

MORTALITY SPECIAL INCIDENTS

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

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This report summarizes mortality rates between July and December 2009 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.

Acumen develops this report along with several others under a risk management contract with DDS.

This report summarizes mortality rates for DDS consumers between January and June 2010. The two main goals of this report are:

1. Update time trends in mortality rates from our earlier reports to include data through June 2010. 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 analyze the incident reports associated with the spike. By doing so, we can detect patterns that may lead to strategies to prevent similar events in the future. There were no spikes in the Jan-June 2010 period, but a spike now appears for December 2009 that did not appear earlier.

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), and
3. The Early Start Report (ESR).

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 has been stable over time.

Table 1: Reported Deaths for DDS Consumers
DDS Consumers, January-June 2010 Compared to Previous Periods

	Jan-Jun 2009 (Last Year)	Jul-Dec 2009 (Last Period)	Jan-Jun 2010 (This Period)
Number of Consumers	225,475	228,756	226,987
Number of Reported Deaths	804	830	778
Deaths per 1000 Consumers	3.56	3.63	3.43

Key Findings:

- Between January and June 2010, the number of deaths per 1000 consumers was somewhat lower than in the previous period.
- When late reported deaths are included, we expect this period's rate to be comparable to the same period last year (Jan-Jun 2009).
- Mortality rates have been very stable over time, with minor decreases in summer months.

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).

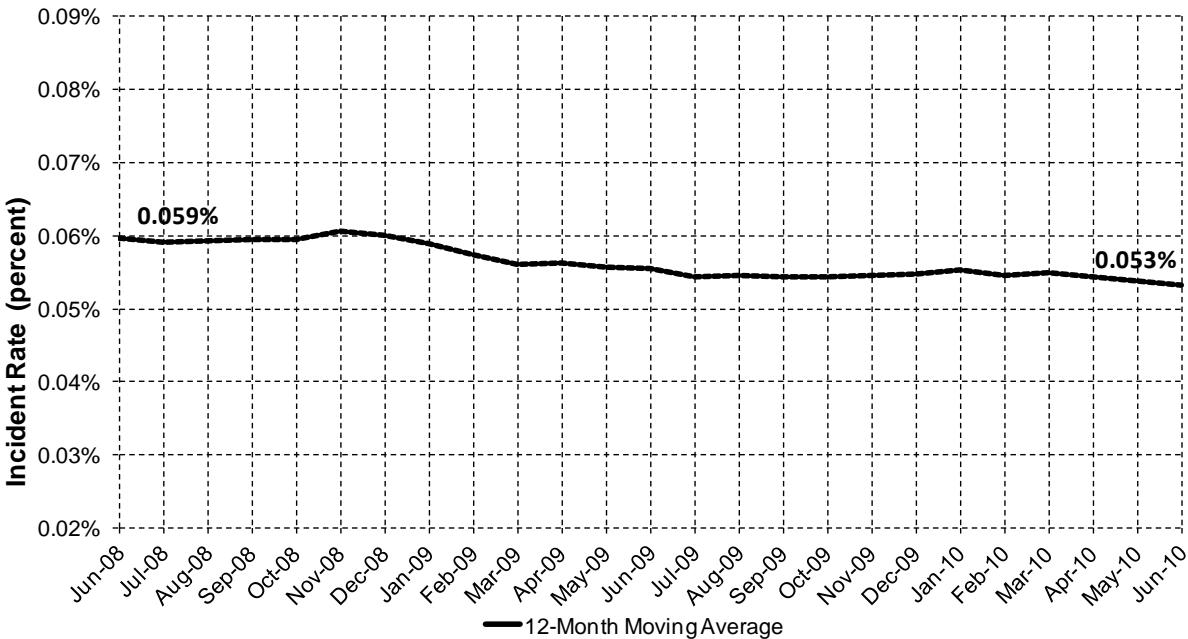
Number of Consumers refers to the average number of consumers served by regional centers in each month during the six-month period. This total is less than the number of consumers ever served by regional centers during the six-month period.

Deaths per 1000 Consumers is calculated by dividing the number of reported deaths by the number of consumers, multiplied by 1000. Note that this total includes Early Start consumers, who were not included in counts in previous reports.

The data used to generate this report were provided to Acumen in July 2010. 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, statewide mortality rates have declined over the past two years.

