

Annual Mortality Report 2012

Home & Community-Based Services (Waiver Programs)

Office for Citizens with Developmental Disabilities

Louisiana Department of Health & Hospitals

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EXECUTIVE SUMMARY

The Office for Citizens with Developmental Disabilities (OCDD) is committed to strengthening the network of supports delivered to individuals in the Developmental Disabilities Medicaid Waiver Services System. The OCDD utilizes a Mortality Review Committee (MRC) as part of its quality enhancement system to study and disseminate aggregate information regarding mortality in order to better understand and address the conditions, which lead to waiver participants' deaths. The Department of Health and Hospitals (DHH) goal is to focus resources and technical assistance in aspects of waiver service that have the most impact on waiver participants' well-being.

The OCDD Annual Mortality Report 2012 presents findings by the MRC on deaths that occurred in the OCDD Home and Community-Based Services (HCBS) waiver populations between July 1, 2011 and June 30, 2012 (Louisiana state fiscal year 2011/12). The Report also provides comparable data for previous years to better identify trends that may emerge over time. The Report constitutes an important tool for the OCDD to focus attention on patterns and trends related to mortality in the population of Louisiana citizens who participate in services delivered through the waiver program.

The unduplicated count of participants for all four OCDD waivers was 11,706 individuals throughout the state fiscal year 2011/12. This is a net increase of 14 percent from June 30, 2011 when the census was 10,300. It is important to note that beginning with this annual report, the census count process has shifted to unduplicated number of participants throughout the entire year as opposed to previous years when the census number as of June 30th (closing date of the fiscal year) was used.

One hundred thirteen (113) OCDD waiver participants died in the State of Louisiana between July 1, 2011 and June 30, 2012. The rate per 1000 waiver participants is equivalent to 9.7, compared to the rate for the previous FY 2010/11 equivalent of 9.5 per 1000 waiver participants. The predominant nature of death was due to medical/health conditions. Heart disease, the leading cause of death again for FY 2011/12 was comparable to that reported for the general population of the United States and Louisiana. Five (5) deaths were categorized as being a result of caregiver neglect by paid or natural supports. DHH Health Standards (licensing) reviewed all cases of death for waiver participants when the death occurred while waiver direct service worker services were on duty. Twelve deaths involving paid waiver supports were investigated by DHH Health Standards (licensing), with eleven investigations resulting in substantiated failure by the direct service provider to meet minimal licensing standards, most often in the areas of adequate staff training and supervision. In three additional cases where waiver services were on duty at the time of death, Health Standards chose not to investigate because the individuals had a documented terminal illness and hospice services. Two (2) participant deaths were the result of vehicular accidents. There were no deaths as a result of homicide or suicide.

Annual Mortality Report 2012

Louisiana Office for Citizens with Developmental Disabilities (OCDD)

INTRODUCTION

Scope

The OCDD Annual Mortality Report 2012 presents aggregate information on the deaths of OCDD Home and Community-Based Services (HCBS) waiver participants that occurred from July 1, 2011 through June 30, 2012 regardless of age or circumstances of death. Deaths of individuals who were registered in the Developmental Disabilities (DD) Services System but were not receiving waiver services at the time of death are not included in this report. Deaths of other Louisiana citizens who do not receive DD waiver services are not included in the OCDD Annual Mortality Report.

OCDD operates four waivers: New Opportunities Waiver (NOW); Residential Options Waiver (ROW); Supports Waiver (SW); and Children's Choice Waiver (CC). The Mortality Review Committee reviews 100 percent of deaths within the census of these four HCBS waivers and produces the Annual Mortality Report.

Mortality Reporting & Review

Act No. 345 of the 2009 Louisiana Regular Legislative Session re-enacted and amended Revised Statute 44:4.1 (B)(24) and enacted Revised Statute 40:2020 relative to the authority of the Department of Health & Hospitals (DHH) to conduct certain mortality reviews, and provided for legislative intent, definitions and duties, records, confidentiality, public records exemptions and for related matters. The OCDD Mortality Review Committee was established in January 2009. The Committee commenced its mortality reviews with deaths that occurred beginning July 1, 2008. OCDD conducts reviews and reports annual findings on a State fiscal year cycle (July 1-June 30).

