

MORTALITY SPECIAL INCIDENTS

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

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Acumen, LLC

Acumen, LLC

500 Airport Blvd., Suite 365

Burlingame, CA 94010

This report summarizes mortality rates between January and June 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 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 2009. The two main goals of this report are:

1. Update time trends in mortality rates from our earlier reports to include data through June 2009. DDS can use this report to

observe long term trends in statewide mortality rates, comparing the most recent 6-month period to the three previous 6-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 reported spikes in the most recent 6-month period (Jan-Jun 2009).

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.

Unadjusted mortality rates increased compared to last period, but were well below rates for the same period last year.

Table 1: Reported Deaths for DDS Consumers

	Jan-Jun 2008 (Last Year)	Jul-Dec 2008 (Last Period)	Jan-Jun 2009 (This Period)
Number of Consumers	193,428	195,104	195,664
Number of Reported Deaths	905	730	774
Deaths per 1000 Consumers	4.68	3.74	3.96

Key Findings:



- Between January and June 2009, the number of deaths per 1000 consumers was 6% higher than it was during the previous 6-month period.
- Mortality rates are typically higher during winter. We have observed winter increases in statewide mortality rates during each of the past four years.
- Compared to the same period last year (Jan-Jun 2008), the number of deaths per 1000 consumers fell by 15%.

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).

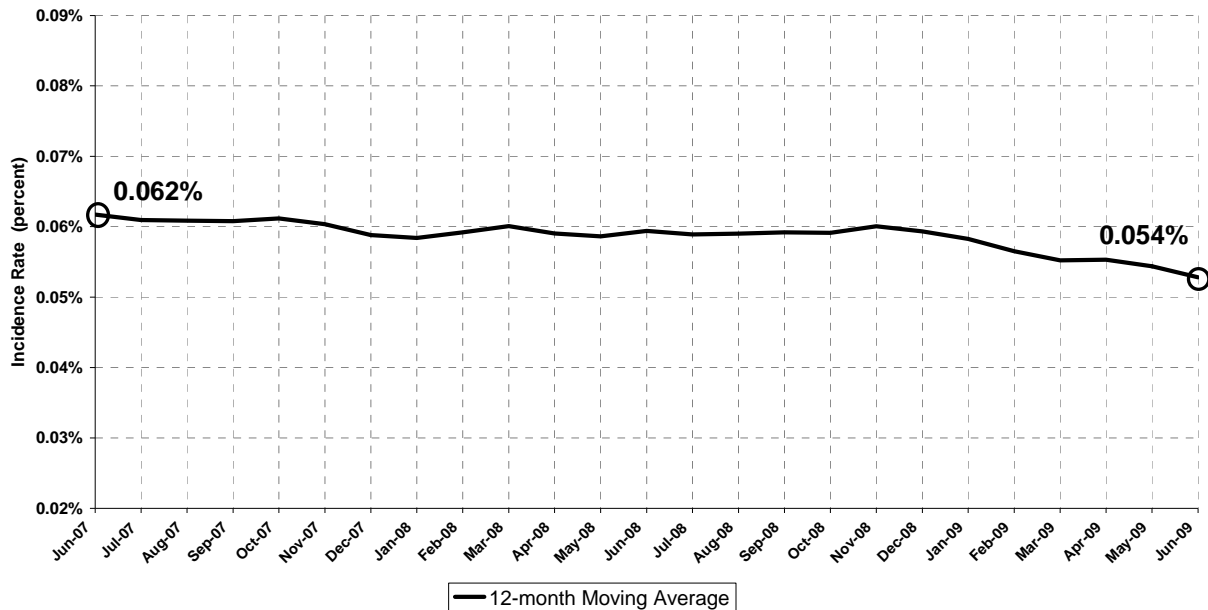
Number of Consumers refers to the average number of consumers served by regional centers in each month during the 6-month period. Note that this total is less than the number of consumers ever served by regional centers during the 6-month period.

Deaths per 1000 Consumers is calculated by dividing the number of reported deaths by the number of consumers, multiplied by 1000.

The data used to generate this report were provided to Acumen in August 2009. 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 for the most recent period may rise slightly as additional mortality data are reported to DDS.

Controlling for consumer characteristics, there has been a slow, long-term decline in statewide mortality rates since June 2007.

**Figure 1: Mortality Incidents, Statewide Case-Mix Adjusted Trend
DDS Consumers since June 2007**



Key Findings:

- The trend in statewide mortality rates has decreased steadily over the past two years, from 0.062% in June 2007 to 0.054% in June 2009.
- Much of this decrease was concentrated in the most recent 6-month period, although rates in the most recent three months may rise slightly as late-reported incidents are added to the data.

