 0<br>0.00   | 12<br>10.71   |
| Total                       | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

8. My practice is accessible by public transportation.

| accessible<br>by private<br>transp | Pediatrician or FP |              |             | Total         |
|------------------------------------|--------------------|--------------|-------------|---------------|
|                                    | family pr          | pediatric    | missing     |               |
| No                                 | 7<br>19.44         | 15<br>20.00  | 1<br>100.00 | 23<br>20.54   |
| Yes                                | 27<br>75.00        | 60<br>80.00  | 0<br>0.00   | 87<br>77.68   |
| Missing,<br>blank                  | 2<br>5.56          | 0<br>0.00    | 0<br>0.00   | 2<br>1.79     |
| Total                              | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

9. I accept CYSHCN patients with most types of insurance, including Medicaid and/or LaCHIP.

| accept<br>most types<br>of<br>insurance | Pediatrician or FP |              |             | Total         |
|-----------------------------------------|--------------------|--------------|-------------|---------------|
|                                         | family pr          | pediatric    | missing     |               |
| No                                      | 5<br>13.89         | 6<br>8.00    | 0<br>0.00   | 11<br>9.82    |
| Yes                                     | 30<br>83.33        | 69<br>92.00  | 1<br>100.00 | 100<br>89.29  |
| Missing,<br>blank                       | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| Total                                   | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

10. My patients can speak directly to me when needed.

| patients can speak<br>directly to me | Pediatrician or FP |              |             | Total         |
|--------------------------------------|--------------------|--------------|-------------|---------------|
|                                      | family pr          | pediatric    | missing     |               |
| always                               | 12<br>33.33        | 27<br>36.00  | 0<br>0.00   | 39<br>34.82   |
| usually                              | 12<br>33.33        | 37<br>49.33  | 0<br>0.00   | 49<br>43.75   |
| sometimes                            | 11<br>30.56        | 9<br>12.00   | 1<br>100.00 | 21<br>18.75   |
| not applicable, this                 | 1<br>2.78          | 1<br>1.33    | 0<br>0.00   | 2<br>1.79     |
| Missing,<br>blank                    | 0<br>0.00          | 1<br>1.33    | 0<br>0.00   | 1<br>0.89     |
| Total                                | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

11. My staff or I provide my patients with a written plan of care that addresses the patients' and families' needs and improves collaboration of care among other providers, agencies, and organizations.

| provide patients with<br>written care plan | Pediatrician or FP |              |             | Total         |
|--------------------------------------------|--------------------|--------------|-------------|---------------|
|                                            | family pr          | pediatric    | missing     |               |
| always                                     | 3<br>8.33          | 9<br>12.00   | 0<br>0.00   | 12<br>10.71   |
| usually                                    | 9<br>25.00         | 23<br>30.67  | 0<br>0.00   | 32<br>28.57   |
| sometimes                                  | 17<br>47.22        | 32<br>42.67  | 0<br>0.00   | 49<br>43.75   |
| never                                      | 5<br>13.89         | 8<br>10.67   | 0<br>0.00   | 13<br>11.61   |
| not applicable, this                       | 2<br>5.56          | 3<br>4.00    | 1<br>100.00 | 6<br>5.36     |
| Total                                      | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

12. My CYSHCN patients' plans of care involve coordination with the patients' schools so that their special health needs are addressed.

| health plan involves<br>coordination with<br>schools | Pediatrician or FP |              |             | Total         |
|------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                      | family pr          | pediatric    | missing     |               |
| always                                               | 3<br>8.33          | 16<br>21.33  | 0<br>0.00   | 19<br>16.96   |
| usually                                              | 11<br>30.56        | 24<br>32.00  | 1<br>100.00 | 36<br>32.14   |
| sometimes                                            | 19<br>52.78        | 31<br>41.33  | 0<br>0.00   | 50<br>44.64   |
| never                                                | 1<br>2.78          | 2<br>2.67    | 0<br>0.00   | 3<br>2.68     |
| not applicable, this                                 | 2<br>5.56          | 2<br>2.67    | 0<br>0.00   | 4<br>3.57     |
| Total                                                | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

13. My practice has a system in place to alert me when my patients have been hospitalized so that I can schedule an office visit to review the clinical information with the patients/families.

| system to alert when<br>patient is<br>hospitalized | Pediatrician or FP |              |             | Total         |
|----------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                    | family pr          | pediatric    | missing     |               |
| always                                             | 5<br>13.89         | 14<br>18.67  | 0<br>0.00   | 19<br>16.96   |
| usually                                            | 10<br>27.78        | 26<br>34.67  | 1<br>100.00 | 37<br>33.04   |
| sometimes                                          | 7<br>19.44         | 14<br>18.67  | 0<br>0.00   | 21<br>18.75   |
| never                                              | 6<br>16.67         | 14<br>18.67  | 0<br>0.00   | 20<br>17.86   |
| not applicable, this                               | 8<br>22.22         | 7<br>9.33    | 0<br>0.00   | 15<br>13.39   |
| Total                                              | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

14. When I refer a patient for specialty care, my staff or I do the following:

a) Assist the family with communicating clinical information to the sub-specialist.

| assist with<br>communicating<br>clinical info to<br>sub-specialist | Pediatrixian or FP |              |             | Total         |
|--------------------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                                    | family pr          | pediatric    | missing     |               |
| always                                                             | 21<br>58.33        | 42<br>56.00  | 0<br>0.00   | 63<br>56.25   |
| usually                                                            | 13<br>36.11        | 26<br>34.67  | 1<br>100.00 | 40<br>35.71   |
| sometimes                                                          | 2<br>5.56          | 7<br>9.33    | 0<br>0.00   | 9<br>8.04     |
| Total                                                              | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

b) Share information with the family and sub-specialist that provides the specific reason for the referral.

| share info that<br>provides the specific<br>reason for referral | Pediatrixian or FP |              |             | Total         |
|-----------------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                                 | family pr          | pediatric    | missing     |               |
| always                                                          | 26<br>72.22        | 48<br>64.00  | 1<br>100.00 | 75<br>66.96   |
| usually                                                         | 10<br>27.78        | 22<br>29.33  | 0<br>0.00   | 32<br>28.57   |
| sometimes                                                       | 0<br>0.00          | 5<br>6.67    | 0<br>0.00   | 5<br>4.46     |
| Total                                                           | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

c) Discuss the results and recommendations from the sub-specialist visit with the child/youth and family, and integrate the recommendations in the child/youth's plan of care.

| discuss results from<br>and recs from<br>sub-specialist with<br>family | Pediatrician or FP |              |             | Total         |
|------------------------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                                        | family pr          | pediatric    | missing     |               |
| always                                                                 | 17<br>47.22        | 42<br>56.00  | 1<br>100.00 | 60<br>53.57   |
| usually                                                                | 17<br>47.22        | 28<br>37.33  | 0<br>0.00   | 45<br>40.18   |
| sometimes                                                              | 0<br>0.00          | 3<br>4.00    | 0<br>0.00   | 3<br>2.68     |
| never                                                                  | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| not applicable, this                                                   | 1<br>2.78          | 2<br>2.67    | 0<br>0.00   | 3<br>2.68     |
| Total                                                                  | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