In 2009, OCDD issued *Operational Instruction F-1: Mortality Review Process* for the process of reviewing deaths that occurred in the OCDD waiver census. The process provides for the formation of the Mortality Review Committee (MRC) to conduct the steps outlined in the Operational Instruction. The MRC has the option to make recommendations for certain systemic changes by a direct service provider or support coordinator or within the OCDD itself when those actions are identified during the mortality review as potentially negative to the welfare of other waiver recipients in that provider's care. The MRC does not replace the State's Protective Services Units or the licensing arm of DHH (Health Standards Section), which has broad investigative and enforcement authority over licensed service providers.

Improvement to the MRC process since 2011 that has enhanced the discovery and reporting of information has been the continued refinement of the MRC database to permit a broader scope of comparisons and correlations.

Sources of information reviewed by the MRC include:

- *OTIS* (Online Tracking Incident System) - This database is used by case managers, local governing entities (LGEs) and Adult/Elderly Protective Services to document critical incidents. It yields demographic information that is uploaded from the Medicaid data contractor as well as documentation of the sequence of dates, events and activities associated with each critical incident. The MRC reviews all OTIS critical incident reports for the year prior to death of each waiver participant.
- *Comprehensive Plans of Care* - The Comprehensive Plan of Care (or CPOC) for each waiver participant provides information about health issues that were identified at the time the plan was formulated, health changes which resulted in revision to the plan, and strategies which were proposed to meet the participant's needs.
- *Death certificates* - The DHH Office of Public Health, through a Memorandum of Understanding with OCDD and the directive of LA R.S. 40:2020, provides confidential, certified copies of death certificates of waiver participants upon request from the OCDD Critical Incidents program manager. The death certificate establishes time, place and cause of death, as well as whether an autopsy was performed.
- *Medical records* - LA R.S. 40:2020 additionally charges OCDD with obtaining medical records for the purpose of conducting mortality review. Records for the period of one year prior to death are sought to further determine the continuity of health care that was provided.
- *Provider records* - Direct service providers and support coordinators are required by LA R.S. 40:2020 to make available to the MRC all their records pertaining to the deceased individual. Additionally, providers must divulge all training records for staff.
- *Investigative findings* - Investigation of the death of a waiver participant is the responsibility of the Louisiana DHH Health Standards Section (HSS), the State's Protective Services offices, and law enforcement when the death is suspicious or is part of a criminal investigation.

The MRC coordinator and a designee identify and enter all pertinent factual information gleaned from the records listed above into the MRC database upon notification to OCDD of a death, and as records related to the MRC review are forwarded to OCDD from the local governing entities. The Committee conducts monthly meetings to review this information, validate cause of death for each decedent, and examine the events preceding each decedent's death. When a death is believed to have been preventable, the Committee issues a request for a Corrective Action Plan (CAP) directed to the direct service provider, and/or the support coordination agency and/or the local governing entity. The CAP is designed to bring to the attention of each of the aforementioned entities that those actions or practices should be examined more closely, with a desirable outcome of strengthening the provision of services for waiver participants and reduce the future risk of events that lead to avoidable deaths. DHH Health Standards, Adult Protective Services, Elderly Protective Services and the Department of Family and Children Protective Services may also investigate independent of the Mortality Review Committee process and issue corrective actions based on the scope of their authority.

The Mortality Review Committee is comprised of the following membership:

- OCDD state clinical director or designee medical consultant (chairperson)
- Licensed clinical social worker (coordinator)
- OCDD critical incidents program manager (co-coordinator)
- OCDD quality section program monitor
- Developmental disabilities council advocate
- Ad hoc participation from disciplines including, but not limited to, physician, psychiatrist, or allied health therapist when questions arise, which require specific opinion.