Figure 1: Mortality Incidents, Statewide Case-Mix Adjusted Monthly Trend DDS Consumers since June 2008



Key Findings:

- The trend in statewide average monthly mortality rates has decreased over the past two years, from 0.059% in June 2008 to 0.053% in June 2010.
- Much of this decrease reflects a downward shift over FY 2008-2009. Prior to that time, the trend in the mortality rate was relatively steady around 0.059%. During FY 2009-2010, the trend has been consistently lower.

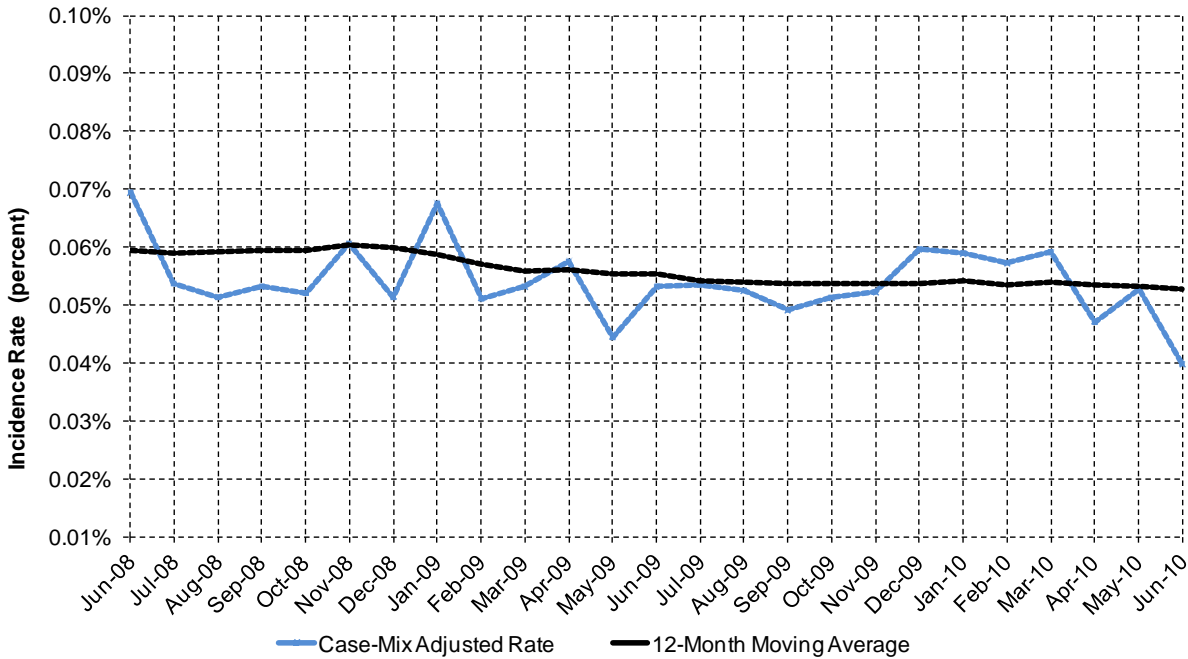
More About These Data

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.

Mortality rates were somewhat elevated between December 2009 and March 2010 but lower in recent months.

**Figure 2: Statewide Mortality Rates, DDS Consumers
Case-Mix Adjusted Monthly Rates since June 2008**



Key Findings:

