# **MORTALITY SPECIAL INCIDENTS**

**Semi-Annual Report Submitted to the California Department of Developmental Services** 

JULY-DECEMBER 2015



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This report summarizes mortality rates between July and December 2015 for DDS consumers living in the community. It compares mortality rates across recent years and identifies months in which mortality rates were unusually high.

# DDS can use this report to track mortality rates over time and monitor the effectiveness of risk management activities.

As one element of risk management and quality assurance, the California Department of Developmental Services (DDS) and California's network of regional centers monitor the occurrence of adverse events, captured through Special Incident Reports (SIRs), to identify trends and develop strategies to prevent and mitigate risks. As required by Title 17, Section 54327 of the California Code of Regulations, vendors and long-term health care facilities report occurrences of suspected abuse, suspected neglect, injury requiring medical attention, unplanned hospitalization, and missing persons if they occur when a consumer is receiving services funded by a regional center (under vendored care). In addition, any occurrence of consumer mortality or a consumer being the victim of a crime must be reported whether or not it occurred while the consumer was under vendored care. Mission Analytics Group (Mission) develops this report along with several others under a risk management contract with DDS.

This report summarizes mortality rates for DDS consumers between July and December 2015. There are two main goals of this report:

- Update time trends in mortality rates from our earlier reports to include data through December 2015. DDS can use this report to observe long-term trends in statewide mortality rates, comparing the most recent six-month period to previous six-month periods.
- 2. Identify months in which statewide mortality rates were unusually high. For those months showing a statewide spike in mortality rates, we conduct additional analyses. By doing so, we can detect patterns that may lead to strategies to prevent similar events in the future.

The rates and graphs presented in this report were constructed using data from the SIR System since 2002. These data are augmented with three additional data sources maintained by DDS:

- 1. The Client Master File (CMF)
- The Client Development Evaluation Report (CDER)
- 3. The Purchase of Service

This report presents findings based on statistical analyses that measure a consumer's risk of experiencing a special incident. Further details are found at the bottom of each subsequent page.

# **Changes in the Mortality Incident Rate**

## Table 1: Reported Deaths for DDS Consumers, July-December 2015 Compared with Previous Periods

	Jul-Dec 2014 (Last Year)	Jan–Jun 2015 (Last Period)	Jul–Dec 2015 (This Period)
Number of Consumers	273,974	280,809	287,886
Number of Reported Deaths	887	1,009	851
Deaths per 1,000 Consumers	3.24	3.59	2.96

### **Key Findings:**



- The number of deaths per 1,000 consumers is lower in this period than in the January-June 2015 period, at 2.96 compared with 3.59. This difference is statistically significant.
- The mortality rate is lower in this period than in the same period one year ago. This difference is also statistically significant.

#### **More About These Data**

This report summarizes mortality rates for consumers living in the community (i.e., consumers receiving services from a regional center who do not reside in a developmental center or state-operated facility).

**Number of Consumers** refers to the average number of consumers served by regional centers in each month during the six-month period. This total is less than the number of all consumers served by regional centers at any time during the six-month period. The number of consumers reported for July-December 2014 and January-June 2015 is lower than previously reported due to data cleaning of records for non-active clients.

**Deaths per 1,000 Consumers** is calculated by dividing the number of reported deaths by the number of consumers, multiplied by 1,000.

The data used to generate this report were provided to Mission in February 2015. Although all deaths are reportable as special incidents, it may take time for deaths among consumers not under vendored care to be reported to the regional centers by parents/guardians. For this reason, it is common that additional mortality incidents are entered into the SIR System over time. Thus, the number of reported deaths may rise slightly as additional mortality data are reported to DDS. This is most likely to affect the count for the most recent period, but counts for earlier periods are also updated over time.

# **Trend of Mortality Incident Rate**

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Figure 1: Mortality Incidents, Statewide Case-Mix Adjusted Monthly Trend
DDS Consumers since December 2013

# Key Findings:

- The moving average is slightly lower than it was two years ago, 0.058% compared to 0.060% (not shown on graph due to rounding).
- Over the past two years, the trend in the statewide average monthly mortality rate has remained relatively constant.

#### **More About These Data**

The line in Figure 1 represents a 12-month moving average for all DDS consumers. It is calculated by taking an average of statewide mortality rates from the most recent 12-month period.

The line in Figure 1 also accounts for the differences in the characteristics of the consumer population over time. This approach, called "case-mix adjustment," controls for consumer characteristics and removes these effects from the calculated trend. For example, the share of the population over the age of 65 might increase, which would cause mortality rates to increase.