15. My practice has a central record-keeping system with the following characteristics:

a) Meets HIPAA confidentiality criteria

| record-keep<br>ing meets<br>HIPAA<br>criteria | Pediatrician or FP |              |             | Total         |
|-----------------------------------------------|--------------------|--------------|-------------|---------------|
|                                               | family pr          | pediatric    | missing     |               |
| No                                            | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| Yes                                           | 35<br>97.22        | 74<br>98.67  | 1<br>100.00 | 110<br>98.21  |
| Missing,<br>blank                             | 0<br>0.00          | 1<br>1.33    | 0<br>0.00   | 1<br>0.89     |
| Total                                         | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

b) Records patient demographics and contact information

| record-keeping<br>records<br>demographics<br>and<br>contact<br>info | Pediatrician or FP |              |             | Total         |
|---------------------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                                     | family pr          | pediatric    | missing     |               |
| No                                                                  | 0<br>0.00          | 1<br>1.33    | 0<br>0.00   | 1<br>0.89     |
| Yes                                                                 | 36<br>100.00       | 74<br>98.67  | 1<br>100.00 | 111<br>99.11  |
| Total                                                               | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

c) Records patient billing/insurance information

| record-keeping<br>records<br>billing/insurance<br>info | Pediatrician or FP |              |             | Total         |
|--------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                        | family pr          | pediatric    | missing     |               |
| No                                                     | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| Yes                                                    | 35<br>97.22        | 75<br>100.00 | 1<br>100.00 | 111<br>99.11  |
| Total                                                  | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |



d) Records patient clinical record charting

| record-keeping<br>clinical<br>record<br>charting | Pediatrician or FP |              |             | Total         |
|--------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                  | family pr          | pediatric    | missing     |               |
| No                                               | 1<br>2.78          | 3<br>4.00    | 0<br>0.00   | 4<br>3.57     |
| Yes                                              | 34<br>94.44        | 71<br>94.67  | 1<br>100.00 | 106<br>94.64  |
| Missing,<br>blank                                | 1<br>2.78          | 1<br>1.33    | 0<br>0.00   | 2<br>1.79     |
| Total                                            | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

e) Can produce electronic prescriptions

| produces<br>electronic<br>prescriptions | Pediatrician or FP |              |             | Total         |
|-----------------------------------------|--------------------|--------------|-------------|---------------|
|                                         | family pr          | pediatric    | missing     |               |
| No                                      | 21<br>58.33        | 47<br>62.67  | 0<br>0.00   | 68<br>60.71   |
| Yes                                     | 14<br>38.89        | 26<br>34.67  | 1<br>100.00 | 41<br>36.61   |
| Missing,<br>blank                       | 1<br>2.78          | 2<br>2.67    | 0<br>0.00   | 3<br>2.68     |
| Total                                   | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

f) Tracks and records patient referrals, specialists, labs, tests, and hospitalizations/ER histories

| tracks<br>patient<br>histories' | Pediatrician or FP |              |             | Total         |
|---------------------------------|--------------------|--------------|-------------|---------------|
|                                 | family pr          | pediatric    | missing     |               |
| No                              | 15<br>41.67        | 18<br>24.00  | 0<br>0.00   | 33<br>29.46   |
| Yes                             | 21<br>58.33        | 57<br>76.00  | 1<br>100.00 | 79<br>70.54   |
| Total                           | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

g) Allows the transfer of medical records between medical providers

| record-keeping allows transfer of medical records | Pediatrician or FP |              |             | Total         |
|---------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                   | family pr          | pediatric    | missing     |               |
| No                                                | 10<br>27.78        | 15<br>20.00  | 0<br>0.00   | 25<br>22.32   |
| Yes                                               | 26<br>72.22        | 58<br>77.33  | 1<br>100.00 | 85<br>75.89   |
| Missing, blank                                    | 0<br>0.00          | 2<br>2.67    | 0<br>0.00   | 2<br>1.79     |
| Total                                             | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

h) Copies of patients' records are made available to patients and their families on request at no cost

| record-keeping make records available to families | Pediatrician or FP |              |             | Total         |
|---------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                   | family pr          | pediatric    | missing     |               |
| No                                                | 12<br>33.33        | 31<br>41.33  | 0<br>0.00   | 43<br>38.39   |
| Yes                                               | 24<br>66.67        | 41<br>54.67  | 1<br>100.00 | 66<br>58.93   |
| Missing, blank                                    | 0<br>0.00          | 3<br>4.00    | 0<br>0.00   | 3<br>2.68     |
| Total                                             | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

i) Identification of special health-care needs status on patients' medical records

| record-keeping ID<br>CYSHCN | Pediatrician or FP |              |             | Total         |
|-----------------------------|--------------------|--------------|-------------|---------------|
|                             | family pr          | pediatric    | missing     |               |
| No                          | 12<br>33.33        | 27<br>36.00  | 0<br>0.00   | 39<br>34.82   |
| Yes                         | 23<br>63.89        | 48<br>64.00  | 1<br>100.00 | 72<br>64.29   |
| Missing,<br>blank           | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| Total                       | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

16. I use pediatric growth and developmental screening tools at 9, 18, and 24-30 months, as well as when I and/or my patients' families have concerns.

| use<br>pediatric<br>growth and<br>development<br>screening<br>tools | Pediatrician or FP |              |             | Total         |
|---------------------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                                     | family pr          | pediatric    | missing     |               |
| No                                                                  | 5<br>13.89         | 5<br>6.67    | 0<br>0.00   | 10<br>8.93    |
| Yes                                                                 | 26<br>72.22        | 69<br>92.00  | 1<br>100.00 | 96<br>85.71   |
| N/A                                                                 | 3<br>8.33          | 1<br>1.33    | 0<br>0.00   | 4<br>3.57     |
| Missing,<br>blank                                                   | 2<br>5.56          | 0<br>0.00    | 0<br>0.00   | 2<br>1.79     |
| Total                                                               | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| use ASQ | Pediatrician or FP |              |             | Total         |
|---------|--------------------|--------------|-------------|---------------|
|         | family pr          | pediatric    | missing     |               |
| No      | 31<br>86.11        | 47<br>62.67  | 0<br>0.00   | 78<br>69.64   |
| Yes     | 5<br>13.89         | 28<br>37.33  | 1<br>100.00 | 34<br>30.36   |
| Total   | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |
| use CDC | Pediatrician or FP |              |             | Total         |
|         | family pr          | pediatric    | missing     |               |

|       |        |        |        |        |
|-------|--------|--------|--------|--------|
| No    | 22     | 64     | 0      | 86     |
|       | 61.11  | 85.33  | 0.00   | 76.79  |
| Yes   | 14     | 11     | 1      | 26     |
|       | 38.89  | 14.67  | 100.00 | 23.21  |
| Total | 36     | 75     | 1      | 112    |
|       | 100.00 | 100.00 | 100.00 | 100.00 |

| use PEDS | Pediatrician or FP |           |         | Total  |
|----------|--------------------|-----------|---------|--------|
|          | family pr          | pediatric | missing |        |
| No       | 32                 | 63        | 1       | 96     |
|          | 88.89              | 84.00     | 100.00  | 85.71  |
| Yes      | 4                  | 12        | 0       | 16     |
|          | 11.11              | 16.00     | 0.00    | 14.29  |
| Total    | 36                 | 75        | 1       | 112    |
|          | 100.00             | 100.00    | 100.00  | 100.00 |

