MORTALITY SPECIAL INCIDENTS

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

JANUARY-JUNE 2016
INTRODUCTION AND BACKGROUND

This report summarizes mortality rates between January and June 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 (SIR), 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.

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 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 June 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 since 2002. 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, January–June 2016 Compared with Previous Periods

<table>
<thead>
<tr>
<th></th>
<th>Jan–Jun 2015 (Last Year)</th>
<th>Jul–Dec 2015 (Last Period)</th>
<th>Jan–Jun 2016 (This Period)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Individuals</td>
<td>280,639</td>
<td>287,763</td>
<td>293,959</td>
</tr>
<tr>
<td>Number of Reported Deaths</td>
<td>1,020</td>
<td>891</td>
<td>1,036</td>
</tr>
<tr>
<td>Deaths per 1,000 Individuals</td>
<td>3.63</td>
<td>3.10</td>
<td>3.52</td>
</tr>
</tbody>
</table>

**Key Findings:**

- The number of deaths per 1,000 individuals is higher in this period than in the July – December 2015 period, at 3.52 compared with 3.10. This difference is statistically significant.
- The mortality rate is lower in the January – June 2016 period than in the same period one year ago.

### More About These Data

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 2015 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 August 2016. 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.
Figure 1: Mortality Incidents, Statewide Case-Mix Adjusted Monthly Trend
DDS Individuals since June 2014

Key Findings:
- The moving average is slightly higher than it was two years ago, at 0.0605% compared to 0.0599%. Due to rounding, this is not shown on the graph.
- The trend in the statewide average monthly mortality rate has remained relatively constant since June 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.
Key Findings:

- Mortality rates were well above the long-term trend from December 2015 to February 2016, including a recent high of 0.075% in February 2016. After this spike, the rate once again resembled 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 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 June 2014

**Key Findings:**

- The statewide mortality rate was at a rate above the “high” threshold in January 2016 and slightly above the “very high” threshold in February 2016.

- The mortality rate stayed close to the long-term trend rate, about 0.0605%, from March to May 2016, but fell below to 0.053% in June 2016.

**More About These Data**

The updated mortality risk model includes all individuals 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
June 2015 – June 2016

Key Findings:

- For June 2015–June 2016, the adjusted regional center mortality rates ranged from about 25% below to nearly 40% above the statewide average.

- In the last semi-annual period, Tri-Counties Regional Center (TCRC) had the highest mortality rate, at 33% above the statewide average. TCRC’s rate fell substantially in the current period.

- Golden Gate Regional Center (GGRC) now has returned to having the highest mortality rate. GGRC had the highest mortality rate among the regional centers from July 2013 to June 2015. 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,**
**January–June 2016 Compared with Same Period Last Year**

<table>
<thead>
<tr>
<th>Characteristics in CMF</th>
<th>Share of Individuals (%)</th>
<th>Number of Deaths</th>
<th>Deaths/1,000 Jan–Jun 2016</th>
<th>Change from Jan–Jun 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 to 13</td>
<td>31%</td>
<td>62</td>
<td>0.8</td>
<td>-8%</td>
</tr>
<tr>
<td>14 to 21</td>
<td>20%</td>
<td>66</td>
<td>1.3</td>
<td>10%</td>
</tr>
<tr>
<td>22 to 31</td>
<td>19%</td>
<td>85</td>
<td>1.7</td>
<td>-32%</td>
</tr>
<tr>
<td>32 to 41</td>
<td>11%</td>
<td>89</td>
<td>3.3</td>
<td>-17%</td>
</tr>
<tr>
<td>42 to 51</td>
<td>8%</td>
<td>116</td>
<td>5.7</td>
<td>-6%</td>
</tr>
<tr>
<td>52 to 61</td>
<td>7%</td>
<td>229</td>
<td>12.7</td>
<td>12%</td>
</tr>
<tr>
<td>62+</td>
<td>4%</td>
<td>337</td>
<td>31.2</td>
<td>2%</td>
</tr>
<tr>
<td>Residency Type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Home</td>
<td>76%</td>
<td>296</td>
<td>1.5</td>
<td>-20%</td>
</tr>
<tr>
<td>CCF</td>
<td>9%</td>
<td>241</td>
<td>10.2</td>
<td>13%</td>
</tr>
<tr>
<td>ILS/SLS</td>
<td>10%</td>
<td>124</td>
<td>4.8</td>
<td>12%</td>
</tr>
<tr>
<td>SNF/ICF</td>
<td>3%</td>
<td>252</td>
<td>29.9</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>71</td>
<td>14.6</td>
<td>55%</td>
</tr>
</tbody>
</table>

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

### Key Findings:
- Individuals that are 22 to 31 years of age had a mortality rate that was 32% lower than in the same period last year. This change was statistically significant.
- Mortality rates decreased by 20% for individuals living at home. This was a statistically significant change.
- For individuals in “Other” residences, about 2% of all individuals, mortality rates increased 55% from the same period last year. This difference was statistically significant.

### More About These Data
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, January-June 2016 Compared with Same Period Last Year

<table>
<thead>
<tr>
<th>Characteristics in CDER</th>
<th>Share of Individuals (%)</th>
<th>Number of Deaths</th>
<th>Deaths/1,000 Jan–Jun 2016</th>
<th>Change from Jan–Jun 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild to Moderate ID</td>
<td>47%</td>
<td>502</td>
<td>4.1</td>
<td>-1%</td>
</tr>
<tr>
<td>Profound to Severe ID</td>
<td>9%</td>
<td>314</td>
<td>13.7</td>
<td>-2%</td>
</tr>
<tr>
<td>Unspecified ID</td>
<td>8%</td>
<td>53</td>
<td>2.7</td>
<td>13%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>14%</td>
<td>275</td>
<td>7.7</td>
<td>0%</td>
</tr>
<tr>
<td>Autism</td>
<td>33%</td>
<td>44</td>
<td>0.5</td>
<td>1%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>15%</td>
<td>333</td>
<td>8.6</td>
<td>-5%</td>
</tr>
</tbody>
</table>

**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 13% higher for individuals with Unspecified ID. Compared with the same period a year ago, the mortality rate was 5% lower for individuals with an Epilepsy diagnosis. These changes are not statistically significant.

- Last period’s semi-annual report found a 108% increase in the mortality rate among individuals with an Autism diagnosis compared to the prior year. Mission reviewed all of the mortality SIRs for individuals with autism as well as the longer-term pattern in mortality rates. This review found no systemic issues in the July-December 2015 mortalities. The comparison period (July-December 2014) showed an unusually low rate. The rates for the January to June 2015 and January to June 2016 periods are consistent with mortality rates observed over time for individuals with Autism.

**More About These Data**

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.

**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 is back to ranking the highest out of the 21 regional centers for the year ending in June 2016.

- Mission conducted additional review of the deaths among individuals with autism during this period to look for any systematic issues or concerns. This review did not find any consistent patterns. Review of data over a number of years of mortality data for these individuals showed that the July-December 2014 mortality rate was unusually low.

**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.

- TCRC’s mortality rate has been trending down for the past 12 months. From July 2015-June 2016, TCRC ranks 14th out of the 21 regional centers.

- 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 CDER and in 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.