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Figure 2: Statewide Mortality Rates, DDS Consumers Case-Mix Adjusted Monthly Rates since December 2013

### **Key Findings:**



- Mortality rates were below the long-term trend from May 2015 through November 2015. During the month of December; however, the mortality rate rose to a level that is slightly above the long-term trend.
- Additional deaths will likely be included as mortality reports are completed over time and may increase the rate (see "More About These Data" on page 2).

### **More About These Data**

The line in Figure 2 is case-mix adjusted, accounting for changes in the consumer population. See the "More About These Data" section on page 3 for further details.

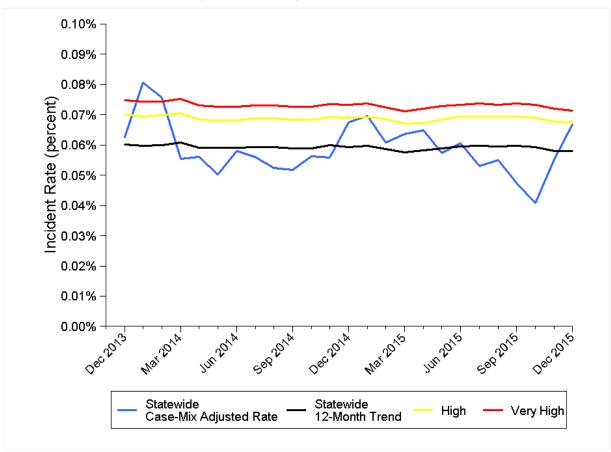


Figure 3: Statewide Mortality Rates, DDS Consumers Case-Mix Adjusted Monthly Rates since December 2013

# Key Findings:

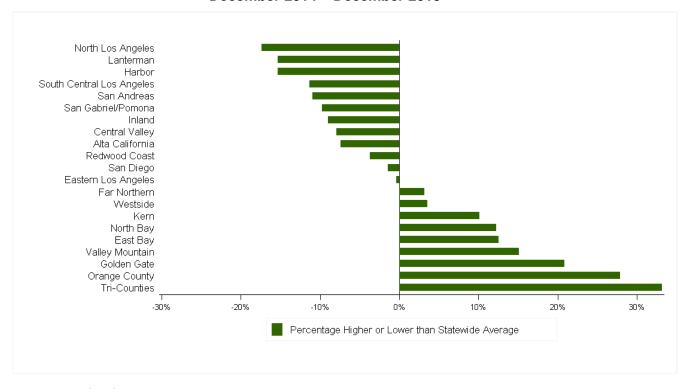
 Although the statewide mortality rate increased in the month of December, its long-term trend for most of the period as well as the monthly rate remained below the "high" threshold.

#### **More About These Data**

The updated mortality risk model includes all consumers age three years and over living in the community, regardless of residence status. Residence type (including no residential services) is included as a risk factor in calculating adjusted rates. Figure 3 identifies mortality incident rates that are unusually high and therefore classified as a "spike." A rate that rises above the yellow line in a given month will occur randomly in only one month out of 20 (less than 5% of the time) and is considered "High." A rate that rises above the red line in a given month will occur randomly less than 1% of the time. Rates above the red line, therefore, are very unlikely to be chance events and are classified as "Very High."

# **Mortality Incident Rate by Regional Center**

Figure 4: Mortality Rates by Regional Center Compared with Statewide Average
December 2014 – December 2015



# Key Findings:



- For December 2014–December 2015, the adjusted regional center mortality rates ranged from nearly 17% below to 33% above the statewide average.
- Golden Gate Regional Center (GGRC) no longer has the highest mortality rate. From June 2013 to June 2015, GGRC had the highest mortality rate. However, its rate fell substantially in 2015.
- Tri-Counties Regional Center (TCRC) now has the highest mortality rate, which was 33% above the statewide average. Its rate has increased over the last year.

#### **More About These Data**

The percentages above are case-mix adjusted, meaning that they account for differences in the characteristics of the consumer population over time. See page 3 for more details.

# Mortality Incident Rate by Age and Residential Setting

Table 2: Breakdown of Reported Deaths by Age and Residence Type DDS Consumers Age 3 and Up,

July-December 2015 Compared with Same Period Last Year

Characteristics in CMF	Share of Consumers (%)	Number of Deaths	Deaths/1,000 Jul-Dec 2015	Change from Jul-Dec 2014
Age				
3 to 13	31%	45	0.6	-29%
14 to 21	20%	62	1.2	-8%
22 to 31	19%	96	2.0	-5%
32 to 41	11%	82	3.1	12%
42 to 51	8%	97	4.7	-4%
52 to 61	7%	190	10.7	-2%
62+	4%	234	22.4	-16%
Residency Type				
Family Home	75%	258	1.4	-18%
CCF	9%	170	7.1	-5%
ILS/SLS	10%	104	4.1	-1%
SNF/ICF	3%	218	25.8	1%
Other	2%	56	11.6	44%

Bold indicates a statistically significant difference at the 95% confidence level.