| use PEDS:DM | Pediatrician or FP |           |         | Total  |
|-------------|--------------------|-----------|---------|--------|
|             | family pr          | pediatric | missing |        |
| No          | 34                 | 67        | 1       | 102    |
|             | 94.44              | 89.33     | 100.00  | 91.07  |
| Yes         | 2                  | 8         | 0       | 10     |
|             | 5.56               | 10.67     | 0.00    | 8.93   |
| Total       | 36                 | 75        | 1       | 112    |
|             | 100.00             | 100.00    | 100.00  | 100.00 |

| use BDIST | Pediatrician or FP |           |         | Total  |
|-----------|--------------------|-----------|---------|--------|
|           | family pr          | pediatric | missing |        |
| No        | 36                 | 75        | 1       | 112    |
|           | 100.00             | 100.00    | 100.00  | 100.00 |
| Total     | 36                 | 75        | 1       | 112    |
|           | 100.00             | 100.00    | 100.00  | 100.00 |

| Brigance<br>Screens | Pediatrician or FP |           |         | Total  |
|---------------------|--------------------|-----------|---------|--------|
|                     | family pr          | pediatric | missing |        |
| No                  | 36                 | 75        | 1       | 112    |
|                     | 100.00             | 100.00    | 100.00  | 100.00 |
| Total               | 36                 | 75        | 1       | 112    |
|                     | 100.00             | 100.00    | 100.00  | 100.00 |

| use<br>denver-II<br>test | Pediatrician or FP |           |         | Total  |
|--------------------------|--------------------|-----------|---------|--------|
|                          | family pr          | pediatric | missing |        |
| No                       | 26                 | 57        | 0       | 83     |
|                          | 72.22              | 76.00     | 0.00    | 74.11  |
| Yes                      | 10                 | 18        | 1       | 29     |
|                          | 27.78              | 24.00     | 100.00  | 25.89  |
| Total                    | 36                 | 75        | 1       | 112    |
|                          | 100.00             | 100.00    | 100.00  | 100.00 |

| use PDQ-II | Pediatrician or FP |           |         | Total  |
|------------|--------------------|-----------|---------|--------|
|            | family pr          | pediatric | missing |        |
| No         | 34                 | 52        | 0       | 86     |
|            | 94.44              | 69.33     | 0.00    | 76.79  |
| Yes        | 2                  | 23        | 1       | 26     |
|            | 5.56               | 30.67     | 100.00  | 23.21  |
| Total      | 36                 | 75        | 1       | 112    |
|            | 100.00             | 100.00    | 100.00  | 100.00 |

| use R-PDQ | Pediatrician or FP |           |         | Total  |
|-----------|--------------------|-----------|---------|--------|
|           | family pr          | pediatric | missing |        |
| No        | 36                 | 68        | 1       | 105    |
|           | 100.00             | 90.67     | 100.00  | 93.75  |
| Yes       | 0                  | 7         | 0       | 7      |
|           | 0.00               | 9.33      | 0.00    | 6.25   |
| Total     | 36                 | 75        | 1       | 112    |
|           | 100.00             | 100.00    | 100.00  | 100.00 |

| use other<br>tool | Pediatrician or FP |              |             | Total         |
|-------------------|--------------------|--------------|-------------|---------------|
|                   | family pr          | pediatric    | missing     |               |
| No                | 34<br>94.44        | 67<br>89.33  | 1<br>100.00 | 102<br>91.07  |
| Yes               | 2<br>5.56          | 8<br>10.67   | 0<br>0.00   | 10<br>8.93    |
| Total             | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| tool used-<br>N/A | Pediatrician or FP |              |             | Total         |
|-------------------|--------------------|--------------|-------------|---------------|
|                   | family pr          | pediatric    | missing     |               |
| No                | 35<br>97.22        | 75<br>100.00 | 1<br>100.00 | 111<br>99.11  |
| Yes               | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| Total             | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

17. I use pediatric behavioral checklists when I and/or my patients' families have concerns.

| use<br>pediatric<br>behavioral<br>checklist | Pediatrician or FP |              |             | Total         |
|---------------------------------------------|--------------------|--------------|-------------|---------------|
|                                             | family pr          | pediatric    | missing     |               |
| No                                          | 20<br>55.56        | 22<br>29.33  | 1<br>100.00 | 43<br>38.39   |
| Yes                                         | 16<br>44.44        | 53<br>70.67  | 0<br>0.00   | 69<br>61.61   |
| Total                                       | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| use<br>pediatric<br>symptom<br>checklist | Pediatrician or FP |              |             | Total         |
|------------------------------------------|--------------------|--------------|-------------|---------------|
|                                          | family pr          | pediatric    | missing     |               |
| No                                       | 32<br>88.89        | 59<br>78.67  | 1<br>100.00 | 92<br>82.14   |
| Yes                                      | 4<br>11.11         | 16<br>21.33  | 0<br>0.00   | 20<br>17.86   |
| Total                                    | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

use child  
behavior

Pediatrician or FP

| checklist | family pr | pediatric | missing | Total  |
|-----------|-----------|-----------|---------|--------|
| No        | 29        | 69        | 1       | 99     |
|           | 80.56     | 92.00     | 100.00  | 88.39  |
| Yes       | 7         | 6         | 0       | 13     |
|           | 19.44     | 8.00      | 0.00    | 11.61  |
| Total     | 36        | 75        | 1       | 112    |
|           | 100.00    | 100.00    | 100.00  | 100.00 |

| use NICHQ | Pediatrician or FP |           |         | Total  |
|-----------|--------------------|-----------|---------|--------|
|           | family pr          | pediatric | missing |        |
| No        | 32                 | 39        | 1       | 72     |
|           | 88.89              | 52.00     | 100.00  | 64.29  |
| Yes       | 4                  | 36        | 0       | 40     |
|           | 11.11              | 48.00     | 0.00    | 35.71  |
| Total     | 36                 | 75        | 1       | 112    |
|           | 100.00             | 100.00    | 100.00  | 100.00 |

| use ECBI | Pediatrician or FP |           |         | Total  |
|----------|--------------------|-----------|---------|--------|
|          | family pr          | pediatric | missing |        |
| No       | 36                 | 75        | 1       | 112    |
|          | 100.00             | 100.00    | 100.00  | 100.00 |
| Total    | 36                 | 75        | 1       | 112    |
|          | 100.00             | 100.00    | 100.00  | 100.00 |

| use SESBI-R | Pediatrician or FP |           |         | Total  |
|-------------|--------------------|-----------|---------|--------|
|             | family pr          | pediatric | missing |        |
| No          | 36                 | 75        | 1       | 112    |
|             | 100.00             | 100.00    | 100.00  | 100.00 |
| Total       | 36                 | 75        | 1       | 112    |
|             | 100.00             | 100.00    | 100.00  | 100.00 |

| use other<br>checklist | Pediatrician or FP |              |             | Total         |
|------------------------|--------------------|--------------|-------------|---------------|
|                        | family pr          | pediatric    | missing     |               |
| No                     | 33<br>91.67        | 63<br>84.00  | 1<br>100.00 | 97<br>86.61   |
| Yes                    | 3<br>8.33          | 12<br>16.00  | 0<br>0.00   | 15<br>13.39   |
| Total                  | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