More About These Data

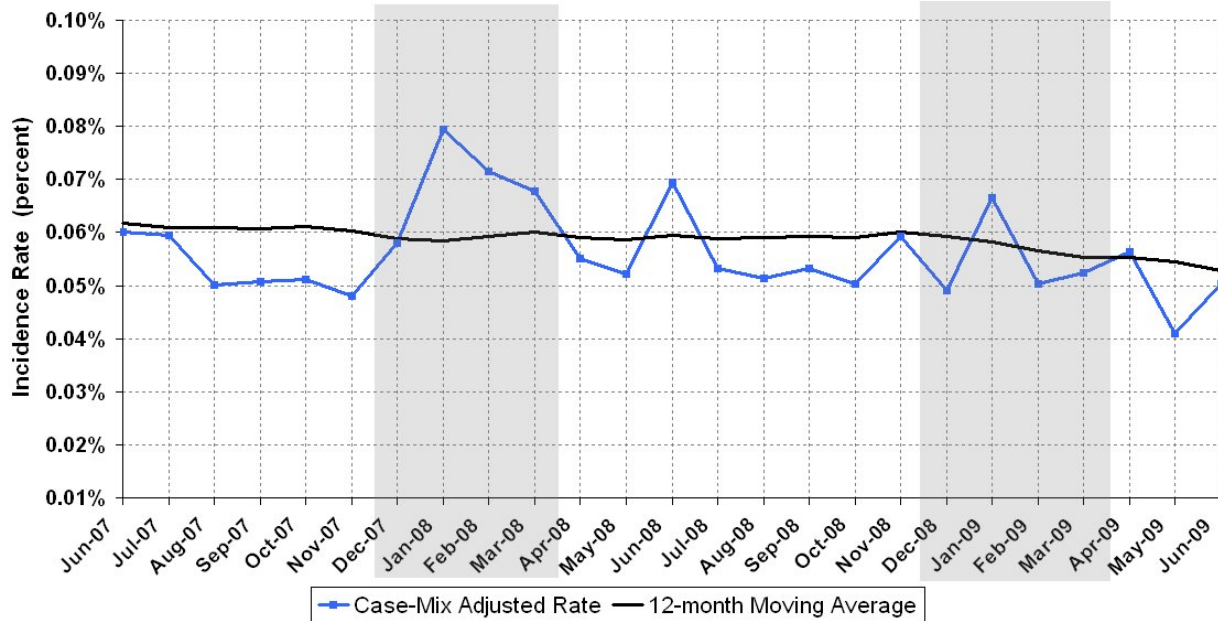
The line in Figure 1 represents a 12-month moving average for all DDS consumers. It is calculated by taking an average of statewide mortality rates from the most recent 12-month period.

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 in the most recent 6-month period may rise slightly as late-reported incidents are added to the data. These incidents, most of them among the in-home consumer population, will be reflected in subsequent semi-annual reports.

The mortality rate rose in January 2009, although the increase was lower in magnitude and duration than in the previous year.

**Figure 2: Statewide Mortality Rates, DDS Consumers
Case-Mix Adjusted Monthly Rates since June 2007**



Key Findings:



- Except in January, mortality rates in the most recent 6-month period (blue line) were near or below the long-term average (black line).
- Unlike the previous few years, January-March 2009 did not see a sustained increase in statewide mortality rates; after January, monthly rates fell to near or below the long-term average.