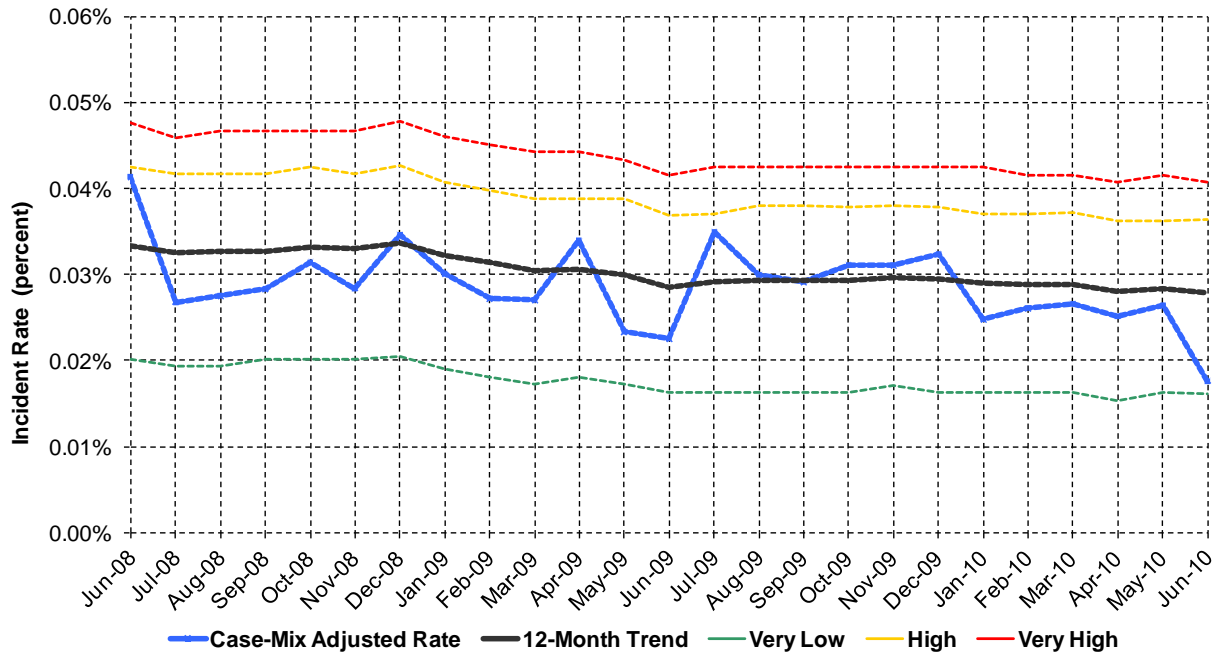
- After peaking in December, monthly mortality rates (blue line) continued to be above the long-term average (black line) until April 2010, when they returned to lower spring and summer rates.
- Mortality rates early in 2010 were higher than during the same period a year ago. We review these data in greater detail in the following pages.
- Additional deaths are likely to be included as mortality reviews are completed over time and will 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.

For the in-home population, mortality rates were below the long-term average from January to June 2010.

Figure 3: Statewide Mortality Rates, In-home Consumers Case-Mix Adjusted Monthly Rates since June 2008



Key Findings:

- Mortality rates for the in-home population were below the long-term average during each month from January through June 2010.