18. My staff or I discuss with my CYSHCN patients and/or their families about the need for and acquisition of the following services and resources (select all that apply):

| a) | discuss<br>respite<br>care | Pediatrician or FP |              |             | Total         |
|----|----------------------------|--------------------|--------------|-------------|---------------|
|    |                            | family pr          | pediatric    | missing     |               |
|    | No                         | 29<br>80.56        | 52<br>69.33  | 0<br>0.00   | 81<br>72.32   |
|    | Yes                        | 7<br>19.44         | 23<br>30.67  | 1<br>100.00 | 31<br>27.68   |
|    | Total                      | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| b) | discuss<br>durable<br>medical<br>equipment | Pediatrician or FP |              |             | Total         |
|----|--------------------------------------------|--------------------|--------------|-------------|---------------|
|    |                                            | family pr          | pediatric    | missing     |               |
|    | No                                         | 7<br>19.44         | 18<br>24.00  | 1<br>100.00 | 26<br>23.21   |
|    | Yes                                        | 29<br>80.56        | 57<br>76.00  | 0<br>0.00   | 86<br>76.79   |
|    | Total                                      | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |



|            |        |                    |           |         |       |
|------------|--------|--------------------|-----------|---------|-------|
| c)         |        |                    |           |         |       |
| discuss    |        | Pediatrician or FP |           |         |       |
| assistive  |        | family pr          | pediatric | missing | Total |
| transporta |        |                    |           |         |       |
| tion       |        |                    |           |         |       |
| No         | 25     | 43                 | 1         | 69      |       |
|            | 69.44  | 57.33              | 100.00    | 61.61   |       |
| Yes        | 11     | 32                 | 0         | 43      |       |
|            | 30.56  | 42.67              | 0.00      | 38.39   |       |
| Total      | 36     | 75                 | 1         | 112     |       |
|            | 100.00 | 100.00             | 100.00    | 100.00  |       |

|            |        |                    |           |         |       |
|------------|--------|--------------------|-----------|---------|-------|
| d)         |        |                    |           |         |       |
| discuss LA |        | Pediatrician or FP |           |         |       |
| medicaid/L |        | family pr          | pediatric | missing | Total |
| aCHIP      |        |                    |           |         |       |
| No         | 15     | 18                 | 0         | 33      |       |
|            | 41.67  | 24.00              | 0.00      | 29.46   |       |
| Yes        | 21     | 57                 | 1         | 79      |       |
|            | 58.33  | 76.00              | 100.00    | 70.54   |       |
| Total      | 36     | 75                 | 1         | 112     |       |
|            | 100.00 | 100.00             | 100.00    | 100.00  |       |

|         |        |                    |           |         |       |
|---------|--------|--------------------|-----------|---------|-------|
| e)      |        |                    |           |         |       |
| discuss |        | Pediatrician or FP |           |         |       |
| SSI     |        | family pr          | pediatric | missing | Total |
| No      | 26     | 51                 | 0         | 77      |       |
|         | 72.22  | 68.00              | 0.00      | 68.75   |       |
| Yes     | 10     | 24                 | 1         | 35      |       |
|         | 27.78  | 32.00              | 100.00    | 31.25   |       |
| Total   | 36     | 75                 | 1         | 112     |       |
|         | 100.00 | 100.00             | 100.00    | 100.00  |       |

|    |                                            |                    |           |         |        |
|----|--------------------------------------------|--------------------|-----------|---------|--------|
| f) | discuss<br>dept of<br>social<br>services:L | Pediatrician or FP |           |         |        |
|    | RS                                         | family pr          | pediatric | missing | Total  |
|    | No                                         | 28                 | 58        | 0       | 86     |
|    |                                            | 77.78              | 77.33     | 0.00    | 76.79  |
|    | Yes                                        | 8                  | 17        | 1       | 26     |
|    |                                            | 22.22              | 22.67     | 100.00  | 23.21  |
|    | Total                                      | 36                 | 75        | 1       | 112    |
|    |                                            | 100.00             | 100.00    | 100.00  | 100.00 |

|    |                                |                    |           |         |        |
|----|--------------------------------|--------------------|-----------|---------|--------|
| g) | discuss<br>title V<br>programs | Pediatrician or FP |           |         |        |
|    |                                | family pr          | pediatric | missing | Total  |
|    | No                             | 26                 | 44        | 1       | 71     |
|    |                                | 72.22              | 58.67     | 100.00  | 63.39  |
|    | Yes                            | 10                 | 31        | 0       | 41     |
|    |                                | 27.78              | 41.33     | 0.00    | 36.61  |
|    | Total                          | 36                 | 75        | 1       | 112    |
|    |                                | 100.00             | 100.00    | 100.00  | 100.00 |

|    |                                                                            |                    |           |         |        |
|----|----------------------------------------------------------------------------|--------------------|-----------|---------|--------|
| h) | discuss<br>office for<br>citizens<br>with<br>developmental<br>disabilities | Pediatrician or FP |           |         |        |
|    |                                                                            | family pr          | pediatric | missing | Total  |
|    | No                                                                         | 33                 | 60        | 1       | 94     |
|    |                                                                            | 91.67              | 80.00     | 100.00  | 83.93  |
|    | Yes                                                                        | 3                  | 15        | 0       | 18     |
|    |                                                                            | 8.33               | 20.00     | 0.00    | 16.07  |
|    | Total                                                                      | 36                 | 75        | 1       | 112    |
|    |                                                                            | 100.00             | 100.00    | 100.00  | 100.00 |

|       |         |                    |           |         |        |
|-------|---------|--------------------|-----------|---------|--------|
| i)    | discuss | Pediatrician or FP |           |         |        |
|       | early   |                    |           |         |        |
|       | steps   | family pr          | pediatric | missing | Total  |
| <hr/> |         |                    |           |         |        |
|       | No      | 24                 | 5         | 0       | 29     |
|       |         | 66.67              | 6.67      | 0.00    | 25.89  |
| <hr/> |         |                    |           |         |        |
|       | Yes     | 12                 | 70        | 1       | 83     |
|       |         | 33.33              | 93.33     | 100.00  | 74.11  |
| <hr/> |         |                    |           |         |        |
|       | Total   | 36                 | 75        | 1       | 112    |
|       |         | 100.00             | 100.00    | 100.00  | 100.00 |

|       |            |                    |           |         |        |
|-------|------------|--------------------|-----------|---------|--------|
| j)    | discuss    | Pediatrician or FP |           |         |        |
|       | head start | family pr          | pediatric | missing | Total  |
| <hr/> |            |                    |           |         |        |
|       | No         | 20                 | 16        | 0       | 36     |
|       |            | 55.56              | 21.33     | 0.00    | 32.14  |
| <hr/> |            |                    |           |         |        |
|       | Yes        | 16                 | 59        | 1       | 76     |
|       |            | 44.44              | 78.67     | 100.00  | 67.86  |
| <hr/> |            |                    |           |         |        |
|       | Total      | 36                 | 75        | 1       | 112    |
|       |            | 100.00             | 100.00    | 100.00  | 100.00 |

|       |         |                    |           |         |        |
|-------|---------|--------------------|-----------|---------|--------|
| k)    | discuss | Pediatrician or FP |           |         |        |
|       | IEP     | family pr          | pediatric | missing | Total  |
| <hr/> |         |                    |           |         |        |
|       | No      | 31                 | 22        | 0       | 53     |
|       |         | 86.11              | 29.33     | 0.00    | 47.32  |
| <hr/> |         |                    |           |         |        |
|       | Yes     | 5                  | 53        | 1       | 59     |
|       |         | 13.89              | 70.67     | 100.00  | 52.68  |
| <hr/> |         |                    |           |         |        |
|       | Total   | 36                 | 75        | 1       | 112    |
|       |         | 100.00             | 100.00    | 100.00  | 100.00 |

