Louisiana

Birth Defects

Monitoring Network

2023 Annual Legislative Report

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LOUISIANA DEPARTMENT OF HEALTH

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Acknowledgements:

The Louisiana Birth Defects Monitoring Network's (LBDMN) surveillance system and public health actions as described in this report fulfill the legislative mandate of Louisiana Revised Statutes Title 40, Part VII, Sections 31.41–31.48 to maintain "a system to collect, analyze, and disseminate data regarding birth defects in the state and to provide information to families of children born with birth defects regarding services available in their community and the development of appropriate prevention programs."

The federal Title V Maternal and Child Health (MCH) Block Grant provides funding for LBDMN surveillance activities.

We recognize the LBDMN Data Collection Specialists and Case Review Coding Specialist who abstracted the medical records to collect these data. Their dedication and hard work made this report possible.

We are thankful for the volunteer members of the LBDMN Advisory Board, who provide clinical expertise for the operations and management of the birth defects surveillance system.

Lastly, we honor the families of children impacted by birth defects represented in this report. It is our sincere hope that the activities of LBDMN will improve the systems of care serving Louisiana's families.

Contents

Introduction

The Louisiana Birth Defects Monitoring Network (LBDMN) within the Bureau of Family Health (BFH), Office of Public Health (OPH), Louisiana Department of Health (LDH) is responsible for surveillance of birth defects in Louisiana's children. Mandated in 2004, it was the intent of the legislature to "establish a system to collect, analyze, and disseminate data regarding birth defects in the state and to provide information to families of children born with birth defects regarding services available in their community and the development of appropriate prevention programs" (Louisiana Revised Statute (R.S.) 40:31.43 and Louisiana Administrative Code (LAC Title 48, Part V, Subpart 55, Chapters 161 & 163 et al. see Appendix A).

The following report summarizes the key findings related to the prevalence of birth defects and performance of this essential surveillance system.

Our Mission

LBDMN's mission is to collect, analyze, and disseminate high quality, timely, actionable data to inform policy and to improve Louisiana's maternal health system to eliminate preventable birth defects, mitigate disability, and connect families with resources to improve their quality of life.

What We Do

The LBDMN incorporates evidence-based public health surveillance best practices including current technology and advanced methodologies to conduct active surveillance of birth defects in children born in Louisiana. Monitoring the health status of newborns provides population-based data to inform policies, educate the public, and support efforts in the state to improve maternal and child health outcomes and prevent new occurrences of birth defects. LBDMN can evaluate concerns about unexpected groups of birth defects (cluster investigation) as well as the effectiveness of preventive interventions.

Who We Serve

As a part of BFH's system of monitoring birth outcomes in the state, the LBDMN supports:

- Policy makers, by identifying risk factors such as maternal exposures and chronic conditions potentially linked to specific birth conditions, and identifying preventive strategies to decrease birth defects;
- Families of infants with birth defects, from birth to 3 years of age, by informing them of appropriate medical, educational, public health, and peer support resources available in their region;
- Men and women of reproductive age, by providing birth defects prevention education materials via our website;
- Researchers from the Centers for Disease Control and Prevention (CDC), universities, and other states investigating possible causes of specific birth defects.

LBDMN identifies approximately 1,500 children with specified birth defects annually, averaging 260 per 10,000 live births. Since 2005, LBDMN has investigated potential birth defects among 48,167 children [10/2023]. LBDMN case definition criteria include all of the following:

- The child must have a major structural, functional, or genetic birth defect. Major defects are generally those that can adversely affect the child's health and development. Children who have minor defects posing no significant health or social burdens are excluded.
- The mother's residence at the time of the birth must be the state of Louisiana as determined by the mother's hospital records, or if still in question, by vital records birth registration data.
- Diagnosis of the qualifying condition must be made before the child's 3rd birthday.
- Pregnancy outcomes include only live births with a gestational age at birth of at least 20 weeks. In the absence of an age estimate, the infant must have a birth weight of at least 350 grams.

Services Provided

LBDMN is a core activity of BFH's Title V Maternal Child Health programs to identify and support children and youth with special health care needs (CYSHCN) and their families.

LBDMN provides:

- Active public health surveillance of hospital discharges of newborns until 3 years of age for major structural, functional, or genetic birth defects.
- A partnership with the BFH Family Resource Center to link families of children under three years of age with specified birth defects to health, social, and developmental resources.
- Prevention of future birth defects through public awareness campaigns in partnership with national, state, and local stakeholders such as CDC, National Birth Defects Prevention Network, Louisiana Chapters of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists, March of Dimes, regional Families Helping Families, and Spina Bifida of Louisiana. Campaigns include education to inform men and women of reproductive age of healthy prenatal lifestyle choices such as daily consumption of 400 micrograms of folic acid daily; reducing exposures to infections and toxins; and controlling chronic conditions such diabetes and hypertension to prevent risks of associated birth defects.

Operations

Role of the Bureau of Family Health

This public health activity, supported by senior epidemiologists and health policy leaders, is carried out by a statewide network of regionally assigned Data Collection Specialists (DCS) who evaluate patient discharge information of newborns until 3 years of age. Staff review records from all birthing hospitals in Louisiana, as well as at Children's Hospital, Ochsner Medical Center, and Tulane University Medical Center in New Orleans. The LBDMN maintains a longitudinal data system of all children born in Louisiana diagnosed with a structural, functional, and/or genetic birth defect. Maternal and Child Health epidemiologists statistically analyze de-identified medical record data for patterns and trends over time. LBDMN links families to health, social service, and developmental resources for children identified with specified birth defects through partnership with BFH Family Resource Center.