Due to the small size of the OCDD waiver mortality sample, at times throughout this report results may be expressed in actual numbers rather than rates. Rates, when used to compare disparate population groups, are calculated as: $n \times 1,000 / \text{Total Waiver Population}$ and are *crude* rates as opposed to *adjusted*, unless otherwise noted. Calculations are based on the certified waiver census effective June 30, 2012. "Certified" census refers to those individuals actually receiving services rather than the total number of individuals who are eligible or are still in the process of becoming eligible.

END OF INTRODUCTION

WAIVER DEMOGRAPHICS

Waiver demographics presented in *Tables 1* and *2* and *Figure 1* provide general information regarding the geographic distribution of all OCDD waiver participants across the State, the age group distribution and breakdown by gender as of June 30, 2012. The comparison to mortality rate can be found within report in the *Mortality Information* and *Trends* sections.

Census for Waiver Participants

The census for the four developmental disability waivers is noted by local governing entity distribution in *Table 1*. Note that for the time period covered in this report, Regions operated under the supervision of OCDD, and Districts or Authorities were independent governing entities.

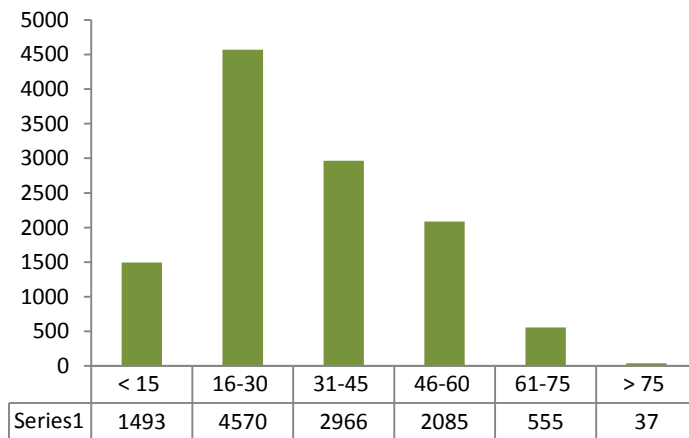
Table 1. Certified census for waiver participation as of June 30, 2012

Region/District/ Authority	Waiver				TOTALS
	NOW	SW	CC	ROW	
Metropolitan Human Services District	568	112	100	0	780
Capital Area Human Services District	1193	183	161	2	1539
S. Central Louisiana Human Services Authority	810	239	145	0	1194
Acadiana Area Human Services District	1410	310	222	6	1948
Region 5	479	101	77	2	659
Region 6	599	122	72	7	800
Region 7	700	286	129	1	1116
Region 8	756	206	120	4	1086
Florida Parishes Human Services Authority	955	148	241	5	1349
Jefferson Parish Human Services Authority	889	177	169	0	1235
Totals	8359	1884	1436	27	11706

Age Groups

The ages of waiver participants is distributed by age groups in *Figure 1* (below).

Figure 1. Waiver census by age group for FY 2011/12



Gender

Table 2. Gender representation in OCDD waivers for FY 2011/12

Age Group	Male (N)	Female (N)
15 and younger	948	545
16-30	2698	1871
31-45	1639	1327
46-60	1143	942
61-75	291	266
76 and older	13	23
Total	6732	4974

