

MORTALITY SPECIAL INCIDENTS

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

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INTRODUCTION AND BACKGROUND

This report summarizes mortality rates between July and December 2016 for DDS individuals 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 must report *any occurrence* of mortality whether or not it occurred while the individual was under vendored care.

This report summarizes mortality rates for DDS individuals between January and June 2016. There are two main goals of this report:

1. Update time trends in mortality rates from our earlier reports to include data through December 2016. 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. These data are augmented with three additional data sources maintained by DDS:

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

This report presents findings based on statistical analyses that measure an individual'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 Individuals,
July–December 2016 Compared with Previous Periods**

	Jul–Dec 2015 (Last Year)	Jan–Jun 2016 (Last Period)	Jul–Dec 2016 (This Period)
Number of Individuals	287,685	293,895	301,206
Number of Reported Deaths	899	1,091	938
Deaths per 1,000 Individuals	3.12	3.71	3.11

Key Findings:



- The number of deaths per 1,000 individuals is lower in July – December 2016 than in the last semi-annual period, at 3.11 compared with 3.71. This difference is statistically significant.
- The mortality rate is similar in this period to the same period one year ago.

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

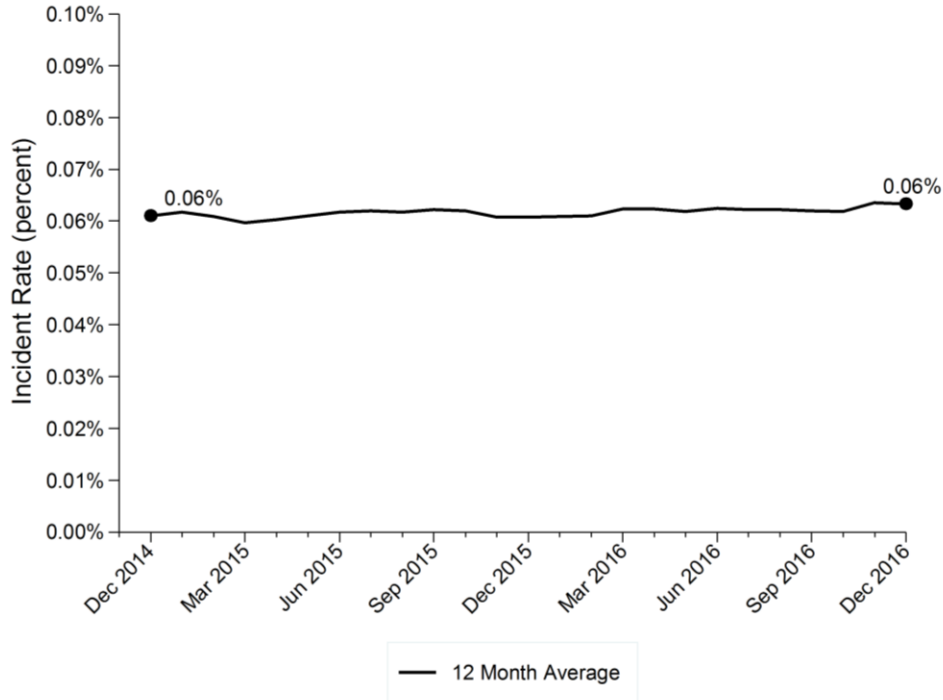
Number of Individuals refers to the average number of individuals served by regional centers in each month during the six-month period. This total is less than the number of all individuals served by regional centers at any time during the six-month period. The number of individuals reported for July-December 2015 and January-June 2016 is lower than previously reported due to data cleaning of records for non-active clients.

Deaths per 1,000 Individuals is calculated by dividing the number of reported deaths by the number of individuals, multiplied by 1,000.

The data used to generate this report were provided to Mission in February 2017. Although all deaths are reportable as special incidents, it may take time for deaths among individuals 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

**Figure 1: Mortality Incidents, Statewide Case-Mix Adjusted Monthly Trend
DDS Individuals since December 2014**



Key Findings:

- Adjusted for client characteristics, the 12-month average monthly mortality rate has increased slightly since the last semi-annual period, going from 0.0624% (0.633 per 1000) as of June 2016 to 0.0633% in December 2016.
- In December 2016, the 12-month moving average rate was somewhat higher than the 0.0617% as of December 2014.