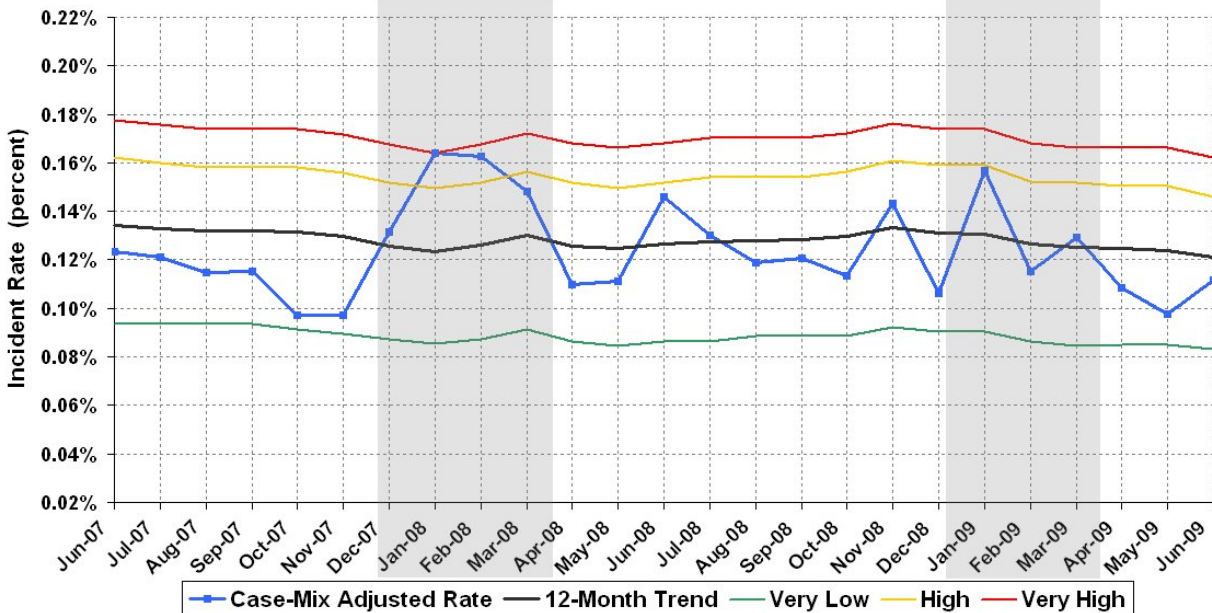
More About These Data

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.

Mortality rates for April, May, and June 2009 may rise slightly as late-reported incidents are added to the data.

The January increase in mortality rates occurred among out-of-home consumers, but did not cross the high threshold.

Figure 3: Statewide Mortality Rates, Out-of-home Consumers Case-Mix Adjusted Monthly Rates since June 2007



Key Findings:

- Mortality rates for the out-of-home population were generally near the long-term average between January and June 2009.
- January 2009 saw an increase in mortality rates. However, this rate did not cross the “high” threshold, meaning the increase was not statistically significant. (See More About These Data for additional details.)
- Similar to the rates depicted in the previous graph, the winter increase in mortality rates among the out-of-home population was lower in magnitude and duration compared to the previous winter.

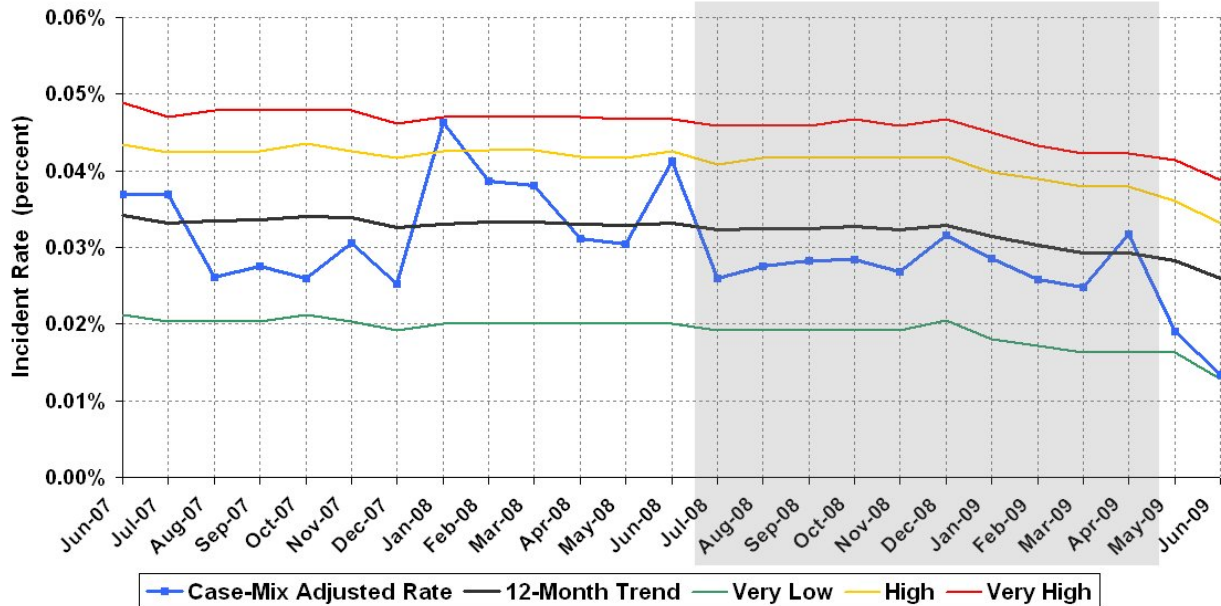
More About These Data

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 line in this graph identifies whether a rate is unusually high. This may occur randomly in only one month out of twenty (less than 5% of the time). A rate that rises above the red line in a given month may occur randomly in one month out of one hundred (less than 1% of the time). Rates above the red or yellow lines, therefore, are very unlikely to be chance events.

For the in-home population, mortality rates over the last 12 months appear to have leveled out below the long-term average.