|       |            |                    |           |         |        |
|-------|------------|--------------------|-----------|---------|--------|
| l)    | discuss    | Pediatrician or FP |           |         |        |
|       | 504        |                    |           |         |        |
|       | accommodat | family pr          | pediatric | missing | Total  |
|       | ions       |                    |           |         |        |
| <hr/> |            |                    |           |         |        |
|       | No         | 31                 | 24        | 1       | 56     |
|       |            | 86.11              | 32.00     | 100.00  | 50.00  |
| <hr/> |            |                    |           |         |        |
|       | Yes        | 5                  | 51        | 0       | 56     |
|       |            | 13.89              | 68.00     | 0.00    | 50.00  |
| <hr/> |            |                    |           |         |        |
|       | Total      | 36                 | 75        | 1       | 112    |
|       |            | 100.00             | 100.00    | 100.00  | 100.00 |

|    |         |  |
|----|---------|--|
| m) | discuss |  |
|----|---------|--|

| occupation<br>al, physical, and<br>speech<br>therapies | Pediatrician or FP |              |             | Total         |
|--------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                        | family pr          | pediatric    | missing     |               |
| No                                                     | 12<br>33.33        | 5<br>6.67    | 0<br>0.00   | 17<br>15.18   |
| Yes                                                    | 24<br>66.67        | 70<br>93.33  | 1<br>100.00 | 95<br>84.82   |
| Total                                                  | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

n)

| discuss<br>WIC | Pediatrician or FP |              |             | Total         |
|----------------|--------------------|--------------|-------------|---------------|
|                | family pr          | pediatric    | missing     |               |
| No             | 14<br>38.89        | 7<br>9.33    | 0<br>0.00   | 21<br>18.75   |
| Yes            | 22<br>61.11        | 68<br>90.67  | 1<br>100.00 | 91<br>81.25   |
| Total          | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

o)

| discuss<br>families<br>helping<br>families | Pediatrician or FP |              |             | Total         |
|--------------------------------------------|--------------------|--------------|-------------|---------------|
|                                            | family pr          | pediatric    | missing     |               |
| No                                         | 33<br>91.67        | 45<br>60.00  | 1<br>100.00 | 79<br>70.54   |
| Yes                                        | 3<br>8.33          | 30<br>40.00  | 0<br>0.00   | 33<br>29.46   |
| Total                                      | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

p)

| discuss<br>other<br>service | Pediatrician or FP |              |             | Total         |
|-----------------------------|--------------------|--------------|-------------|---------------|
|                             | family pr          | pediatric    | missing     |               |
| No                          | 36<br>100.00       | 71<br>94.67  | 1<br>100.00 | 108<br>96.43  |
| Yes                         | 0<br>0.00          | 4<br>5.33    | 0<br>0.00   | 4<br>3.57     |
| Total                       | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

q)

| discussed<br>none of<br>the above | Pediatrician or FP |              |             | Total         |
|-----------------------------------|--------------------|--------------|-------------|---------------|
|                                   | family pr          | pediatric    | missing     |               |
| No                                | 36<br>100.00       | 74<br>98.67  | 1<br>100.00 | 111<br>99.11  |
| Yes                               | 0<br>0.00          | 1<br>1.33    | 0<br>0.00   | 1<br>0.89     |
| Total                             | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

19. The transition process from my care to adult medical care for my adolescent patients with special health care needs (YSHCN) and their families involves the following:

a)

| patient<br>has<br>establishd<br>adult<br>primary<br>care<br>provider | Pediatrician or FP |              |             | Total         |
|----------------------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                                      | family pr          | pediatric    | missing     |               |
| No                                                                   | 10<br>27.78        | 15<br>20.00  | 0<br>0.00   | 25<br>22.32   |
| Yes                                                                  | 18<br>50.00        | 54<br>72.00  | 0<br>0.00   | 72<br>64.29   |
| Missing,<br>blank                                                    | 8<br>22.22         | 6<br>8.00    | 1<br>100.00 | 15<br>13.39   |
| Total                                                                | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

|    |                                                 |                    |           |         |        |
|----|-------------------------------------------------|--------------------|-----------|---------|--------|
| b) | staff discusses health/dental insurance options | Pediatrician or FP |           |         |        |
|    |                                                 | family pr          | pediatric | missing | Total  |
|    | No                                              | 16                 | 43        | 0       | 59     |
|    |                                                 | 44.44              | 57.33     | 0.00    | 52.68  |
|    | Yes                                             | 11                 | 24        | 0       | 35     |
|    |                                                 | 30.56              | 32.00     | 0.00    | 31.25  |
|    | Missing, blank                                  | 9                  | 8         | 1       | 18     |
|    |                                                 | 25.00              | 10.67     | 100.00  | 16.07  |
|    | Total                                           | 36                 | 75        | 1       | 112    |
|    |                                                 | 100.00             | 100.00    | 100.00  | 100.00 |

|    |                                                     |                    |           |         |        |
|----|-----------------------------------------------------|--------------------|-----------|---------|--------|
| c) | staff discusses eligibility for community resources | Pediatrician or FP |           |         |        |
|    |                                                     | family pr          | pediatric | missing | Total  |
|    | No                                                  | 20                 | 48        | 0       | 68     |
|    |                                                     | 55.56              | 64.00     | 0.00    | 60.71  |
|    | Yes                                                 | 5                  | 18        | 0       | 23     |
|    |                                                     | 13.89              | 24.00     | 0.00    | 20.54  |
|    | Missing, blank                                      | 11                 | 9         | 1       | 21     |
|    |                                                     | 30.56              | 12.00     | 100.00  | 18.75  |
|    | Total                                               | 36                 | 75        | 1       | 112    |
|    |                                                     | 100.00             | 100.00    | 100.00  | 100.00 |

|    |                                                                    |                    |           |         |        |
|----|--------------------------------------------------------------------|--------------------|-----------|---------|--------|
| d) | staff<br>discusses<br>vocational<br>and/or<br>education<br>choices | Pediatrician or FP |           |         |        |
|    |                                                                    | family pr          | pediatric | missing | Total  |
|    | No                                                                 | 14                 | 35        | 0       | 49     |
|    |                                                                    | 38.89              | 46.67     | 0.00    | 43.75  |
|    | Yes                                                                | 10                 | 33        | 0       | 43     |
|    |                                                                    | 27.78              | 44.00     | 0.00    | 38.39  |
|    | Missing,<br>blank                                                  | 12                 | 7         | 1       | 20     |
|    |                                                                    | 33.33              | 9.33      | 100.00  | 17.86  |
|    | Total                                                              | 36                 | 75        | 1       | 112    |
|    |                                                                    | 100.00             | 100.00    | 100.00  | 100.00 |

|    |                                                                 |                    |           |         |        |
|----|-----------------------------------------------------------------|--------------------|-----------|---------|--------|
| e) | discusses<br>patient's<br>role in<br>managing<br>health<br>care | Pediatrician or FP |           |         |        |
|    |                                                                 | family pr          | pediatric | missing | Total  |
|    | No                                                              | 4                  | 26        | 0       | 30     |
|    |                                                                 | 11.11              | 34.67     | 0.00    | 26.79  |
|    | Yes                                                             | 20                 | 42        | 0       | 62     |
|    |                                                                 | 55.56              | 56.00     | 0.00    | 55.36  |
|    | Missing,<br>blank                                               | 12                 | 7         | 1       | 20     |
|    |                                                                 | 33.33              | 9.33      | 100.00  | 17.86  |
|    | Total                                                           | 36                 | 75        | 1       | 112    |
|    |                                                                 | 100.00             | 100.00    | 100.00  | 100.00 |