Role of the Advisory Board

As mandated in the authorizing statute, LA R.S. 40:31.43, an advisory board of volunteer stakeholders appointed by the secretary of LDH guides LBDMN.

The role of the LBDMN advisory board as prescribed in the law is *"to make recommendations on the implementation and continuing operation of the surveillance system."* Notices of meetings, agendas, and minutes are posted on the Louisiana Boards & Commissions website.

LA R.S. 40:31.43 mandates that the advisory board consist of nine members representing maternal fetal medicine, pediatrics, genetics, epidemiology, parents of children with birth defects, and persons with birth defects. Along with other OPH partners, these subject matter experts provide expertise and perspective to guide LBDMN staff in surveillance operations, referral to resources initiatives, and birth defects prevention strategies.

Current law specifies board membership by medical institution affiliations, some of which have changed over time. In addition, since the initial law established the network and board, the focus of the work shifted from surveillance system organization and implementation to moving birth defects data to action by informing recommendations of strategies to improve Louisiana's maternal child health system.

LBDMN is working with the BFH Policy and Legislative Team to revitalize our advisory board. The advisory board needs additional subject matter expertise related to improving maternal health, the diagnosis and treatment of children identified with birth defects, and improving pediatric systems of care, e.g. pediatric cardiology, pediatric craniofacial surgery, pediatric social worker, and pediatric clinic nurse.

Data to Action Spotlight: Birth Defects Case Review Model 2.0

In 2023, LBDMN completed evaluation of the advisory board's Birth Defects Case Review Model pilot reported in the 2022 legislative report. This evaluation indicated the original goal to identify causes and risk factors for the prevention of birth defects was unrealistic given the limitations of prenatal information available in the medical record.

In FY2024, while keeping the pilot model frameworks, Birth Defects Case Review Model 2.0 will narrow to a more specific and attainable purpose to identify gaps or issues of late diagnosis, treatment, and referral of children with specified birth defects. In Louisiana, cardiovascular system defects are the most common finding accounting for 64.2% of birth defects. Using LBDMN Core Congenital Heart Defects in 2022 births and matching with BFH Family Resource Center data we will evaluate if the child was:

- diagnosed in a timely manner;
- treated in a timely manner;
- referred to early intervention in a timely manner; and
- evaluated for early intervention services in a timely manner.

Methodology

LBDMN contacts health providers to find cases and collect data. Potential cases of interest are identified from hospital discharge indices, Medicaid, Louisiana Hospital Inpatient Discharge Data (LAHIDD), as well as birth, death, and fetal death record data from the Louisiana Vital Records Electronic Event Registration System (LEERS). Medical and vital statistic records are reviewed to collect and validate data among children diagnosed from birth up to their third birthday.

The LBDMN Registered Nurse Case Review Clinical Coding Specialist and/or the LBDMN Program Manager review data for completeness and coding accuracy prior to including in the Registry and designating as available for reporting. Data are stored and managed in a database integrated with LEERS birth and death certificates as well as Early Hearing Detection and Intervention (LA-EHDI) data.

Not all defects are evident at birth; therefore, LBDMN includes children diagnosed before their third birthday allowing adequate time to capture all birth defects within our case definition. Additionally, this timeframe allows hospitals adequate records processing and reporting as well as time for staff to

abstract medical records to capture all diagnoses identified among those born in each calendar year. Please refer to Appendix A for the Case Ascertainment\Review\Quality Assurance flow chart.

Diagnoses by International Classification of Diseases -Version 10 (ICD-10) billing codes are converted to the appropriate corresponding codes from the CDC clinical coding system based on the British Pediatric Association and Classification of Diseases. Prevalence rate is calculated as the number of children with birth defects per 10,000 total live births. There is an exception for hypospadias and Turner Syndrome, which is limited to males and females, respectively. LBDMN reports data in three-year increments to have an adequate number of cases to be representative at the state level when stratified by race/ethnicity and type of major birth defects.

Findings

Of 173,037 children born between 2018 and 2020, 4,573 children were diagnosed with at least one birth defect, yielding an overall prevalence of 264.2 per 10,000 live births or 2.64%. Among children with birth defects, cardiovascular system defects (64.2%) were the most common followed, in order of occurrence, by defects of the genitourinary, musculoskeletal, chromosomal, orofacial, gastrointestinal, central nervous, eye, and ear/face/neck systems. Other birth defects contributed just under 1% (Table 1).

Table 1: Type of birth defects by organ and chromosome system among children with birth defects, 2018-2020 (n = 4,573)

Organ and chromosomal system	Number	Percent*
Cardiovascular	2935	64.2
Genitourinary	759	16.6
Musculoskeletal	537	11.7
Chromosomal	466	10.2
Oro-facial	341	7.5
Gastrointestinal	195	4.3
Central Nervous System	171	3.7
Eye	61	1.3
Ear, Face, and Neck	27	0.6
Other	32	0.7

** Because one child may have more than one birth defect, the total percentages are greater than 100% when totaled.*

The six most common specific birth defects overall, regardless of the organ or chromosomal system to which it belongs, with a prevalence greater than 10 per 10,000 live births among children born in 2018-2020 included: atrial septal defect (111.2), hypospadias (70.2), ventricular septal defect (54.9), clubfoot (12.8), Down syndrome (12.6), and cleft palate without cleft lip (9.4). Stratified by organ and chromosomal system, the most common birth defects were as follows:

- *cardiovascular*: atrial septal defects and ventricular septal defects
- *genitourinary*: hypospadias
- *central nervous*: spina bifida
- *eyes*: congenital cataract and anophthalmia/microphthalmia
- *ear, face, and neck*: anotia/microtia
- *orofacial*: cleft palate without cleft lip

- *gastrointestinal*: small intestinal atresia or stenosis
- *musculoskeletal*: clubfoot and craniosynostosis
- *chromosomal*: Down syndrome (Table 2).