Figure 4: Statewide Mortality Rates, In-home Consumers Case-Mix Adjusted Monthly Rates since June 2007



Key Findings:

- The seasonal trend that sees increased mortality rates in the winter was not observed in 2009 among the in-home population.
- Mortality rates for the in-home population appear to have leveled out at a rate below the 12-month trend.
- We expect mortality figures in May and June 2009 to rise slightly as late-reported deaths are added to the data.

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 licensed residential services, SLS, or ILS.

This graph identifies mortality incident rates that are unusually high, and therefore classified as a “spike.” For example, a rate that rises above the yellow line in a given month probably did *not* occur due to chance, since this will occur randomly in only one month out of twenty (less than 5% of the time). 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 or yellow lines, therefore, are very unlikely to be chance events and are classified as “spikes.”

Breaking rates down by age and residence, mortality rates decreased for most categories of consumers.

**Table 2: Breakdown of Reported Deaths by Age and Residence Type
DDS Consumers, Jan-Jun 2009 Compared to Same Period Last Year**

	Share of Consumers	Deaths /1000 Jan-Jun 2009	Change from Jan-Jun 2008
Age			
3 to 13	30%	0.8	-49.6%
14 to 21	21%	1.5	-20.8%
22 to 31	17%	2.0	-27.3%
32 to 41	11%	3.3	-11.3%
42 to 51	11%	5.5	-20.6%
52 to 61	7%	11.7	-18.1%
62+	3%	32.1	+10.6%
Residency Type			
Home	71%	1.6	-29.0%
Community Care	12%	6.7	-8.7%
ILS/SLS	10%	4.4	+2.8%
SNF/ICF	5%	25.0	-8.5%
Other	2%	9.8	+9.5%

Key Findings:

- Compared to the same period last year, raw mortality rates decreased in all age categories except consumers aged 62+. Additionally, mortality rates decreased in all residence categories except for consumers living in ILS/SLS and consumers living in Other settings. These raw rates are unadjusted, and do not reflect differences in risk of mortality by group.
- Mortality rates for in-home consumers decreased by 32% compared to the same period last year. However, rates for the in-home population are likely to rise as late-reported deaths are added to the data.

More About These Data

The rates shown above are raw rates and do not account for changes in consumer characteristics.

Community Care: Setting such as a Community Care facility (CCF) and other community settings, not including home of a family member or guardian, ILS/SLS, and SNF/ICF.

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.

Breaking rates down by diagnosis, mortality rates decreased for all categories of consumers except autism.

**Table 3: Breakdown of Reported Deaths by Diagnosis
DDS Consumers, Jan-Jun 2009 Compared to Same Period Last Year**

Diagnosis	Share of Consumers	Deaths /1000 Jan-Jun 2009	Jan-Jun 2008 (last year)
Mild to Moderate MR	55%	3.3	-11.8%
Profound to Severe MR	12%	10.7	-13.9%
Unspecified MR	7%	2.7	-21.5%
Cerebral Palsy	17%	6.4	-14.0%
Autism	21%	0.6	+10.8%
Epilepsy	19%	6.5	-21.1%

Key Findings:


- Compared to the same period last year, raw mortality rates decreased in all diagnosis categories except consumers with autism. These raw rates are not adjusted to reflect differences in risk of mortality by group.
- Mortality rates for consumers with autism increased by 10.8% compared to the same period last year.
 - This increase is not statistically significant, as the total number of deaths among consumers with autism is small. Because of the small number of cases, a few additional deaths will have a large impact on mortality rates.
 - This increase appears to be driven by approximately five additional deaths among consumers aged 32-41. After investigating the individual incident reports among this demographic, we did not find any statistically significant trends.

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%.

Current activities include mortality review guidelines for regional centers and reports on long-term trends.

Status on Current Activities:

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- *Mortality Review Guidelines:* Acumen, in partnership with DDS and the regional centers, has developed a set of mortality review guidelines for California's regional centers. Included in these guidelines are tools to help regional center staff at all stages of the mortality review process. Acumen has also developed a separate report describing best practices in mortality reviews from other states.
 - *Long-term Increases in Mortality Rates:* Every three months, Acumen distributes a quarterly report to each regional center summarizing trends and changes in mortality rates. Earlier this year, we revised the reports to identify long-term changes in incident rates as well as monthly spikes. Should regional centers experience a long-term increase in mortality rates, Acumen has also developed a method to analyze these rates and propose 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. Consistent with our increased focus on longer-term trends, regional centers now report back on quarterly spikes in special incident rates rather than monthly 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.

Planned Activities:

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- *Mortality Review Guidelines:* Acumen led two WebEx training sessions in January 2010 to introduce the Mortality Review Guidelines to regional center staff. In mid-March, Acumen will post the guidelines on ProgramInfo, a website for risk management activities.
 - *Reporting Back by Regional Centers:* DDS and Acumen will continue to collect information from regional centers on how they respond to increases in their mortality rates.