|    |                                              |                    |           |         |        |
|----|----------------------------------------------|--------------------|-----------|---------|--------|
| f) | staff<br>discusses<br>counseling<br>to youth | Pediatrician or FP |           |         |        |
|    |                                              | family pr          | pediatric | missing | Total  |
|    | No                                           | 9                  | 24        | 0       | 33     |
|    |                                              | 25.00              | 32.00     | 0.00    | 29.46  |
|    | Yes                                          | 14                 | 44        | 0       | 58     |
|    |                                              | 38.89              | 58.67     | 0.00    | 51.79  |
|    | Missing,<br>blank                            | 13                 | 7         | 1       | 21     |
|    |                                              | 36.11              | 9.33      | 100.00  | 18.75  |
|    | Total                                        | 36                 | 75        | 1       | 112    |
|    |                                              | 100.00             | 100.00    | 100.00  | 100.00 |

g)  
transition |

| serves not applicable | Pediatrician or FP |              |             | Total         |
|-----------------------|--------------------|--------------|-------------|---------------|
|                       | family pr          | pediatric    | missing     |               |
| No                    | 10<br>27.78        | 67<br>89.33  | 0<br>0.00   | 77<br>68.75   |
| Yes                   | 26<br>72.22        | 8<br>10.67   | 1<br>100.00 | 35<br>31.25   |
| Total                 | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

20. For my CYSHCN patients, I schedule extra time or extend the time for their office visits when indicated.

| schedule extra time for CYSHCN patients | Pediatrician or FP |              |             | Total         |
|-----------------------------------------|--------------------|--------------|-------------|---------------|
|                                         | family pr          | pediatric    | missing     |               |
| always                                  | 4<br>11.11         | 28<br>37.33  | 1<br>100.00 | 33<br>29.46   |
| usually                                 | 14<br>38.89        | 26<br>34.67  | 0<br>0.00   | 40<br>35.71   |
| sometimes                               | 13<br>36.11        | 15<br>20.00  | 0<br>0.00   | 28<br>25.00   |
| never                                   | 2<br>5.56          | 3<br>4.00    | 0<br>0.00   | 5<br>4.46     |
| not applicable, this                    | 2<br>5.56          | 3<br>4.00    | 0<br>0.00   | 5<br>4.46     |
| Missing, blank                          | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| Total                                   | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |



21. I provide my patients interpreters/translators in my practice.

| provide patients with<br>interpreters | Pediatrician or FP |              |             | Total         |
|---------------------------------------|--------------------|--------------|-------------|---------------|
|                                       | family pr          | pediatric    | missing     |               |
| always                                | 4<br>11.11         | 11<br>14.67  | 0<br>0.00   | 15<br>13.39   |
| usually                               | 2<br>5.56          | 16<br>21.33  | 0<br>0.00   | 18<br>16.07   |
| sometimes                             | 11<br>30.56        | 18<br>24.00  | 0<br>0.00   | 29<br>25.89   |
| never                                 | 8<br>22.22         | 21<br>28.00  | 1<br>100.00 | 30<br>26.79   |
| not applicable, this                  | 10<br>27.78        | 9<br>12.00   | 0<br>0.00   | 19<br>16.96   |
| Missing,<br>blank                     | 1<br>2.78          | 0<br>0.00    | 0<br>0.00   | 1<br>0.89     |
| Total                                 | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

22. Which of the following characteristics of the patient or family do you incorporate into a patient's plan of care and take into consideration when communicating health information (select all that apply):

a)

| consider<br>educationa<br>l level | Pediatrician or FP |              |             | Total         |
|-----------------------------------|--------------------|--------------|-------------|---------------|
|                                   | family pr          | pediatric    | missing     |               |
| No                                | 4<br>11.11         | 3<br>4.00    | 0<br>0.00   | 7<br>6.25     |
| Yes                               | 32<br>88.89        | 72<br>96.00  | 1<br>100.00 | 105<br>93.75  |
| Total                             | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

b)

| consider<br>cultural<br>background | Pediatrixian or FP |              |             | Total         |
|------------------------------------|--------------------|--------------|-------------|---------------|
|                                    | family pr          | pediatric    | missing     |               |
| No                                 | 3<br>8.33          | 9<br>12.00   | 0<br>0.00   | 12<br>10.71   |
| Yes                                | 33<br>91.67        | 66<br>88.00  | 1<br>100.00 | 100<br>89.29  |
| Total                              | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

c)

| consider<br>religion,<br>gender<br>roles,<br>ethnicity,<br>language | Pediatrixian or FP |              |             | Total         |
|---------------------------------------------------------------------|--------------------|--------------|-------------|---------------|
|                                                                     | family pr          | pediatric    | missing     |               |
| No                                                                  | 5<br>13.89         | 14<br>18.67  | 0<br>0.00   | 19<br>16.96   |
| Yes                                                                 | 31<br>86.11        | 61<br>81.33  | 1<br>100.00 | 93<br>83.04   |
| Total                                                               | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

d)

| consider<br>socioecono<br>mic status | Pediatrixian or FP |              |             | Total         |
|--------------------------------------|--------------------|--------------|-------------|---------------|
|                                      | family pr          | pediatric    | missing     |               |
| No                                   | 4<br>11.11         | 14<br>18.67  | 0<br>0.00   | 18<br>16.07   |
| Yes                                  | 32<br>88.89        | 61<br>81.33  | 1<br>100.00 | 94<br>83.93   |
| Total                                | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

|    |                                |                    |           |         |        |
|----|--------------------------------|--------------------|-----------|---------|--------|
| e) | consider household composition | Pediatrician or FP |           |         |        |
|    |                                | family pr          | pediatric | missing | Total  |
|    | No                             | 6                  | 12        | 0       | 18     |
|    |                                | 16.67              | 16.00     | 0.00    | 16.07  |
|    | Yes                            | 30                 | 63        | 1       | 94     |
|    |                                | 83.33              | 84.00     | 100.00  | 83.93  |
|    | Total                          | 36                 | 75        | 1       | 112    |
|    |                                | 100.00             | 100.00    | 100.00  | 100.00 |

|    |                                    |                    |           |         |        |
|----|------------------------------------|--------------------|-----------|---------|--------|
| f) | consider louisiana resident status | Pediatrician or FP |           |         |        |
|    |                                    | family pr          | pediatric | missing | Total  |
|    | No                                 | 28                 | 48        | 1       | 77     |
|    |                                    | 77.78              | 64.00     | 100.00  | 68.75  |
|    | Yes                                | 8                  | 27        | 0       | 35     |
|    |                                    | 22.22              | 36.00     | 0.00    | 31.25  |
|    | Total                              | 36                 | 75        | 1       | 112    |
|    |                                    | 100.00             | 100.00    | 100.00  | 100.00 |