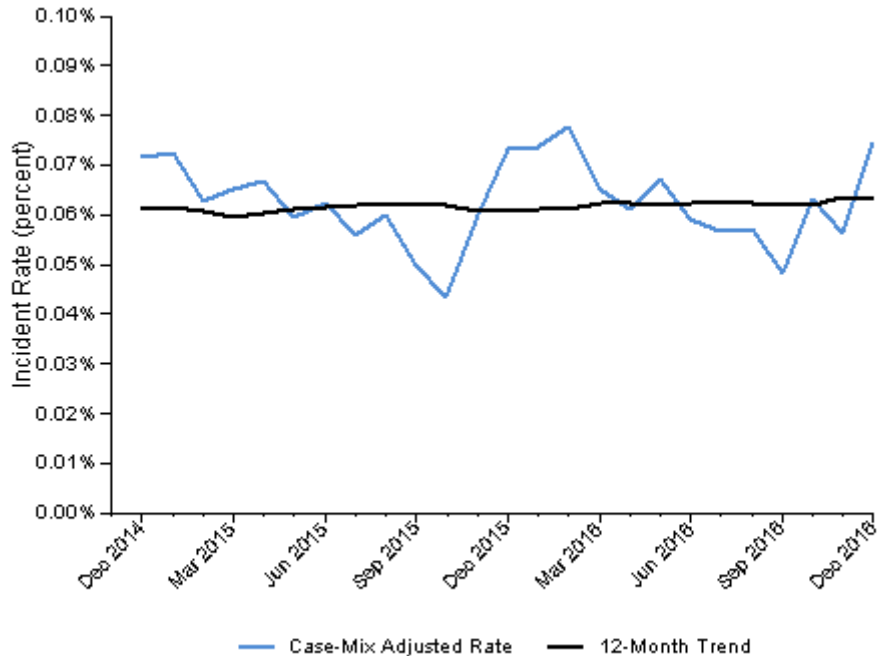
More About These Data

The line in Figure 1 represents a 12-month moving average for all DDS individuals. 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 population over time. This approach, called “case-mix adjustment,” controls for individual 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.

Trend of Mortality Incident Rate

**Figure 2: Statewide Mortality Rates, DDS Individuals
Case-Mix Adjusted Monthly Rates since December 2014**



Key Findings:

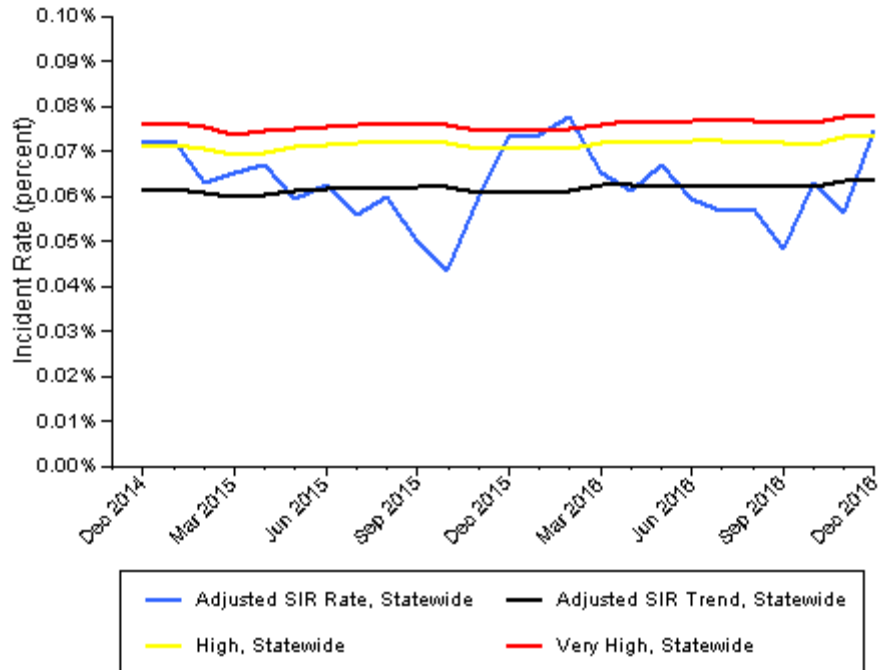
- Mortality rates are commonly lower in the summer and fall and then higher in the winter and spring. The decline in summer of 2016 was smaller than during the same period in 2015.
- Mortality rates were below the long-term trend for most of this semi-annual period. The rate was above the trend line in December 2016 at 0.0746%.
- 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 population. See the “More About These Data” section on page 3 for further details.