Table 2: Occurrence of specific birth defects by organ and chromosomal system, 2018-2020 (N = 173,037)

System	Birth defects	Number	%	Prev.	95%CI
	Total	**4573**		**264.28**	**256.7, 272.1**
Central nervous (n = 171)	Spina bifida without anencephalus	51	29.8	2.9	2.2, 3.9
	Encephalocele	26	15.2	1.5	1.0, 2.2
	Anencephalus	24	14.0	1.4	0.9, 2.1
	Holoprosencephaly	24	14.0	1.4	0.9, 2.1
Eyes (n = 61)	Congenital cataract	35	57.4	2.0	1.4, 2.8
	Anophthalmia/microphthalmia	27	44.3	1.6	1.0, 2.3
Ear, face, neck (n = 27)	Anotia/microtia	26	96.3	1.5	1.0, 2.2
Cardiovascular (n = 2,935)	Atrial septal defect	1927	68.0	111.2	106.3, 116.3
	Ventricular septal defect	951	33.5	54.9	51.4, 58.5
	Pulmonary valve atresia and stenosis	189	6.7	10.9	9.4, 12.6
	Atrioventricular septal defect	144	5.1	8.3	7.0, 9.8
	Coarctation of the aorta	91	3.2	5.3	4.2, 6.4
	Tetralogy of Fallot	77	2.7	4.4	3.5, 5.6
	Double outlet right ventricle	52	1.8	3.0	2.2, 3.9
	Transposition of the great arteries	44	1.6	2.5	1.8, 3.4
	Hypoplastic left heart syndrome	38	1.3	2.2	1.6, 3.0
	Dextro-transposition of great arteries	37	1.3	2.1	1.5, 2.9
	Aortic valve stenosis	22	0.8	1.3	0.8, 1.9
	Interrupted aortic arch	16	0.6	0.9	0.5, 1.5
	Tricuspid valve atresia and stenosis	16	0.6	0.9	0.5, 1.5
	Tricuspid valve atresia	14	0.5	0.8	0.4, 1.4
	Ebstein anomaly	12	0.4	0.7	0.4, 1.2
	Total anomalous pulmonary venous connection	12	0.4	0.7	0.4, 1.2
	Common truncus	11	0.4	0.6	0.3, 1.1
	Pulmonary valve atresia	7	0.2	0.4	0.2, 0.8
Oro-facial (n = 341)	Cleft palate without cleft lip	163	47.8	9.4	8.0, 11.0
	Cleft lip with cleft palate	117	34.3	6.8	5.6, 8.1
	Cleft lip without cleft palate	59	17.3	3.4	2.6, 4.4
	Choanal atresia	15	4.4	0.9	0.5, 1.4
Gastrointestinal (n = 195)	Small intestinal atresia/stenosis	86	44.1	5.0	4.0, 6.1
	Rectal and large intestinal atresia/stenosis	73	37.4	4.2	3.3, 5.3
	Esophageal atresia/tracheoesophageal fistula	31	15.9	1.8	1.2, 2.5
	Biliary atresia	13	6.7	0.8	0.4, 1.3
Genitourinary (n = 759)	Hypospadias*	621	81.8	70.2	64.8, 76.0
	Renal agenesis/hypoplasia	100	13.2	5.8	4.7, 7.0
	Congenital posterior urethral valves*	24	3.2	2.7	1.7, 4.0
Musculoskeletal (n = 537)	Clubfoot	222	41.3	12.8	11.2, 14.6
	Craniosynostosis	150	27.9	8.7	7.3, 10.2
	Gastroschisis	53	9.9	3.1	2.3, 4.0
	Limb deficiencies (reduction defects)	49	9.1	2.8	2.1, 3.7
	Diaphragmatic hernia	43	8.0	2.5	1.8, 3.3
	Omphalocele	36	6.7	2.1	1.5, 2.9
Chromosomal (n = 466)	Trisomy 21 (Down syndrome)	218	46.8	12.6	11.0, 14.4
	Trisomy 18	33	7.1	1.9	1.3, 2.7
	Deletion 22 q11	30	6.4	1.7	1.2, 2.5
	Trisomy 13	16	3.4	0.9	0.5, 1.5
	Turner syndrome**	16	3.4	1.9	1.1, 3.1

**Prevalence limited to male (88,451); **Prevalence limited to female (84,583)*

Stratified by race and ethnicity, the total prevalence of birth defects was a bit higher in non-Hispanic white (NHW) (266.4) than in non-Hispanic black (NHB) (264.6). The five most common birth defects with a prevalence equal or greater than 10 per 10,000 live births in both groups included atrial septal defect (NHW: 104.7 vs. NHB: 123.8), ventricular septal defect (NHW: 54.8 vs. NHB: 51.1), hypospadias (NHW: 78.5 vs. NHB: 64.5), clubfoot (NHW: 12.8 vs. NHB: 13.6), and Down syndrome (NHW: 12.9 vs. NHB: 9.6). In addition, cleft palate without cleft lip (11.1) and craniosynostosis (9.7) were seen with a prevalence greater than 10 per 10,000 live births in NHW while pulmonary valve atresia and stenosis were higher among NHB (13.5). (Table 3).

