OVERRIDE

In response to direction from the Quality Framework issued by the Centers for Medicare and Medicaid Services (CMS) in 2004, the Division of Developmental Disabilities (DDD) created an on-line reporting system for Unusual Incident Reporting (UIR) that was implemented on January 1, 2005. The system allows Adjustment Training Centers (ATC) to submit required reports via computer and allows DDD to analyze data. The intent of this state-of-the-art approach to entering incident data and sending it to a protected collection area was to streamline the reporting process for providers and allow the Division to analyze data at an unprecedented level. Because the implementation of this system coincides with the first day of the calendar year, UIR Annual Reports are issued in keeping with the calendar year as opposed to the fiscal year.

Generally, the population covered by the UIR system is limited to all people receiving Home and Community Based Services (HCBS) waiver funding in DDD’s comprehensive waiver and Community Training Services (CTS). However, the incident numbers contained within this report may include some individuals on the service record who do not receive HCBS or CTS funding. Some agencies choose to utilize the on-line system as a way to track incidents for people whose services are funded by the school district or private pay, although DDD does not require the submission of an UIR in these circumstances.

This is the third annual trend analysis issued by DDD related to this data. It is a summary review of the data submitted by the 19 ATCs and aggregated for calendar year 2007. Our intent is to issue a comprehensive trend analysis on an annual basis while providing provider-specific reports to each ATC on a quarterly basis. The purpose of the report is to provide information about trends, remain vigilant for emerging issues, and use data to plan, prioritize and implement preventative and proactive initiatives. We hope that these reports will be helpful to ATC administrators in support of their agency’s quality control and improvement systems, including managing their local incident reporting system and comparing their data with statewide aggregate information.

Attached to this document is a data run of all UIRs for all agencies for 2007 including:
- Total number of persons supported by the HCBS waiver and CTS general fund dollars per agency;
- Total number of incident reports submitted per agency;
- A breakdown of reports by category per agency; and
- Information regarding the total statewide number of incidents by category as well as system-wide averages for each category.
The process for managing the UIR system is truly a joint collaboration between the Division and each of South Dakota’s provider agencies. The agencies are to be commended for their fulfillment of responsibilities related to notification to the Division, submission of UIRs and responsiveness to the Division’s requests for follow-up.

The Program Specialist assigned to each ATC is responsible for reviewing all UIRs filed by their agency. The Division also has a UIR/Quality Assurance (QA) Team that coordinates a DDD-staffed peer review process for each UIR. This peer review system is designed to ensure that the ATC has completed all necessary follow-up, timelines are met, and that any additional third party reporting (e.g., to the Attorney General’s Medicaid Fraud unit) has occurred. This second review of each UIR has increased the Division’s ability to address any gaps in handling the UIR and create consistent expectations for follow up.

Additionally, the UIR/QA Team conducts a random sample of UIRs as a third quality assurance checkpoint on a monthly basis. The random sample process has been very helpful in screening for any delays in follow-up as well as timeline compliance issues. Division nurses review each UIR that involves any health or medication issues.

On a quarterly basis, the UIR/QA Team collects the previous three months data and review trends by agency and by UIR category. Staff use a root cause analysis process to determine areas of concern that might benefit from changes in policy and practice by any and all ATCs. A root cause analysis is a process for identifying the basic or causal factor(s) that underlies variation in performance, including the occurrence of a sentinel event.

**SYSTEMS IMPROVEMENTS IN 2007**

1. DDD recognized the need to increase the specificity of the “Other” category and determined four major themes that required further articulation in the reporting template. These are as follows:
   a. Increase in behavioral issues (e.g., aggression and self-abuse);
   b. Medical diagnosis (e.g., contagious disease, cancer);
   c. Illegal activity (e.g., stealing, shoplifting); and
   d. Jeopardizing personal safety (e.g., allowing strangers into a residence, safety while crossing the street).

2. DDD expanded the system to strengthen its ability to monitor incidents of mortality. This information will give DDD the ability to correlate information about the following items:
   a. Level of supervision;
   b. Funding source;
   c. Gender; and
   d. Age.

3. A feature was added to the web-based program that provides immediate notification to the Office of Recoveries upon the death of an individual funded through the comprehensive HCBS waiver.
REGULATORY AUTHORITY

The authority behind the submission of incident reports is as follows:

*Administrative Rule 46:11:03:02. Incident reports – submission to the Division.*
The ATC must submit an incident report and the form, DHS-DD-708 (this web-based reporting method replaced form DHS-DD-708), furnished by the Division for any unusual accident or injury involving a consumer receiving services. The ATC shall give verbal notice or a facsimile of the incident to the Division within 48 hours or the next working day, whichever occurs first, once the ATC becomes aware of the incident. The ATC shall submit a written incident report to the Division within seven calendar days after the verbal notice. A report must be submitted in the following instances:

1. Death;
2. Life-threatening illnesses or injuries, whether hospitalization occurs or not;
3. Alleged instances of abuse, neglect, or exploitation against or by consumers;
4. Changes in health or behavior that may jeopardize continued services;
5. Serious medication errors;
6. Illness or injuries that resulted from unsafe or unsanitary conditions; and
7. Any illegal activity that involves a consumer.