Mortality Incident Rate over Time

**Figure 3: Statewide Mortality Rates, DDS Individuals
Case-Mix Adjusted Monthly Rates since December 2014**



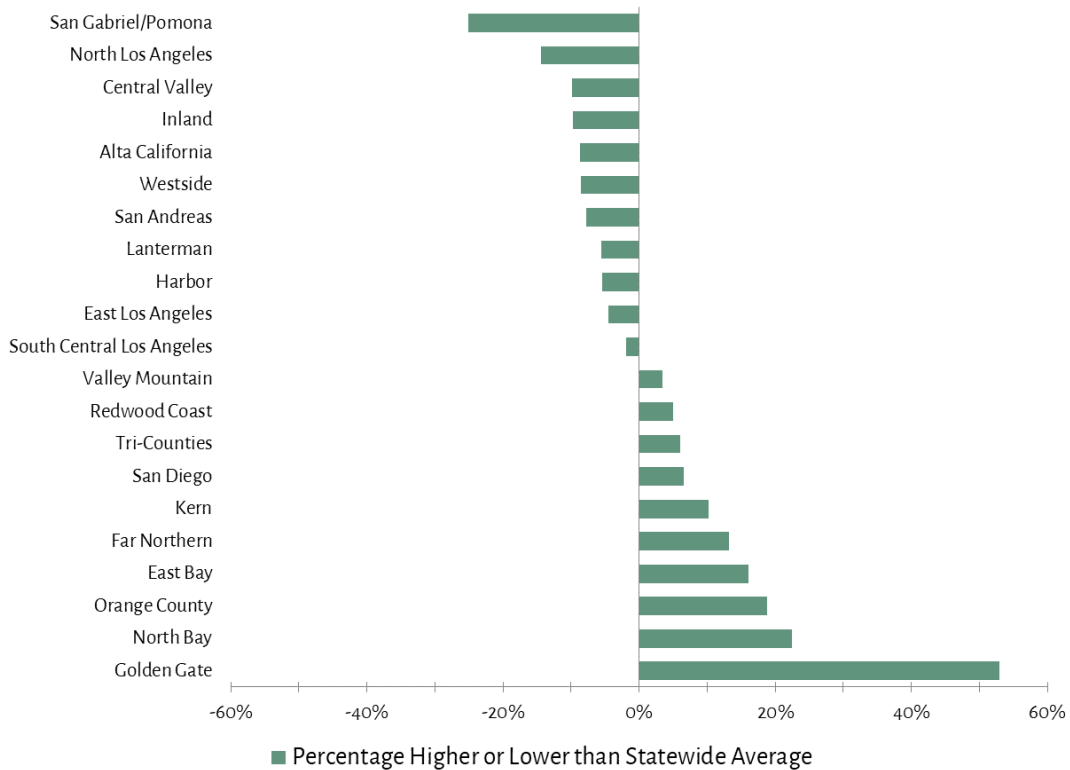
Key Findings:

- The statewide mortality rate has been near or below the long term trend from July – November 2016.
- The mortality rate was slightly above the “high” threshold in December 2016.