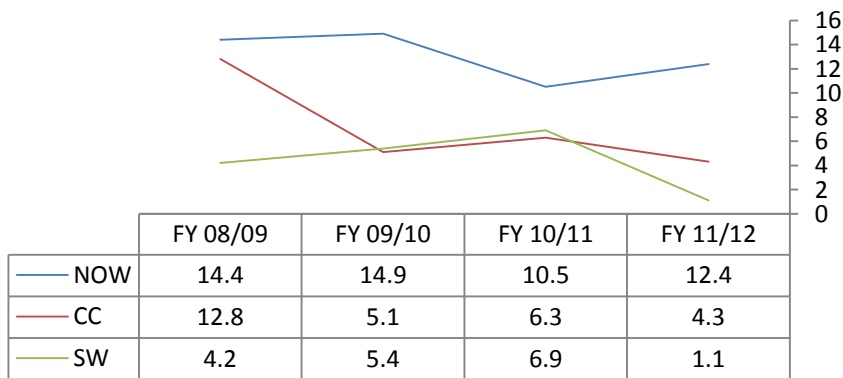
MORTALITY INFORMATION

There were a total of 113 mortality cases reported in OCDD waiver services for fiscal year 2011/12. NOW reported 105 deaths of participants; SW reported two (2) deaths, and CC reported six (6) deaths. No ROW participants died. Mortality for each waiver is expressed in rate per 1000 participants in *Figure 2*. The NOW provides services to the largest, most diverse group of Louisiana citizens who are eligible for a HCBS waiver through OCDD. It includes a broader range of ages and scope of services than the CC, SW and ROW. In addition, NOW is used by individuals transitioning out of large public institutional settings, which includes some of Louisiana’s most vulnerable population with developmental disabilities. CC waiver participants reside in their family’s homes with family included as natural supports.

Rates for NOW, CC & SW

The mortality rates for the three waivers where deaths were recorded for fiscal years 2008/09 through 2011/12 are illustrated in *Figure 2*. The rate for NOW participants, after dropping in FY 2010/11, showed an upward trend in FY 2011/12. Conversely, CC and SW mortality rates dropped below the rates for the past two years.

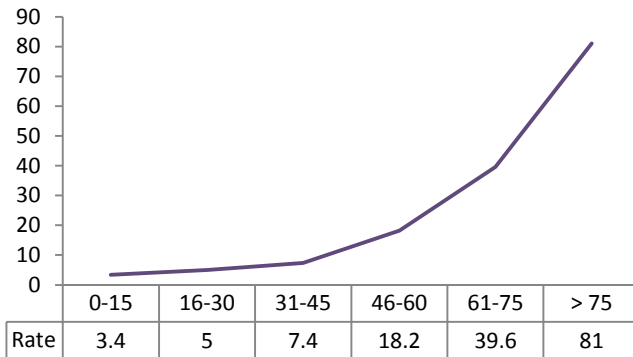
Figure 2. OCDD waiver mortality rate per 1,000 participants for FY 2008/09 - 2011/12



Age

The rate of death by age group is illustrated in *Figure 3*. The graph tracks a predictable steady increase with age.

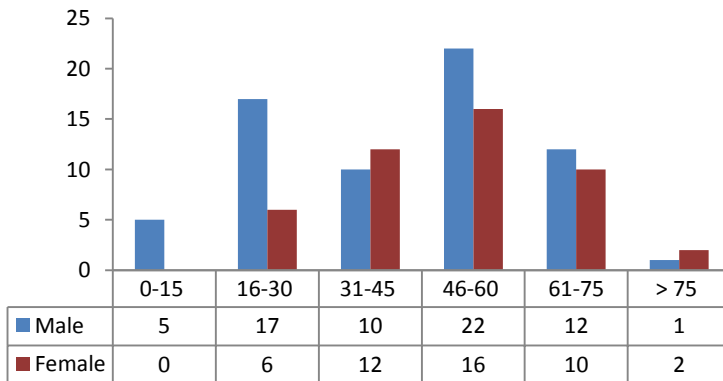
Figure 3. OCDD waiver population mortality rate per 1,000 participants by age group for FY 2011/12



Gender

Forty-six females and 67 males died during the FY 2011/12. A closer look at the actual number of males and females who died within the age groups represented in *Figure 4* reveals that the number of males between the ages of 16 and 30 who died was 183 percent greater than the number of females. The gender breakdown of the overall waiver census (see Table 2) indicates that there are 44 percent more males than females in that age group.

Figure 4. Waiver mortality count by gender & age group for FY 2011/12



Circumstances Surrounding Incidents of Mortality

Deaths are categorized by the MRC as “expected” or “unexpected.” Expected deaths include those resulting from a documented medical diagnosis of terminal disease, an irreversible deterioration of health, or certain congenital conditions that carry a poor prognosis for a full life span. The determination of expected death is based on supporting documentation provided by direct service providers, support coordinators, family members, hospital records, physician reports, hospice or home health Plans of Care (when these services were used) and coroners’ findings, which confirmed presence of a terminal health condition. Unexpected deaths include deaths with findings of a medical condition that would not be considered terminal or otherwise meeting the definition of expected death. Whenever possible, information from the provider’s critical incident report is validated with hospital or emergency room records for cases that are categorized as unexpected. Death was determined to be unexpected in 72 cases.