Table 3: Occurrence of specific birth defects by organ and chromosomal system and race and ethnicity, 2018-2020

	Non-Hispanic White		**Non-Hispanic Black**		**Hispanic**		**Non-Hispanic Other**	
Birth defects	**n**	**Prevalence, 95%CI**	**n**	**Prevalence, 95%CI**	**n**	**Prevalence, 95%CI**	**n**	**Prevalence, 95%CI**
Total	**2297**	**266.4, 255.6-277.5**	**1710**	**264.6, 252.2-277.5**	**375**	**259.8, 234.1-287.4**	**185**	**245.7, 211.6-283.8**
Central nervous system								
Spina bifida without anencephalus	26	3.0, 2.0-4.4	15	2.3, 1.3--3.8	9	6.2, 2.9-11.8	-	
Anencephalus	15	1.7, 1.0-2.9	6	0.9, 0.3-2.0	-		-	
Encephalocele	9	1.0, 0.5-2.0	14	2.2, 1.2-3.6	-		-	
Holoprosencephaly	7	0.8, 0.3-1.7	12	1.9, 1.0-3.2	-		-	
Eyes								
Congenital cataract	17	2.0, 1.1-3.2	15	2.3, 1.3-3.8	-		0	
Anophthalmia/microphthalmia	11	1.3, 0.6-2.3	9	1.4, 0.6-2.6	-		-	
Ear, face, neck								
Anotia/microtia	9	1.0, 0.5-2.0	7	1.1, 0.4-2.2	9	6.2, 2.9-11.8	-	
Cardiovascular system								
Atrial septal defect	903	104.7, 98.0-111.8	800	123.8, 115.4-132.7	145	100.4, 84.8-118.2	77	102.3, 80.7-127.8
Ventricular septal defect	473	54.8, 50.0-60.0	330	51.1, 45.7-56.9	109	75.5, 62.0-91.1	39	51.8, 36.8-70.8
Pulmonary valve atresia and stenosis	78	9.0, 7.1-11.3	87	13.5, 10.8-16.6	18	12.5, 7.4-19.7	6	8.0, 2.9-17.3
Atrioventricular septal defect	67	7.8, 6.0-9.9	57	8.8, 6.7-11.4	13	9.0, 4.8-15.4	7	9.3, 3.7-19.2
Coarctation of the aorta	53	6.1, 4.6-8.0	31	4.8, 3.3-6.8	6	4.2, 1.5-9.0	-	
Tetralogy of Fallot	41	4.8, 3.4-6.5	26	4.0, 2.6-5.9	7	4.8, 1.9-10.0	-	
Hypoplastic left heart syndrome	25	2.9, 1.9-4.3	11	1.7, 0.9-3.0	2		0	
Transposition of the great arteries	22	2.6, 1.6-3.9	13	2.0, 1.1-3.4	7	4.8, 1.9-10.0	-	
Double outlet right ventricle	21	2.4, 1.5-3.7	25	3.9, 2.5-5.7	5	3.5, 1.1-8.1	-	
Dextro-transposition of great arteries	20	2.3, 1.4-3.6	10	1.5, 0.7-2.8	5	3.5, 1.1-8.1	-	
Aortic valve stenosis	15	1.7, 1.0-2.9	-		-		-	
Interrupted aortic arch	9	1.0, 0.5-2.0	6	0.9, 0.3-2.0	-		0	
Common truncus	9	1.0, 0.5-2.0	-		0		0	
Tricuspid valve atresia and stenosis	8	0.9, 0.4-1.8	-		5	3.5, 1.1-8.1	0	
Tricuspid valve atresia	7	0.8, 0.3-1.7	-		-		0	
Ebstein anomaly	7	0.8, 0.3-1.7	-		-		-	
Total anomalous pulmonary venous connection	7	0.8, 0.3-1.7	-		-		0	
Oro-facial system								
Cleft palate without cleft lip	96	11.1, 9.0-13.6	47	7.3, 5.3-9.7	12	8.3, 4.3-14.5	8	10.6, 4.6-20.9
Cleft lip with cleft palate	64	7.4, 5.7-9.5	33	5.1, 3.5-7.2	13	9.0, 4.8-15.4	7	9.3, 3.7-19.2