# Key Findings:



- Consumers that are 3 to 13 years of age had a mortality rate that was 29% lower than in the same period last year. However, this change was not statistically significant.
- Mortality rates decreased by 18% for consumers living at home. This change was statistically significant.

#### **More About These Data**

The rates shown above are raw rates and do not account for changes in consumer characteristics. <a href="CCF">CCF</a>: Community Care Facility. <a href="ILS/SLS">ILS/SLS</a>: Independent Living Setting or Supported Living Setting. <a href="SNF/ICF">SNF/ICF</a>: Skilled Nursing Facility or Intermediate Care Facility. ICF includes ICF/Developmentally Disabled, ICF/Developmentally Disabled—Habilitation, and ICF/Developmentally Disabled—Nursing. <a href="Other: Settings">Other</a>: Settings such as hospitals, community treatment facilities, family home agencies, rehabilitation centers, psychiatric treatment centers, and correctional institutions. Statistical significance is tested based on a difference in binomial distribution.

# **Mortality Incident Rate by Diagnosis**

Table 3: Breakdown of Reported Deaths by Diagnosis DDS Consumers Age 3 and Up, July-December 2015 Compared with Same Period Last Year

Characteristics in CDER	Share of Consumers (%)	Number of Deaths	Deaths/1,000 Jul-Dec 2015	Change from Jul-Dec 2014
Diagnosis	, ,			
Mild to Moderate ID	48%	393	3.3	-11%
Profound to Severe ID	9%	264	11.5	0%
Unspecified ID	8%	60	3.2	33%
Cerebral Palsy	14%	235	6.6	0%
Autism	32%	40	0.5	108%
Epilepsy	15%	284	7.4	1%

**Bold** indicates a statistically significant difference at the 95% confidence level.

## **Key Findings:**

- Compared with the same period a year ago, the mortality rate was 108% higher for consumers with autism. This difference is statistically significant.
  - Additional analysis on this increase shows that the large difference is, in part, due to an unusually low rate in the July-December 2014 period.
     Still, 0.5 deaths per 1,000 consumers with autism is an unusually high rate for a July-December period, although January-June rates are commonly this high.
  - Of the 40 deaths, 16 occurred among consumers residing in the home of a parent or guardian. The remaining 24 deaths occurred among consumers residing in CCF (11), ILS (3), SLS (3), Nursing (3), ICF (2), and other settings (2).
  - Seven of these deaths occurred among individuals aged 62 or older. In the July-December 2014 comparison period, there were no deaths of individuals with autism aged 62 or older.
  - Among out-of-home consumers, the mortality rate for those with autism was higher for most resident types.
  - Mission will conduct additional review of these incidents.
- Compared with the same period a year ago, the mortality rate was 11% lower for consumers with mild to moderate ID. This change is not statistically significant.

#### **More About These Data**

The rates shown above are raw rates and do not account for changes in consumer characteristics. Most categories above are not mutually exclusive, as consumers may have more than one diagnosis. Percentages, therefore, do not add up to 100%.

# **Key Findings and Activities**

Mortality continues to be a critical focus for risk assessment and mitigation.

### **Discovery Activities:**

- Given GGRC's high mortality rate relative to the statewide rate, Mission conducted a series of technical assistance activities with GGRC regarding mortality SIRs during this semi-annual period. GGRC's mortality rate has been decreasing in 2015 and they now rank 19<sup>th</sup> out of the 21 regional centers for the year ending in December 2015.
- Mission will conduct additional review of the deaths among individuals with autism during this period to look for any systematic issues or concerns.

### Monitoring Activities:

- Follow-Up on Long-Term Increases in Mortality Rates: Each quarter, Mission distributes a report to each regional center summarizing trends and changes in mortality rates. These reports identify long-term changes in incident rates as well as monthly spikes. Mission has developed a method to follow up with regional centers experiencing long-term increases in mortality rates by analyzing their rates and proposing appropriate follow-up measures.
- Reporting Back by Regional Centers: Regional centers experiencing spikes
  in special incident rates provide structured feedback to DDS describing any
  follow-up measures taken to address the spikes. This information on how
  regional centers respond to long-term trends may be used to develop
  strategies on how to mitigate risk to consumers statewide. No Regional
  Centers experienced a spike in mortality SIRs this semi-annual period.
- TCRC had the highest mortality rate over the past 12 months. This was largely due to three monthly spikes (February, March, and June). These monthly spikes did not result in a quarterly spike and they were not unexpectedly high compared to the TCRC trend or that of the rest of the State. Their mortality rate has been trending down for the past 6 months. Mission will continue to monitor this closely.