The MRC discovered that of 41 expected deaths for FY 2011/12, 16 waiver participants were receiving home hospice services and seven (7) waiver participants received center-based hospice. Six (6) participants who died in a rehabilitation/nursing facility died in that setting concurrent with a hospital stay of more than one day and had not yet had their waiver eligibility terminated.

Place of Death

Determination of location of death is dependent on information provided on the death certificate. People using OCDD waiver services more often died at home or in an acute care facility after having been admitted for more than one day (*Table 3*). Forty-four percent died at home; another 31 percent died at an acute care facility after having been admitted for more than (>) one day. Seventeen percent of participants are listed as being hospitalized less than (<) one day and were declared dead in an acute care emergency room.

Table 3. OCDD waiver mortality for FY 2011/12 - Where did people die?

Location listed on death certificate	FY 2009/2010	FY 2010/2011	FY 2011/12
Hospitalized for > 1 day	49	39	35
Hospitalized for < 1 day (E.R.)	12	9	19
At home	40	42	50
Rehab/ Nursing home	Not collected	5	6
Other/Undetermined	Not Collected	3	3

A comparison of the two leading locations of death noted in *Table 3* with the four leading causes of death that occurred in those two locations provides insight regarding management of certain health conditions (see *Table 4*). Participants who died at home as a result of heart disease usually died unexpectedly with little or no warning of distress, although the majority did have such predictors such as high blood pressure, high cholesterol, or obesity with a sedentary lifestyle. Participants whose cause of death was pneumonia and septicemia

Table 4. Comparison of place of death with 4 leading causes of death for FY 2011/12

Acute Care Facility >1 Day		Home or Emergency Room	
Cause of Death	% of Deaths @ Location	Cause of Death	% of Deaths @ Location
Pneumonia (all types)	11	Heart Disease	10
Septicemia	6	Congenital Condition	9
Heart disease	2	Carcinoma	11
Congenital condition	2	Chronic Respiratory	4
All others	79	All others	69

The MRC reviewed risk management efforts that occurred for a period of one year prior to death of each waiver participant by examining OTIS critical incident reports to determine patterns in repetitive incidents (see *Table 5*). Thirty-seven percent of waiver participants across the State died without any previously documented critical incidents related to the health issue that contributed to the cause of death in the year prior to death.

Table 5. Number of individuals with Critical Incident Reports prior to death event for FY 2011/12

Number of Participants per Region/ District/Authority	Number of Critical Incident Reports for Repetitive Incidents											
	0	1	2	3	4	5	6	7	8	9	10	Total
Metropolitan Human Services District	3	4	3	-	2	-	-	-	-	1	-	
Capital Area Human Services District	3	4	-	2	1	-	-	-				
S. Central Louisiana Human Services Authority	4	-	4	2	1	2	1	-	-	-	1	
Acadiana Area Human Services District	6	3	3	-	1	3	1	1	1	-	-	
Region 5	5	2	-	-	1	-	-	-	-	-	-	1
Region 6	6	3	2	3	-	1	-	-	-	-	-	
Region 7	2	2	-	2	1	2	-	1	-	-	-	
Region 8	5	2	-	-	-	-	-	-				
Florida Parishes Human Services Authority	5	1	3	-	-	1	-	-	-	-	-	
Jefferson Parish Human Services Authority	3	1	-	-	1	-	-	-				
Statewide	42	22	15	9	8	8	3	2	1	1	2	113

Investigations

Twenty-six percent of the total deaths recorded for OCDD waiver participants were categorized as suspicious, based on the decision of Health Standards, law enforcement or Protective Services to review. Review of suspicious death is triggered either by evidence that waiver provider staff were on duty at the time of death, or if a complaint was filed by an anonymous reporter, or if medical staff (EMT or emergency room) noticed noted signs of abuse or neglect. Twelve percent of the cases that were screened by Health Standards met criteria for on-site investigation (see *Table 6.*) and resulted in citations that required corrective action plans for provider agency practices such as adequate staff training and clear protocols for staff to use for incident notification. No deaths were directly linked to a neglectful act that required referral to law enforcement for prosecution.