Cleft lip without cleft palate	35	4.1, 2.8-5.6	9	1.4, 0.6-2.6	10	6.9, 3.3-12.7	-	
Choanal atresia	12	1.4, 0.7-2.4	-		-		0	
Gastrointestinal system								
Small intestinal atresia/stenosis	43	5.0, 3.6-6.7	32	5.0, 3.4-7.0	7	4.8, 1.9-10.0	-	
Rectal and large intestinal atresia/stenosis	33	3.8, 2.6-5.4	30	4.6, 3.1-6.6	8	5.5, 2.4-10.9	-	
Esophageal atresia/tracheoesophageal fistula	13	1.5, 0.8-2.6	14	2.2, 1.2-3.6	-		-	
Biliary atresia	5	0.6, 0.2-1.4	7	1.1, 0.4-2.2	0		-	
Genitourinary system								
Hypospadias*	347	78.5, 70.4-87.2	219	64.5, 56.2-73.6	24	32.5, 20.8-48.3	28	72.1, 47.9-104.2
Renal agenesis/hypoplasia	58	6.7, 5.1-8.7	29	4.5, 3.0-6.4	10	6.9, 3.3-12.7	-	
Congenital posterior urethral valves*	9	2.0, 0.9-3.9	12	3.5, 1.8-6.2	-		-	
Musculoskeletal system								
Clubfoot	110	12.8, 10.5-15.4	88	13.6, 10.9-16.8	19	13.2, 7.9-20.6	5	6.6, 2.2-15.5
Craniosynostosis	84	9.7, 7.8-12.1	49	7.6, 5.6-10.0	12	8.3, 4.3-14.5	5	6.6, 2.2-15.5
Gastroschisis	30	3.5, 2.3-5.0	19	2.9, 1.8-4.6	-		-	
Diaphragmatic hernia	23	2.7, 1.7-4.0	15	2.3, 1.3-3.8	-		-	
Limb deficiencies	21	2.4, 1.5-3.7	21	3.3, 2.0-5.0	-		-	
Omphalocele	18	2.1, 1.2-3.3	14	2.2, 1.2-3.6	-		0	
Chromosomal system								
Trisomy 21 (Down syndrome)	111	12.9, 10.6-15.5	62	9.6, 7.4-12.3	29	20.1, 13.5-28.9	15	19.9, 11.2-32.9
Deletion 22 q11	18	2.1, 1.2-3.3	11	1.7, 0.9-3.0	0		-	
Trisomy 18	11	1.3, 0.6-2.3	15	2.3, 1.3-3.8	7	4.8, 1.9-10.0	0	
Trisomy 13	8	0.9, 0.4-1.8	5	0.8, 0.3-1.8	-		0	
Turner syndrome**	8	0.9, 0.4-1.8	7	2.2, 0.9-4.5	-		0	

*- Case number not shown between one and four; *Prevalence limited to male; **Prevalence limited to female*

In addition to providing annual reports to the Louisiana Legislature, LBDMN data are included in biennial reports produced by the National Birth Defects Prevention Network and special reports such as the manuscript *Short Interpregnancy Interval and Prevalence of Birth Defects: A multi-state study* published in the January 2022 special issue of *Birth Defects Research*. NBDPN collects data in odd years and publishes reports in even years. Therefore, LBDMN 2016-2020 data will be published January 2024.

In October 2023, LBDMN supplied 2018-2020 birth defects data to OPH's Environmental Public Health Tracking system, which provides data and information on health outcomes, the environment, population, and exposures. Louisiana is one of 33 state and local health departments, cities, and jurisdictions to be part of the U.S. CDC National Environmental Public Health Tracking Network.

Performance Assessment and Improvements

LBDMN follows national standards and guidelines for birth defects surveillance. CDC monitors national birth defects surveillance through the National Center for Birth Defects and Developmental Disabilities (NCBDDD). NCBDDD coordinates standards for state birth defects programs through the National Birth Defects Prevention Network (NBDPN). The NBDPN Standards Workgroup produces Data Quality Standards and Assessment Tools for population-based birth defects surveillance systems.

Performance standards are used to improve and standardize operations, outcomes, and surveillance functions across state programs, thereby making data comparable at the state, multi-state, and national levels. Eleven data quality measures around completeness, timeliness, and accuracy are associated with three performance levels (1) Rudimentary, (2) Essential, or (3) Optimal.

NBDPN administers the Data Quality Assessment biennially, most recently reported in 2022. Louisiana ranks among the nation's top active surveillance programs in completeness, accuracy, and overall quality. **From 2019 to 2022 assessments, LBDMN increased from Level 1 to Levels 2 and 3 in both data quality measures of timeliness. This means 95-99% of data from NBDPN's lists of 19 *Core* and 33 *Recommended* birth defects are identified, collected, reviewed, and available for reporting within two years of birth.** Per LA R.S. 40:31.42, LBDMN continues to identify and report qualifying birth defects diagnosed before 3 years of age.

Data to Action Spotlight: Referral to Resources

Timely data enables LBDMN to move data to action in the form of meaningful referrals to resources for families. When babies are born with birth defects, families need help learning about complex systems of care and how to navigate those often fragmented systems. LBDMN collaborates with BFH's Family Resource Center (FRC) to conduct one-on-one needs assessments with families of children born with birth defects most likely to affect developmental outcomes.

FRC staff contact families to assess their need for health and social services including specialty medical care, early intervention services, insurance, advocacy, disability agencies, peer support, transportation, food and housing security. BFH Family Resource Specialists facilitate connections to the appropriate resources for these families.

Since 2022, LBDMN has identified 2,514 children born in 2020 – 2023 who may benefit from a referral needs assessment. Currently, we are referring children under 2 years old. This timing is critical for early intervention services through EarlySteps to aid optimal early development, improved health outcomes, and to smooth the process of securing future developmental supports and services if necessary. The eligibility process for support services after 3 years of age is much easier for children who received EarlySteps services.