The updated mortality risk model includes all individuals age three years and older 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
January 2016 – December 2016**



Key Findings:



- For January–December 2016, the adjusted regional center mortality rates ranged from about 25% below to more than 53% above the statewide average.
- Golden Gate Regional Center (GGRC) has had the highest mortality rate among regional centers for the last two semi-annual periods. GGRC’s mortality rate was on average, 1.5 times the state rate in the year prior to December 2016.
 - Recent technical assistance to GGRC indicates that their high mortality rate may reflect data quality issues that affect the case-mix adjustment. Please see the Monitoring Activities section on page 9 for more information.

More About These Data

The percentages above are case-mix adjusted, meaning that they account for differences in the characteristics of the 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 Individuals Age 3 and Up,
July–December 2016 Compared with Same Period Last Year**

Characteristics in CMF	Share of Individuals (%)	Number of Deaths	Deaths/1,000 Jul–Dec 2016	Change from Jul–Dec 2015
Age				
3 to 13	31%	71	0.9	30%
14 to 21	20%	58	1.1	-14%
22 to 31	20%	95	1.9	-7%
32 to 41	11%	83	3.0	-5%
42 to 51	8%	93	4.6	-8%
52 to 61	7%	214	11.8	4%
62+	4%	278	24.8	2%
Residency Type				
Family Home	76%	308	1.5	0%
CCF	9%	170	7.2	-2%
ILS/SLS	10%	117	4.5	9%
SNF/ICF	3%	246	29.5	12%
Other	2%	51	10.2	-14%

Key Findings:

- The mortality rate for individuals ages 3 to 13 is 30% higher in this semi-annual period than in the same period last year. However, this difference is not statistically significant.
- The mortality rate for individuals ages 62 and older increased by 2% after a 16% drop from July – December 2014 to July – December 2015.
- Mortality rates decreased by 14% for individuals in “Other” residence types, after an increase of 44% from July – December 2014 to July–December 2015.

The rates shown above are raw rates and do not account for changes in individual characteristics. CCF: Community Care Facility. ILS/SLS: Independent Living Setting or Supported Living Setting. SNF/ICF: Skilled Nursing Facility or Intermediate Care Facility. ICF includes ICF/Developmentally Disabled, ICF/Developmentally Disabled–Habilitation, and ICF/Developmentally Disabled–Nursing. Other: 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 Individuals Age 3 and Up, July-December 2016 Compared with Same Period Last Year

Characteristics in CDER	Share of Individuals (%)	Number of Deaths	Deaths/1,000 Jul–Dec 2016	Change from Jul–Dec 2015
Diagnosis				
Mild to Moderate ID	46%	473	3.9	12%
Profound to Severe ID	9%	276	12.1	0%
Unspecified ID	8%	53	2.7	-22%
Cerebral Palsy	14%	271	7.6	9%
Autism	34%	32	0.4	-27%
Epilepsy	15%	307	7.9	3%

Key Findings:

- The mortality rate is 27% lower for individuals with Autism than in the same period last year. The rate for individuals with Unspecified ID is 22% lower than the July – December 2015 semi-annual period.
- The mortality rate for individuals with Mild to Moderate ID increased by 12% compared with the same period last year.
- These changes were not statistically significant.

The rates shown above are raw rates and do not account for changes in individual characteristics. Most categories above are not mutually exclusive, as individuals 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.

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 individuals statewide. No Regional Centers experienced a spike in mortality SIRs this semi-annual period.
- Mission continues to work with GGRC regarding their mortality data. After analyzing mortality data for GGRC and the rest of the state, Mission concluded that after accounting for age differences between the GGRC population and the state, the regional center does not appear to have a substantively higher mortality rate. After adjusting for other risk characteristics, the rate appears high because data in the Client Development Evaluation Report (CDER) and in Special Incident Reports (SIRs) indicate that chronic health conditions, special incidents (other than mortality), and other risk factors are much less prevalent than expected given the older caseload at GGRC. In response to the findings that Mission presented, GGRC will take steps to make certain that it reports CDER and SIR data as completely and as accurately as is feasible. Mission will monitor the mortality rate at GGRC over the coming 12 months, for evidence of increased reporting on the CDER and of special incidents.