Table 6. Number of investigated deaths by category for FY 2011/12

Category of Death	Number of Deaths
Neglect	13
Accident	2
Suicide	0
Homicide	0

Table 7. Comparison of nature of death to waiver services provided for FY 2011/12

Waiver Services at time of death:	Nature of Death			
	Medical	Accident	Confirmed Neglect	Suicide
Not schedule/not present	70	2	1	-
Scheduled/not present	1	-	-	-
Scheduled/present	34	-	4	-
Total	105	2	5	-

TRENDS

Mortality Rate for Three Year Period

The mortality rate breakdown for regions, districts and authorities reflects a great degree of variability (see *Table 8*). The small number of deaths makes it difficult to read too deeply into the data; raw numbers have been converted to rate per 1000 for ease in comparison because of the disparity in regional census. As the State system continues to promote community-based services and people transition from institutional care, local governing entities are experiencing a change in the profile of the people they serve. Numerous factors can contribute to the choices people make for their place of domicile. Further study within each District or Authority is warranted.

Table 8. OCDD waiver mortality rate per 1,000 participants for Regions/Districts/Authorities for FY 2009/2010 - FY 2011/2012

Region/District/Authority	FY 2009/2010	FY 2010/2011	FY 2011/2012
Metropolitan Human Services District	7.9	28.4	16.7
Capital Area Human Services District	18.2	6.6	6.5
S. Central Louisiana Human Services Authority	5.8	8.5	12.6
Acadiana Area Human Services District	13.3	8.2	9.8
Region 5	20.0	3.4	13.7
Region 6	7.3	8.1	18.8
Region 7	5.2	16.0	9.0
Region 8	7.9	9.6	6.4
Florida Parishes Human Services Authority	16.5	9.5	7.4
Jefferson Parish Human Services Authority	-	2.8	4.0

Cause of Death

MRC compared the causes of death for the 113 waiver participants included in the aggregated data found in this annual report (see *Table 9*). The “congenital condition” category is assigned based on evidence of a diagnosed condition that is present at birth, is expected to contribute to a shortened life span and for which there is no cure or effective treatment. MRC included deaths resulting from conditions such as complications of cerebral palsy, Down Syndrome *with Alzheimer Disease or other associated complications*, neuronal ceroid lipo-fusinosi, and Prader-Willi Syndrome.

Heart disease as a cause of death for participants in the OCDD waiver services, trends as one of the leading causes of death (*Table 13*). Pneumonia was the leading cause of death in FY 2011/2012. There were no documented cases of influenza as a cause of death. [The Centers for Disease Control and Prevention (CDC) includes both pneumonia and influenza national mortality rates in one category.] Fifty-five percent of waiver participants who died were receiving enteral feeding.

Septicemia as a cause of death decreased for FY 2011/2012. The etiology for sepsis cases has been challenging to track, although it is known to be more common for septicemia to be listed as cause of death for participants who died in acute care facilities (see *Table 4*).

Table 9. Prevalence of ten most frequent causes of death for OCDD waiver Participants for 3 years

FY 2009/2010	FY 2010/2011	FY 2011/2012
Congenital Condition 23.6%	Heart Disease 18.4%	Pneumonia 15.0%
Influenza & Pneumonia 20%	Septicemia 17.3%	Heart Disease 12.4%
Heart Disease 17.3%	Congenital Condition 16.3%	Malignant Neoplasm 10.1%
Septicemia 5.5%	Pneumonia 10.2%	Congenital Condition 10.1%
Accidents 5.5%	Malignant Neoplasm 7.1%	Septicemia 8.8%
Malignant Neoplasm 3.6%	Cerebrovascular Disease 4.1%	Cerebrovascular Disease 6.2%
Chronic Lower Respiratory Disease 3.6%	Kidney Disease 3.1%	Chronic Lower Respiratory Disease 3.5%
Kidney Disease 2.7%	Diabetes Mellitus 2%	Accidents/Trauma 2.7%
Alzheimer's Disease 1%	Chronic Lower Respiratory Disease 1.0%	Kidney Disease 1.8%
All other causes 17.2%	All other causes 20.5%	All other causes 29.4%