Summary

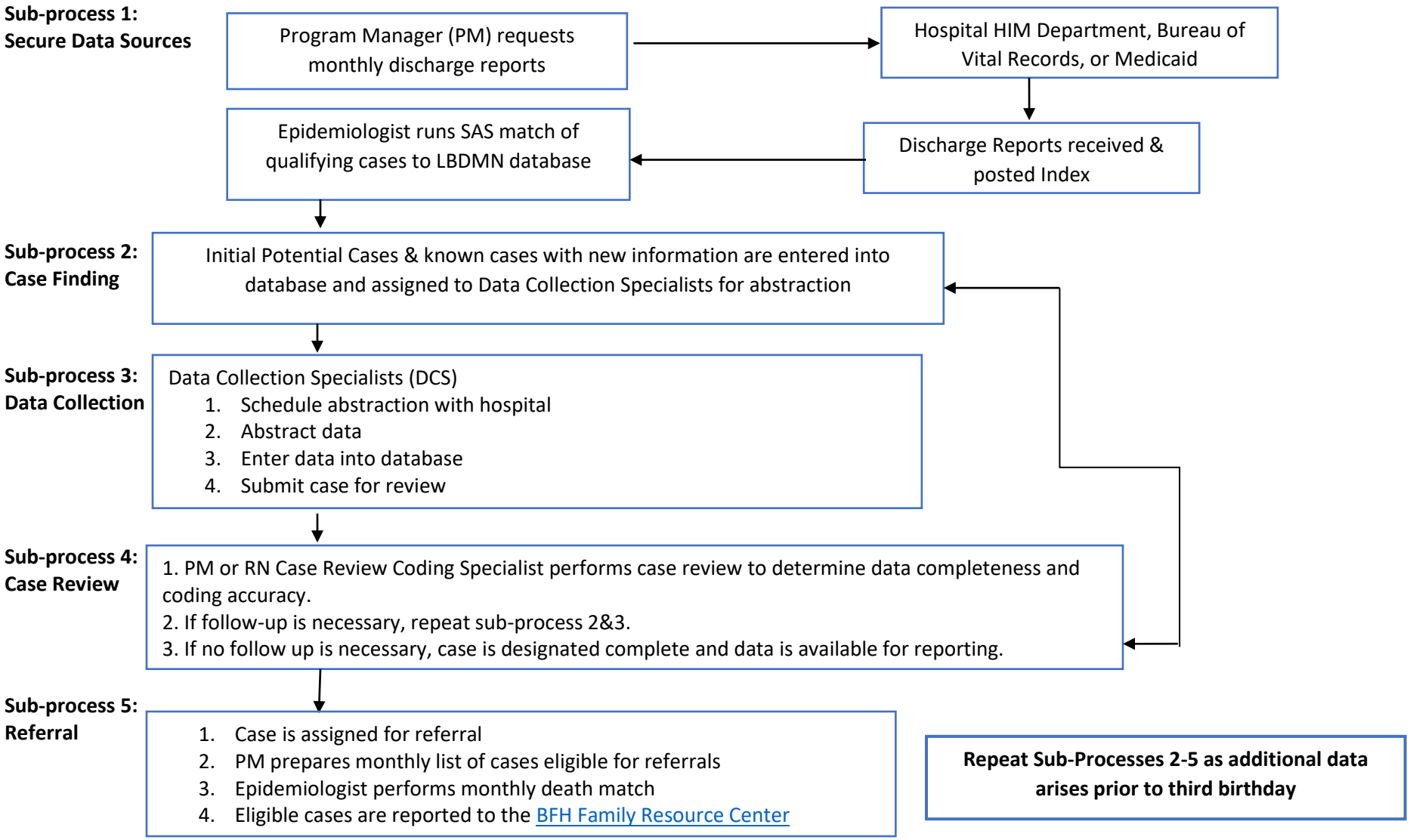
Of 173,037 children born between 2018 and 2020, 4,573 children were diagnosed with at least one birth defect, yielding an overall prevalence of 264.2 per 10,000 live births or 2.64%. According to the CDC, the U.S. average is about 3% of all babies born each year. Among Louisiana children with birth defects born in 2018-2020, cardiovascular system defects (about 64%) were the most common.

As the established statewide mechanism for tracking and monitoring birth defects in Louisiana, LBDMN incorporates evidence-based public health surveillance best practices and continues to seek opportunities for quality improvement. Increased efficiencies in data collection and reporting approaches moved our data to action in 2023 by informing timely referrals to services for families.