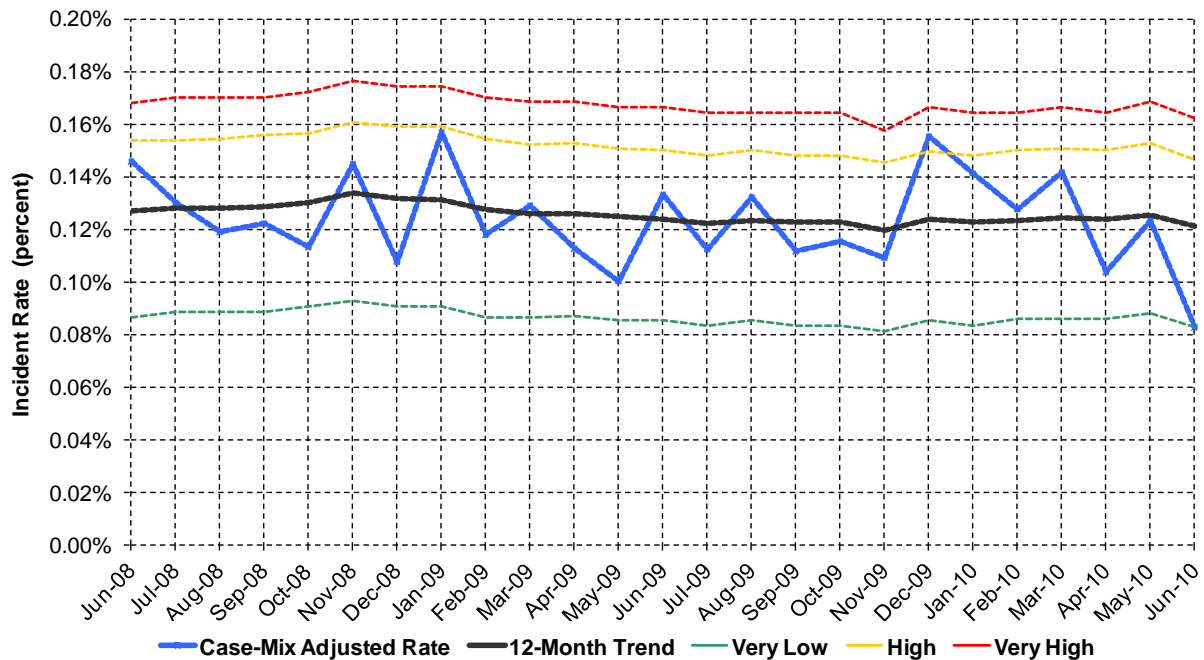
More About These Data

In-home Consumers are defined as individuals residing in their own home or the home of a parent, extended family member, or guardian, and who do not receive Supported Living Services or Independent Living Services.

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.”

The higher mortality rates in early 2010 occurred among the out-of-home population, following a spike in December 2009.

Figure 4: Statewide Mortality Rates, Out-of-home Consumers Case-Mix Adjusted Monthly Rates since June 2008



Key Findings:



- The December 2009 mortality rate among out-of-home consumers crossed the “high” threshold. This spike was not observed in earlier data because it includes some late reported deaths.
- There were no spikes observed for the out-of-home population in the January to June 2010 period.

Follow-Up Activities:

- The December 2009 spike reflects increases at several regional centers, none of which represented a significant spike alone. We will continue to monitor these rates, but no further follow-up is planned.

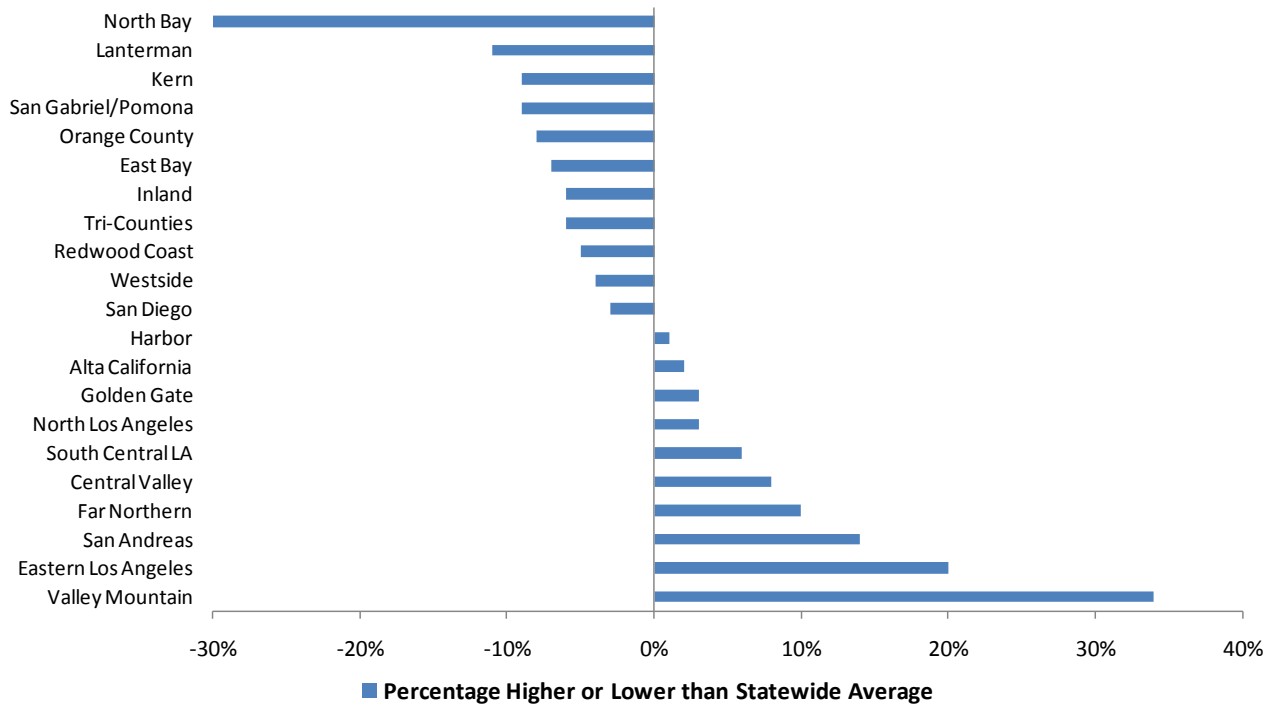
More About These Data

Out-of-home Consumers are defined as individuals residing in community settings such as licensed residential services, Family Home Agency (FHA), Supported Living Services (SLS), or Independent Living Services (ILS).

