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

JULY – DECEMBER 2013
INTRODUCTION AND BACKGROUND

This report summarizes mortality rates between July and December 2013 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 (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 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 develops this report along with several others under a risk management contract with DDS.

1. Update time trends in mortality rates from our earlier reports to include data through December 2013. 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.
3. The Purchase of Service File.

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.
The unadjusted mortality rate decreased in this period.

Table 1: Reported Deaths for DDS Consumers, July–December 2013 Compared to Previous Periods

<table>
<thead>
<tr>
<th></th>
<th>Jul-Dec 2012 (Last Year)</th>
<th>Jan-Jun 2013 (Last Period)</th>
<th>Jul-Dec 2013 (This Period)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Consumers</td>
<td>255,197</td>
<td>259,416</td>
<td>264,649</td>
</tr>
<tr>
<td>Number of Reported Deaths</td>
<td>875</td>
<td>933</td>
<td>784</td>
</tr>
<tr>
<td>Deaths per 1,000 Consumers</td>
<td>3.43</td>
<td>3.60</td>
<td>2.96</td>
</tr>
</tbody>
</table>

**Key Findings:**

- The number of deaths per 1,000 consumers was lower this period than last period (January to June 2013) at 2.96 compared to 3.60. The difference is statistically significant.
- The mortality rate in this period was also lower and the difference is statistically significant from the same period one year ago.
- Additional deaths will likely be included as mortality reviews are completed over time.

**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 per day by regional centers 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.

**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 Analytics in February 2014. 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.
Controlling for consumer characteristics, the statewide mortality rate has declined in this period.

Figure 1: Mortality Incidents, Statewide Case-Mix Adjusted Monthly Trend
DDS Consumers since December 2011

Key Findings:

- The trend in the statewide case-mix adjusted monthly mortality rate declined steadily in this period, continuing a downward trend that began in May 2013.
- In December 2013, the long-term trend in the statewide mortality rate reached its lowest point in the last two years.

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.
Monthly mortality rates were below the long-term trend.

Figure 2: Statewide Mortality Rates, DDS Consumers
Case-Mix Adjusted Monthly Rates since December 2011

Key Findings:

- The statewide mortality rate was at or below the long-term trend for each month in this period, with particularly low rates from July through October 2013.

- There was a more noticeable difference between high winter rates and lower spring and summer rates this year compared to last year, in part because of lower rates in the autumn of 2013.

- Additional deaths will likely be included as mortality reports are received by regional centers 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.
The monthly mortality rate did not approach the high threshold.

Key Findings:
- The statewide adjusted mortality rate was below the long-term trend for most of this period. Monthly trend rates remained below the established thresholds for unexpectedly high rates.

More About These Data
The updated mortality risk model includes all consumers age three 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. This graph 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 twenty (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.”
Variation between regional centers was similar to previous periods.

Figure 4: Mortality Rates by Regional Center Compared to Statewide Average
December 2012 – December 2013

Key Findings:

- For December 2012 to 2013, the adjusted regional center mortality rates ranged from 21% below to 35% above the statewide average.

- No regional center stood out as especially high or low in this period. The variation in rates among regional centers is consistent with the distribution seen in previous periods.

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.
Changes in mortality rates were statistically significant for young children and consumers in SNF/ICF and family home settings.

Table 2: Breakdown of Reported Deaths by Age and Residence Type
DDS Consumers Age 3 and Up, July–December 2013 Compared to Same Period Last Year