23. I have difficulty locating pediatric medical sub-specialists in my geographic area for patient referrals.

|  |                                                 |                    |           |         |        |
|--|-------------------------------------------------|--------------------|-----------|---------|--------|
|  | have difficult locating sub-specialists in area | Pediatrician or FP |           |         |        |
|  |                                                 | family pr          | pediatric | missing | Total  |
|  | always                                          | 4                  | 7         | 0       | 11     |
|  |                                                 | 11.11              | 9.33      | 0.00    | 9.82   |
|  | usually                                         | 11                 | 10        | 1       | 22     |
|  |                                                 | 30.56              | 13.33     | 100.00  | 19.64  |
|  | sometimes                                       | 14                 | 45        | 0       | 59     |
|  |                                                 | 38.89              | 60.00     | 0.00    | 52.68  |
|  | never                                           | 7                  | 13        | 0       | 20     |
|  |                                                 | 19.44              | 17.33     | 0.00    | 17.86  |
|  | Total                                           | 36                 | 75        | 1       | 112    |
|  |                                                 | 100.00             | 100.00    | 100.00  | 100.00 |

|            |                    |           |         |       |
|------------|--------------------|-----------|---------|-------|
| allergy/im | Pediatrician or FP |           |         |       |
| munology   | family pr          | pediatric | missing | Total |

|       |        |        |        |        |
|-------|--------|--------|--------|--------|
| No    | 33     | 70     | 1      | 104    |
|       | 91.67  | 93.33  | 100.00 | 92.86  |
| Yes   | 3      | 5      | 0      | 8      |
|       | 8.33   | 6.67   | 0.00   | 7.14   |
| Total | 36     | 75     | 1      | 112    |
|       | 100.00 | 100.00 | 100.00 | 100.00 |

|            |                    |           |         |        |
|------------|--------------------|-----------|---------|--------|
| cardiology | Pediatrician or FP |           |         | Total  |
|            | family pr          | pediatric | missing |        |
| No         | 32                 | 75        | 1       | 108    |
|            | 88.89              | 100.00    | 100.00  | 96.43  |
| Yes        | 4                  | 0         | 0       | 4      |
|            | 11.11              | 0.00      | 0.00    | 3.57   |
| Total      | 36                 | 75        | 1       | 112    |
|            | 100.00             | 100.00    | 100.00  | 100.00 |

|                 |                    |           |         |        |
|-----------------|--------------------|-----------|---------|--------|
| dermatolog<br>y | Pediatrician or FP |           |         | Total  |
|                 | family pr          | pediatric | missing |        |
| No              | 23                 | 48        | 1       | 72     |
|                 | 63.89              | 64.00     | 100.00  | 64.29  |
| Yes             | 13                 | 27        | 0       | 40     |
|                 | 36.11              | 36.00     | 0.00    | 35.71  |
| Total           | 36                 | 75        | 1       | 112    |
|                 | 100.00             | 100.00    | 100.00  | 100.00 |

|                                          |                    |           |         |        |
|------------------------------------------|--------------------|-----------|---------|--------|
| developmental/behavioral<br>pediatrician | Pediatrician or FP |           |         | Total  |
|                                          | family pr          | pediatric | missing |        |
| No                                       | 19                 | 33        | 0       | 52     |
|                                          | 52.78              | 44.00     | 0.00    | 46.43  |
| Yes                                      | 17                 | 42        | 1       | 60     |
|                                          | 47.22              | 56.00     | 100.00  | 53.57  |
| Total                                    | 36                 | 75        | 1       | 112    |
|                                          | 100.00             | 100.00    | 100.00  | 100.00 |

| endocrinology | Pediatrician or FP |              |             | Total         |
|---------------|--------------------|--------------|-------------|---------------|
|               | family pr          | pediatric    | missing     |               |
| No            | 25<br>69.44        | 51<br>68.00  | 0<br>0.00   | 76<br>67.86   |
| Yes           | 11<br>30.56        | 24<br>32.00  | 1<br>100.00 | 36<br>32.14   |
| Total         | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| gastroenterology | Pediatrician or FP |              |             | Total         |
|------------------|--------------------|--------------|-------------|---------------|
|                  | family pr          | pediatric    | missing     |               |
| No               | 30<br>83.33        | 63<br>84.00  | 0<br>0.00   | 93<br>83.04   |
| Yes              | 6<br>16.67         | 12<br>16.00  | 1<br>100.00 | 19<br>16.96   |
| Total            | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| general surgery | Pediatrician or FP |              |             | Total         |
|-----------------|--------------------|--------------|-------------|---------------|
|                 | family pr          | pediatric    | missing     |               |
| No              | 31<br>86.11        | 70<br>93.33  | 0<br>0.00   | 101<br>90.18  |
| Yes             | 5<br>13.89         | 5<br>6.67    | 1<br>100.00 | 11<br>9.82    |
| Total           | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| genetics | Pediatrician or FP |              |             | Total         |
|----------|--------------------|--------------|-------------|---------------|
|          | family pr          | pediatric    | missing     |               |
| No       | 30<br>83.33        | 68<br>90.67  | 0<br>0.00   | 98<br>87.50   |
| Yes      | 6<br>16.67         | 7<br>9.33    | 1<br>100.00 | 14<br>12.50   |
| Total    | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| hematology<br>/oncology | Pediatrician or FP |              |             | Total         |
|-------------------------|--------------------|--------------|-------------|---------------|
|                         | family pr          | pediatric    | missing     |               |
| No                      | 31<br>86.11        | 70<br>93.33  | 0<br>0.00   | 101<br>90.18  |
| Yes                     | 5<br>13.89         | 5<br>6.67    | 1<br>100.00 | 11<br>9.82    |
| Total                   | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| infectious<br>disease | Pediatrician or FP |              |             | Total         |
|-----------------------|--------------------|--------------|-------------|---------------|
|                       | family pr          | pediatric    | missing     |               |
| No                    | 32<br>88.89        | 62<br>82.67  | 0<br>0.00   | 94<br>83.93   |
| Yes                   | 4<br>11.11         | 13<br>17.33  | 1<br>100.00 | 18<br>16.07   |
| Total                 | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| neonatology | Pediatrician or FP |              |             | Total         |
|-------------|--------------------|--------------|-------------|---------------|
|             | family pr          | pediatric    | missing     |               |
| No          | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |
| Total       | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| neurology | Pediatrician or FP |              |             | Total         |
|-----------|--------------------|--------------|-------------|---------------|
|           | family pr          | pediatric    | missing     |               |
| No        | 22<br>61.11        | 34<br>45.33  | 0<br>0.00   | 56<br>50.00   |
| Yes       | 14<br>38.89        | 41<br>54.67  | 1<br>100.00 | 56<br>50.00   |
| Total     | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| neurosurge<br>ry | Pediatrician or FP |              |             | Total         |
|------------------|--------------------|--------------|-------------|---------------|
|                  | family pr          | pediatric    | missing     |               |
| No               | 30<br>83.33        | 61<br>81.33  | 0<br>0.00   | 91<br>81.25   |
| Yes              | 6<br>16.67         | 14<br>18.67  | 1<br>100.00 | 21<br>18.75   |
| Total            | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| ophthamolo<br>gy | Pediatrician or FP |              |             | Total         |
|------------------|--------------------|--------------|-------------|---------------|
|                  | family pr          | pediatric    | missing     |               |
| No               | 32<br>88.89        | 69<br>92.00  | 1<br>100.00 | 102<br>91.07  |
| Yes              | 4<br>11.11         | 6<br>8.00    | 0<br>0.00   | 10<br>8.93    |
| Total            | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| orhtopedic | Pediatrician or FP |              |             | Total         |
|------------|--------------------|--------------|-------------|---------------|
|            | family pr          | pediatric    | missing     |               |
| No         | 20<br>55.56        | 46<br>61.33  | 0<br>0.00   | 66<br>58.93   |
| Yes        | 16<br>44.44        | 29<br>38.67  | 1<br>100.00 | 46<br>41.07   |
| Total      | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| otolaryngo<br>logy | Pediatrician or FP |              |             | Total         |
|--------------------|--------------------|--------------|-------------|---------------|
|                    | family pr          | pediatric    | missing     |               |
| No                 | 33<br>91.67        | 72<br>96.00  | 1<br>100.00 | 106<br>94.64  |
| Yes                | 3<br>8.33          | 3<br>4.00    | 0<br>0.00   | 6<br>5.36     |
| Total              | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| psychiatry | Pediatrician or FP |              |             | Total         |
|------------|--------------------|--------------|-------------|---------------|
|            | family pr          | pediatric    | missing     |               |
| No         | 16<br>44.44        | 29<br>38.67  | 0<br>0.00   | 45<br>40.18   |
| Yes        | 20<br>55.56        | 46<br>61.33  | 1<br>100.00 | 67<br>59.82   |
| Total      | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| pulmonology | Pediatrician or FP |              |             | Total         |
|-------------|--------------------|--------------|-------------|---------------|
|             | family pr          | pediatric    | missing     |               |
| No          | 28<br>77.78        | 58<br>77.33  | 1<br>100.00 | 87<br>77.68   |
| Yes         | 8<br>22.22         | 17<br>22.67  | 0<br>0.00   | 25<br>22.32   |
| Total       | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| rheumatology | Pediatrician or FP |              |             | Total         |
|--------------|--------------------|--------------|-------------|---------------|
|              | family pr          | pediatric    | missing     |               |
| No           | 26<br>72.22        | 52<br>69.33  | 0<br>0.00   | 78<br>69.64   |
| Yes          | 10<br>27.78        | 23<br>30.67  | 1<br>100.00 | 34<br>30.36   |
| Total        | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