The yellow and red lines in this graph identify whether a rate is unusually high (a spike or statistically significant increase). See the “More About These Data” section on page 5 for further details.

Except for Valley Mountain and North Bay, variation in mortality rates among the 21 regional centers has declined.

**Figure 5: Mortality Rates by Regional Center Compared to Statewide Average
June 2009 – June 2010**



Key Findings:



- Since the previous semi-annual period (July-December 2009), North Bay Regional Center moved from seventh lowest to lowest in its mortality rate.
- Valley Mountain Regional Center (VMRC) continues to have the highest mortality rates, at 34% above the statewide average. However, VMRC did not experience a spike in mortality, and its mortality rate has been falling in recent quarters. This reflects approximate 10 more deaths over the course of a year compared to what would have been expected given the statewide rate.
- Outside of these two extremes, regional center variation on mortality ranges from 10% below the statewide average to 20% above.

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.

Breaking rates down by age and residence, mortality rates increased for consumers aged 22 to 31 or in Community Care.

**Table 2: Breakdown of Reported Deaths by Age and Residence Type
DDS Consumers Aged 3 and Up, Jul-Dec 2009 Compared to Same Period Last Year**

Characteristics in CDER	Share of Consumers	Number of Deaths	Deaths/1000 Jan-Jun 2010	Change from Jan-Jun 2009
Age				
3 to 13	31%	62	1.0	21%
14 to 21	21%	50	1.2	-24%
22 to 31	17%	93	2.7	27%
32 to 41	11%	74	3.4	1%
42 to 51	10%	107	5.2	-6%
52 to 61	7%	154	11.3	-5%
62+	3%	185	28.2	-15%
Residency Type				
Family Home	72%	228	1.6	-5%
CCF	12%	179	7.7	14%
ILS/SLS	10%	88	4.2	-5%
SNF/ICF	4%	193	23.3	-8%
Other	2%	37	10.2	3%

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

Key Findings:

- Compared to the same period last year, raw mortality rates increased by more than 20% for consumers aged 22-31, a statistically significant increase. Other changes in raw rates are not statistically significant.
- Rates decreased in all residence categories except for consumers living in Community Care Facilities (CCF), where the rate increased by 14%, a statistically significant increase.

Follow-Up Activities:

- Acumen will monitor the increases in CCFs and among individuals aged 22 to 31.

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.

Breaking rates down by diagnosis, mortality rates decreased for most groups.

**Table 3: Breakdown of Reported Deaths by Diagnosis
DDS Consumers Aged 3 and Up, Jan-Jun 2010 Compared to Same Period Last Year**

Characteristics in CDER	Share of Consumers	Number of Deaths	Deaths /1000 Jan-Jun 2010	Change from Jan-Jun 2009
Diagnosis				
Mild to Moderate MR	54%	349	3.3	-5%
Profound to Severe MR	12%	268	11.8	6%
Unspecified MR	7%	28	2.0	-26%
Cerebral Palsy	17%	205	6.3	-3%
Autism	22%	24	0.5	-9%
Epilepsy	18%	259	7.2	6%

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

Key Findings:

- Compared to the same period last year, raw mortality rates decreased in all diagnosis categories except consumers with epilepsy and consumers with profound to severe mental retardation. These raw rates are not adjusted to reflect differences in risk of mortality by group.
- None of the changes relative to last year is statistically significant. No follow-up activities are planned.

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%.

Acumen is expanding discovery activities for mortality SIRs and working to improve cause of death reporting.

Although mortality rates have fallen substantially 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, Acumen 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. Acumen has developed a method to follow-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 on how to mitigate risk to consumers statewide.

System Improvement Activities:

- *Mortality Review Guidelines:* Acumen is continuing to support regional centers in the development of improved mortality review methods, following the Mortality Review Guidelines for California's regional centers, developed in partnership with DDS and the regional centers.