Rate of Death by Age

The rate of death for participants under age 45 has decreased over the past three years, while the rate has increased for participants in the age group 46-75. (Table 10)

Table 10. Mortality rate for three years in the OCDD waiver program

Age Group	0-15	16-30	31-45	46-60	61-75	>75
Rate FY 2009/10	5.1 (n=5)	10.7 (n=42)	9.5 (n=25)	12.8 (n=23)	33.7 (n=14)	55.6 (n=1)
Rate FY 2010/11	3.7 (n=4)	6.4 (n=26)	7.6 (n=21)	15.0 (n=29)	31 (n=15)	120 (n=3)
Rate F2011/2012	3.3 (n=5)	5.0 (n=23)	7.4 (n=22)	18.2 (n=38)	39.6 (n=22)	81.1 (n=3)

MORTALITY RATE BENCHMARKS

Comparison to Developmental Disability Populations in Selected States

The rates of death calculated for all states except Louisiana and South Dakota (see *Table 11*), as well as for the United States and the State of Louisiana (see *Table 12*) are adjusted for age. Comparison information from California, Massachusetts, Connecticut and South Dakota was based on the most recent reports available.

Table 11. Comparison of developmental disability systems mortality rates for selected states

State	Year	Service	Number of Deaths	Mortality Rate
California ⁱ	July - December 2009	Independent Living Settings/Supported Living Settings	75	3.7
Massachusetts ⁱⁱ	Calendar Year 2008	Home Based	85	6.9
Connecticut ⁱⁱⁱ	FY 2011	Individualized Home Supports	7	8.7
Louisiana	FY 2011/2012	HCBS	113	14.7
South Dakota ^{iv}	Calendar Year 2010	HCBS	28	10.9

Comparison to General Population of Louisiana and the United States

Table 12. Comparison of Louisiana HCBS mortality rates per 1,000 participants with United States and Louisiana general population mortality rates

LA 2010	OCDD Waiver 2010	OCDD Waiver 2011	OCDD Waiver 2012
9.2	11.3	9.5	14.7 (<i>adjusted</i>)

Comparison of Leading Causes of Death

Overall, the ranking of 10 leading causes of death among OCDD waiver participants is similar to the United States general population (see *Table 13*). The number of deaths that occurred among participants with OCDD waivers was so small that it did not lend itself to comparison to rates for much larger populations. Additionally, sufficient information about rates of each category of cause of death was not always available. Therefore, *Table 13* provides a general comparison of the occurrence of causes of death among the general populations of the United States and the State of Louisiana and the State's OCDD waiver population.

Table 13. Comparison of leading causes of death for the general populations of the United States and Louisiana with OCDD HCBS waiver program participants

Rank	United States Preliminary 2011^v	Louisiana 2010^{vi}	LA/OCDD Waiver FY 2011/2012
1	Diseases of the heart	Diseases of the heart	Pneumonia
2	Malignant neoplasms	Malignant neoplasms	Heart Disease
3	Chronic lower respiratory disease	Accidents	Malignant Neoplasm
4	Cerebrovascular disease	Cerebrovascular disease	Congenital Condition
5	Accidents	Chronic lower respiratory disease	Septicemia
6	Alzheimer's disease	Alzheimer's disease	Cerebrovascular disease
7	Diabetes mellitus	Kidney Disease	Chronic Lower Respiratory Disease
8	Influenza & pneumonia	Influenza & pneumonia	Accidents
9	Kidney Disease	Homicide	Kidney Disease
10	Intentional self-harm	Suicide	All other causes

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