| urology | Pediatrician or FP |              |             | Total         |
|---------|--------------------|--------------|-------------|---------------|
|         | family pr          | pediatric    | missing     |               |
| No      | 32<br>88.89        | 62<br>82.67  | 0<br>0.00   | 94<br>83.93   |
| Yes     | 4<br>11.11         | 13<br>17.33  | 1<br>100.00 | 18<br>16.07   |
| Total   | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |



| other  <br>sub-specialty | Pediatrician or FP |              |             | Total         |
|--------------------------|--------------------|--------------|-------------|---------------|
|                          | family pr          | pediatric    | missing     |               |
| No                       | 34<br>94.44        | 70<br>93.33  | 1<br>100.00 | 105<br>93.75  |
| Yes                      | 2<br>5.56          | 5<br>6.67    | 0<br>0.00   | 7<br>6.25     |
| Total                    | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

24. Barriers that limit my ability to provide public health/community-based referrals for my CYSHCN patients include (select all that apply):

a)

| barrier-lack of time | Pediatrician or FP |              |             | Total         |
|----------------------|--------------------|--------------|-------------|---------------|
|                      | family pr          | pediatric    | missing     |               |
| No                   | 26<br>72.22        | 53<br>70.67  | 0<br>0.00   | 79<br>70.54   |
| Yes                  | 10<br>27.78        | 22<br>29.33  | 1<br>100.00 | 33<br>29.46   |
| Total                | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

b)

| barrier-lack of knowledge about resources | Pediatrician or FP |              |             | Total         |
|-------------------------------------------|--------------------|--------------|-------------|---------------|
|                                           | family pr          | pediatric    | missing     |               |
| No                                        | 16<br>44.44        | 41<br>54.67  | 0<br>0.00   | 57<br>50.89   |
| Yes                                       | 20<br>55.56        | 34<br>45.33  | 1<br>100.00 | 55<br>49.11   |
| Total                                     | 36<br>100.00       | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

|                                                   |        |                    |           |         |       |
|---------------------------------------------------|--------|--------------------|-----------|---------|-------|
| c)                                                |        |                    |           |         |       |
| barrier-lack of knowledge of eligibility criteria |        | Pediatrician or FP |           |         |       |
|                                                   |        | family pr          | pediatric | missing | Total |
| No                                                | 19     | 47                 | 0         | 66      |       |
|                                                   | 52.78  | 62.67              | 0.00      | 58.93   |       |
| Yes                                               | 17     | 28                 | 1         | 46      |       |
|                                                   | 47.22  | 37.33              | 100.00    | 41.07   |       |
| Total                                             | 36     | 75                 | 1         | 112     |       |
|                                                   | 100.00 | 100.00             | 100.00    | 100.00  |       |

|                                   |        |                    |           |         |       |
|-----------------------------------|--------|--------------------|-----------|---------|-------|
| d)                                |        |                    |           |         |       |
| barrier-limited resources in area |        | Pediatrician or FP |           |         |       |
|                                   |        | family pr          | pediatric | missing | Total |
| No                                | 15     | 34                 | 0         | 49      |       |
|                                   | 41.67  | 45.33              | 0.00      | 43.75   |       |
| Yes                               | 21     | 41                 | 1         | 63      |       |
|                                   | 58.33  | 54.67              | 100.00    | 56.25   |       |
| Total                             | 36     | 75                 | 1         | 112     |       |
|                                   | 100.00 | 100.00             | 100.00    | 100.00  |       |

|               |        |                    |           |         |       |
|---------------|--------|--------------------|-----------|---------|-------|
| e)            |        |                    |           |         |       |
| barrier-other |        | Pediatrician or FP |           |         |       |
|               |        | family pr          | pediatric | missing | Total |
| No            | 35     | 69                 | 1         | 105     |       |
|               | 97.22  | 92.00              | 100.00    | 93.75   |       |
| Yes           | 1      | 6                  | 0         | 7       |       |
|               | 2.78   | 8.00               | 0.00      | 6.25    |       |
| Total         | 36     | 75                 | 1         | 112     |       |
|               | 100.00 | 100.00             | 100.00    | 100.00  |       |

f)

| barrier-no<br>ne | Pediaticrician or FP |              |             | Total         |
|------------------|----------------------|--------------|-------------|---------------|
|                  | family pr            | pediatric    | missing     |               |
| No               | 29<br>80.56          | 61<br>81.33  | 1<br>100.00 | 91<br>81.25   |
| Yes              | 7<br>19.44           | 14<br>18.67  | 0<br>0.00   | 21<br>18.75   |
| Total            | 36<br>100.00         | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |

## 26. Medical home Status

| category best<br>captures medical<br>home status of<br>practice | Pediaticrician or FP |              |             | Total         |
|-----------------------------------------------------------------|----------------------|--------------|-------------|---------------|
|                                                                 | family pr            | pediatric    | missing     |               |
| applied                                                         | 0<br>0.00            | 4<br>5.33    | 0<br>0.00   | 4<br>3.57     |
| NCQA-certified                                                  | 5<br>13.89           | 13<br>17.33  | 0<br>0.00   | 18<br>16.07   |
| not interested                                                  | 15<br>41.67          | 25<br>33.33  | 1<br>100.00 | 41<br>36.61   |
| interested and applie                                           | 13<br>36.11          | 25<br>33.33  | 0<br>0.00   | 38<br>33.93   |
| Missing,<br>blank                                               | 3<br>8.33            | 8<br>10.67   | 0<br>0.00   | 11<br>9.82    |
| Total                                                           | 36<br>100.00         | 75<br>100.00 | 1<br>100.00 | 112<br>100.00 |