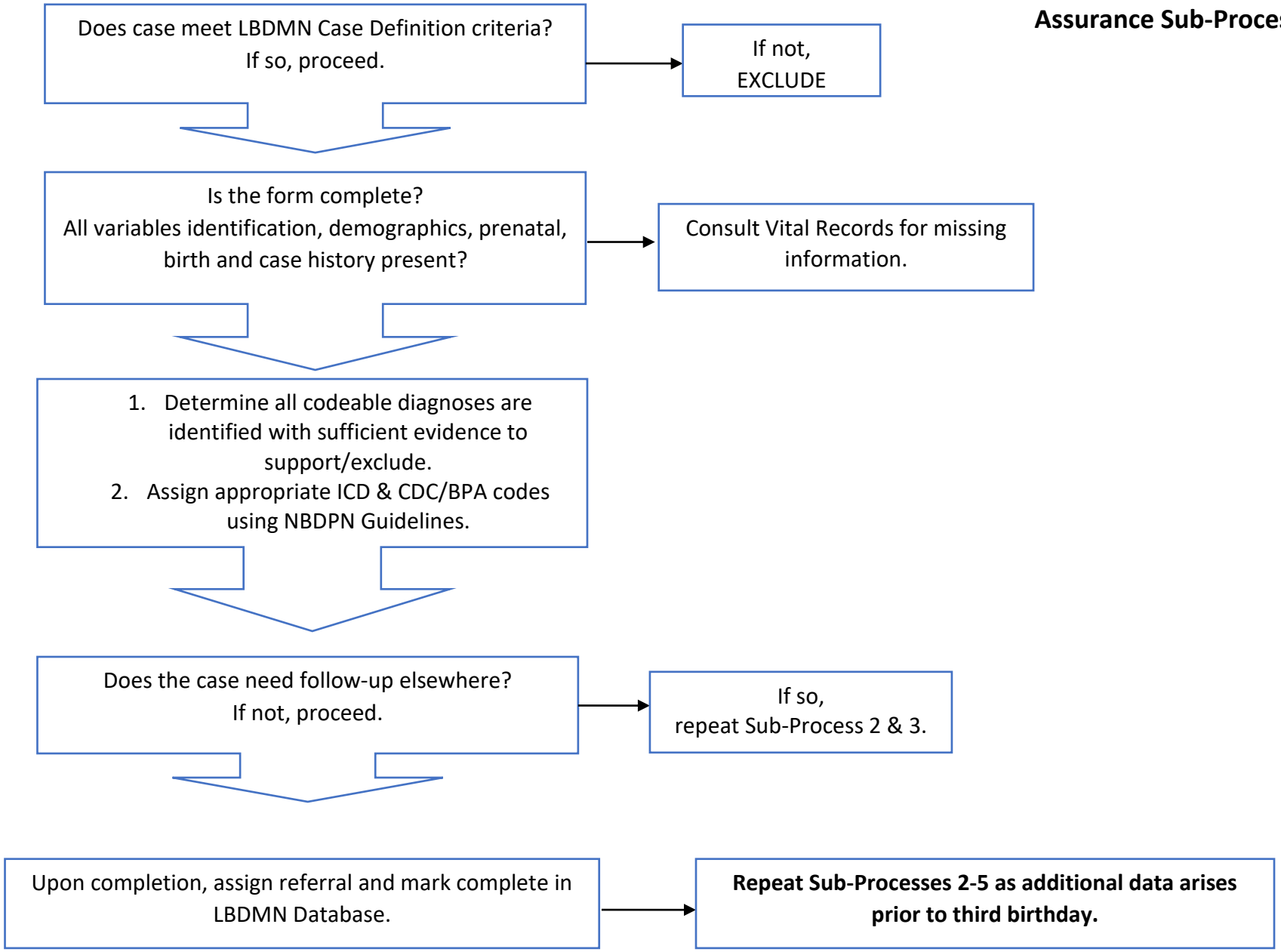
LBDMN data are available at partnersforfamilyhealth.org, at the National Birth Defects Prevention Network, from CDC Data & Statistics on Birth Defects and on the Louisiana's Environmental Public Health Tracking Network health data portal to enable analysis, visualization and reporting. These data are available to environmental and public health practitioners, healthcare providers, community members, policy makers, and others to make data-driven decisions that affect the health of Louisiana residents.

Appendix

Appendix A: Case Ascertainment\Review\Quality Assurance Process Chart



LBDMN Case Review Quality Assurance Sub-Process 4 Steps



Appendix B: Birth Defects Codes and Descriptions

ICD-10 CM CODES BY STANDARD LEVEL	DESCRIPTION	2018-2020 CASE DEFINITION	CDC CODES	REFERRAL
CORE				
Q00.0-Q00.1	Anencephalus	CASE FINDING & CODING	740.000 –740.100	NO
Q05.0-Q05.9	Spina bifida without anencephalus	CASE FINDING & CODING	741.000; 741.020 -741.090; 741.900-	YES
Q07.01		CASE FINDING & CODING	741.010	YES
Q07.03 w/o Q00.0 - Q00.1		CASE FINDING & CODING	741.010	YES
Q20.0	Common Truncus	CASE FINDING & CODING	745.000	YES
Q20.3, Q20.5	TGA	CASE FINDING & CODING	745.100-745.120, 745.180-745.190	YES
Q21.2	AVSD	CASE FINDING & CODING	745.600-745.690	YES
Q21.3	TOF	CASE FINDING & CODING	74.20-745.21	YES
Q23.4	HLHS	CASE FINDING & CODING	746.700	YES
Q26.2	TAPVR	CASE FINDING & CODING	747.420	YES
Q35.1 - Q35.9	Cleft palate without Cleft lip	CASE FINDING & CODING	749.000-749.090	YES
Q36.0 - Q36.9	Cleft lip without Cleft palate	CASE FINDING & CODING	749.100-749.190	YES
Q37.0 - Q37.9	Cleft lip with Cleft palate	CASE FINDING & CODING	749.200-749.290	YES
Q71.0 - Q71.9	Limb reduction defects	CASE FINDING & CODING	755.200-755.290	YES
Q72.0 - Q72.9		CASE FINDING & CODING	755.300-755.390	YES
Q73.0 - Q73.8		CASE FINDING & CODING	755.400-755.490	YES
Q79.2	Omphalocele	CASE FINDING & CODING	756.700	YES
Q79.3	Gastroschisis	CASE FINDING & CODING	756.710	YES
Q90.0 - Q90.9	Trisomy 21	CASE FINDING & CODING	758.000-758.090	YES
RECOMMENDED				
Q01.0 - Q01.9	Encephalocele	CASE FINDING & CODING	742.000-742.090	YES
Q04.2	Holoprosencephaly*	CASE FINDING & CODING	742.260	YES
Q11.0 - Q11.2	Anophthalmia/Microphthalmia	CASE FINDING & CODING	743.000-743.100	YES
Q12.0	Congenital cataract*	CASE FINDING & CODING	743.320-743.326	YES
Q13.1	Aniridia	CASE FINDING & CODING	743.420	YES
Q16.0, Q17.2	Anotia/microtia	CASE FINDING & CODING	744.010, 744.210	YES
Q20.1	DORV	CASE FINDING & CODING	745.130-745.150	YES
Q20.4	Single Ventricle	CASE FINDING & CODING	745.300	YES
Q21.0	VSD	CASE FINDING & CODING	745.400-745.490	YES
Q21.1	ASD	CASE FINDING & CODING	745.500-745.590	YES 745.510 only
Q22.0, Q22.1	Pulmonary valve atresia and stenosis	CASE FINDING & CODING	746.000, 746.010	YES
Q22.4	Tricuspid valve atresia and stenosis	CASE FINDING & CODING	746.100, 746.106	YES
Q22.5	Ebstein anomaly	CASE FINDING & CODING	746.200	YES
Q23.0	Aortic valve stenosis	CASE FINDING & CODING	746.300	YES
Q25.1	COA	CASE FINDING & CODING	747.100-747.190	YES