<table>
<thead>
<tr>
<th>Characteristics in CMF</th>
<th>Share of Consumers</th>
<th>Number of Deaths</th>
<th>Deaths/1,000 Jul-Dec 2013</th>
<th>Change from Jul-Dec 2012</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>45</td>
<td>0.6</td>
<td>-36%</td>
</tr>
<tr>
<td>14 to 21</td>
<td>20%</td>
<td>49</td>
<td>1.0</td>
<td>-17%</td>
</tr>
<tr>
<td>22 to 31</td>
<td>19%</td>
<td>78</td>
<td>1.8</td>
<td>-14%</td>
</tr>
<tr>
<td>32 to 41</td>
<td>10%</td>
<td>54</td>
<td>2.2</td>
<td>-22%</td>
</tr>
<tr>
<td>42 to 51</td>
<td>9%</td>
<td>103</td>
<td>4.9</td>
<td>-20%</td>
</tr>
<tr>
<td>52 to 61</td>
<td>7%</td>
<td>172</td>
<td>10.3</td>
<td>-17%</td>
</tr>
<tr>
<td>62+</td>
<td>4%</td>
<td>230</td>
<td>25.8</td>
<td>0%</td>
</tr>
<tr>
<td>Residency Type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Home</td>
<td>74%</td>
<td>225</td>
<td>1.3</td>
<td>-24%</td>
</tr>
<tr>
<td>CCF</td>
<td>10%</td>
<td>184</td>
<td>7.7</td>
<td>11%</td>
</tr>
<tr>
<td>ILS/SLS</td>
<td>10%</td>
<td>83</td>
<td>3.4</td>
<td>-8%</td>
</tr>
<tr>
<td>SNF/ICF</td>
<td>4%</td>
<td>182</td>
<td>21.5</td>
<td>-20%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>57</td>
<td>13.0</td>
<td>1%</td>
</tr>
</tbody>
</table>

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

**Key Findings:**

- The raw mortality rate was lower than the same period one year ago for all but the oldest consumers. The rate declined 36% for children aged 3 to 13, the one age group with a statistically significant decline.
- Consumers in SNF/ICF and family home settings had lower mortality rates than one year ago; the difference is statistically significant.

**More About These Data**

The rates shown above are raw rates and do not account for changes in consumer characteristics. **CCF:** Community Care Facilities. **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, rehabilitation centers, psychiatric treatment centers, and correctional institutions. Statistical significance is tested based on a difference in binomial distribution.
Mortality rates declined for all diagnosis groups compared to the same period last year.

Table 3: Breakdown of Reported Deaths by Diagnosis
DDS Consumers Age 3 and Up, July–December 2013 Compared to Same Period Last Year

<table>
<thead>
<tr>
<th>Characteristics in CDER</th>
<th>Share of Consumers</th>
<th>Number of Deaths</th>
<th>Deaths/1000 Jul-Dec 2013</th>
<th>Change from Jul-Dec 2012</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>50%</td>
<td>380</td>
<td>3.3</td>
<td>-5%</td>
</tr>
<tr>
<td>Profound to Severe ID</td>
<td>10%</td>
<td>253</td>
<td>10.9</td>
<td>-11%</td>
</tr>
<tr>
<td>Unspecified ID</td>
<td>7%</td>
<td>29</td>
<td>1.7</td>
<td>-43%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>15%</td>
<td>195</td>
<td>5.6</td>
<td>-26%</td>
</tr>
<tr>
<td>Autism</td>
<td>27%</td>
<td>20</td>
<td>0.3</td>
<td>-46%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>16%</td>
<td>251</td>
<td>6.6</td>
<td>-23%</td>
</tr>
</tbody>
</table>

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

Key Findings:

- The fall in mortality rates compared to a year ago occurred across all diagnosis groups.
- Compared to the same period a year ago, there were statistically significant decreases in the mortality rate for four groups: unspecified ID, cerebral palsy, autism, and epilepsy.

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%.
Mission Analytics conducts discovery activities and other support when monitoring indicates rises in mortality SIRs.

Although mortality rates have fallen in the most recent period, mortality continues to be a critical focus for risk assessment and mitigation.

**Discovery Activities:**

- There was no statistically significant statewide increase in mortality rates during this period. Therefore, no additional discovery activities are planned.

**Monitoring Activities:**

- *Follow-Up on Long-Term Increases in Mortality Rates:* Each quarter, Mission Analytics 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 Analytics has developed a method for following up with regional centers experiencing long-term increases in mortality rates, 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 spike. This information on how regional centers respond to long-term trends may be used to develop strategies for how to mitigate risk to consumers statewide.