Q25.2, Q25.4	IAA	CASE FINDING & CODING	747.215-747.217	YES
Q30.0	Choanal atresia	CASE FINDING & CODING	748.000	YES
Q39.0 - Q39.4	TEF/ EA	CASE FINDING & CODING	750.300-750.350	YES
Q41.0 - Q41.9	Small intestine atresia/stenosis	CASE FINDING & CODING	751.100-751.190	YES
Q42.0 - Q42.9	Rectal and large intestine atresia/ stenosis	CASE FINDING & CODING	751.200-751.240	YES (exclude Imperforate anus)
Q44.2 - Q44.3	Biliary atresia*	CASE FINDING & CODING	751.650	YES
Q54.0 - Q54.9 (not Q54.4)	Hypospadias	CASE FINDING & CODING	752.600-752.607;752.620;752.625-752.627	NO
Q60.0 - Q60.6	Renal agenesis/ hypoplasia	CASE FINDING & CODING	753.000-753.010	YES
Q64.10, Q64.19	Bladder exstrophy	CASE FINDING & CODING	753.500	YES
Q64.12	Cloacal exstrophy	CASE FINDING & CODING	751.550	YES
Q64.2	PUV	CASE FINDING & CODING	753.600	YES
Q66.0, Q66.89	Clubfoot	CASE FINDING & CODING	754.500-754.004; 754.730-754.734	YES
Q75.0	Craniosynostosis*	CASE FINDING & CODING	756.000-756.030	YES
Q79.0, Q79.1	Diaphragmatic hernia	CASE FINDING & CODING	756.610-756.616	YES
Q91.0 - Q91.3	Trisomy 18	CASE FINDING & CODING	758.200-758.295	91% mortality rate
Q91.4 - Q91.7	Trisomy 13	CASE FINDING & CODING	758.100-758.190	91% mortality rate
Q93.81	22q11 deletion*	CASE FINDING & CODING	758.370	YES
Q96.0 - Q96.9	Turner syndrome*	CASE FINDING & CODING	758.600-758.690	YES
LBDMN				
Q87.40	Marfan syndrome, Stickler	CODING	759.860	YES
Q87.81	Alport syndrome	CODING	759.870	YES
Q93.3	Other autosomal deletions	CODING	758.380	YES
Q93.4	Cri du chat syndrome (5p deletion)	CODING	758.310	YES
Q93.59	Other deletions of part of a chromosome	CODING	758.390	YES
Q93.7	Deletions with other complex rearrangements	CODING	758.390	YES
Q93.88	Other microdeletions	CODING	758.380	YES
Q93.89	Other deletions from the autosomes	CODING	758.380	YES
Q97.0	Other conditions due to sex chromosome anomalies	CODING	758.8**	YES
Q97.1	Female with more than three X chromosomes	CODING	758.850	YES
Q97.2	Mosaicism, lines with various numbers of X chromosomes	CODING	758.800, 758.820, 758.830	YES
Q97.8	Other specified sexchromosome abnormalities, female phenotype	CODING	758.810	YES
Q98.4	Klinefelter's syndrome	CODING	758.700, 758.710, 758.790	YES
Q98.5	Karyotype 47,XYY	CODING	758.840	YES

Q98.7	Male with sex chromosome mosaicism	CODING	758.840	YES
Q98.8	Other specified sex chromosome abnormalities, male phenotype	CODING	758.820	YES
Q99.2	Fragile X syndrome	CODING	758.880	YES
Q99.8	Other conditions due to autosomal material	CODING	758.580	YES
Q99.8	Other conditions due to chromosome anomalies	CODING	758.880	YES
Q99.9	Conditions due to anomaly of unspecified chromosome	CODING	758.890	YES

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