TOTAL NUMBER OF INCIDENTS

During 2007, the HCBS Waiver and Community Training Services served 2,481 persons, an increase of 47 people from 2006. 1,852 UIRs were filed, an increase of 530 UIRs from 2006. This calculated to an average of 97 UIRs per ATC. The lowest number of UIRs filed by an ATC was 15 and the highest number was 305. The number of UIRs per 100 persons served ranged from a low of 18.8 at one ATC to a high of 202.7 at another ATC. The system wide average per 100 persons served was 82.3.
The highest reporting period for 2007 occurred during July-September. There was a substantial increase of 30 or more UIRs each from three agencies. January-March was the lowest reporting period.

This chart reflects the 12 UIR categories and the number of reports filed per category. Note that the totals of categories do not match the total incidents; some incidents may have been included in more than one category. The “Other” category in this chart includes all death reports (note: 25 deaths were recorded in 2007). Please refer to page six for more detail on the “Other” category.
During calendar year 2007, suspected abuse was the highest reported category. Of these incidents, one hundred forty-three allegations were substantiated while one hundred twenty-seven were not. It is noted that the total number of suspected incidents in this chart do not match the number of suspected incidents in the Categories of UIR chart on the previous page. This is due to ten reports filed in multiple categories. For example, one report is suspected abuse and suspected neglect. [Note: This is new information the division is able to draw from the reports contained in the database.]
There were 332 UIRs, excluding death reports, captured in the “Other” category. One hundred eighty-nine of these UIRs are unique and do not align with any single category. Some examples of these UIRs are:

- Being diagnosed with a terminal illness;
- Discovery of a tumor;
- Missing controlled medications;
- Sudden onset of seizure activity; and
- Forgery.

As with the 2006 report, many UIRs were recorded that do not align with current categories as referenced in the “Systems Improvements in 2007” section on page 2 of this report. The Division identified and added four additional categories to the UIR form. Additionally, after reviewing the 189 UIRs recorded in the “Other” category it was discovered that approximately 40% were categorized incorrectly, meaning the incident should have been recorded in another category of the UIR form.
MORTALITY OVERVIEW 2007

By definition, state developmental disability systems support people from an early age until death. Supporting individuals through the end stages of their life is a critical function that ATCs provide to the people they support. In South Dakota, the relatively low number of people who die each year makes it difficult to detect annual trends. DDD reviews all deaths and conducts investigations of any deaths that are accidental, unexplained, or occur amidst allegations of abuse or neglect.

During 2007, 25 people served died. Eleven people died of unanticipated natural causes and eleven of anticipated natural causes such as cancer. The three reports categorized as undetermined were because a cause of death had not been determined at the time the online report was filed with the division. Some examples of “Natural Causes (Not Anticipated)” are:

- Person had a heart attack;
- Person was elderly and had pneumonia; and
- Person had complications following gastrointestinal bleed.
Cause of Death

A single cause of death is chosen for each person. If an underlying disease is known it is listed as the cause of death, rather than the immediate cause. Consistent with the general population, the underlying disease may have many other health related concerns linked to it. The choice of a single primary cause of death although arbitrary, is important for tracking and trending deaths in the state.

Eighteen of the deaths are identified in three categories for mortality listed in the UIR form—cardiovascular, respiratory disorder, injury related and cancer. If the cause of death did not fall into any of these categories, it was recorded in the “Other” category. The number of UIRs tied to the “Other” category is causally related to the number of Natural Causes (Not Anticipated) listed in the Mortality Overview table one page 8. In many of these incidents the family or guardian chose to not have an autopsy conducted and the coroners report indicated “Natural Causes”.

Site of Death

Thirteen of the deaths occurred in the hospital, seven in a group home with provider supports, three occurred in some other setting (e.g. a nursing home), and two in supervised apartments with provider supports.
The people supported who died in calendar year 2007 received residential supports as follows:

- Seventeen people were receiving services in a group home (Level I) residence;
- Four people were receiving supports in supervised apartments (Level II); and
- Four people were receiving supports in an independent living situation (Level III).
Twenty-four deaths involved people receiving HCBS Comprehensive waiver funding whereas one death involved people receiving Community Training Services.

During 2007, of the twenty-five reported deaths, fourteen were male and eleven were female.
Eight deaths were in the 51-60 and 61-70 age categories followed by three in the 71-80 age category. Two deaths were in the 22-30 and 41-50 age categories. One death in the 18-21 and 81+ categories.

**Mortality Analysis 2005–2007**

The following charts detail mortality information for calendar years 2005, 2006, and 2007 unless otherwise noted. During these calendar years there have been 96 deaths reported to the division, twenty-seven in 2005, forty-four in 2006, and twenty-five in 2007.

**Leading Cause of Death by year**

During the last three years, the leading cause of death has changed each year.
Death due to natural causes, not anticipated, remains the leading type of death during the three-year period accounting for 49% of the deaths.

Over the last three years, 50 deaths have occurred at a hospital setting followed by 28 deaths occurring in a group home setting. Of the deaths that occurred at group home setting 90% were due to natural causes (not anticipated).
The following data was reviewed in calendar year 2006 and 2007. The total number of deaths in the following graphs is 69.

**Residential Services**

This data set indicates the level of residential support provided at the time of death with Level I providing 24 hour/7 day a week supervision, Level II providing supervision during all waking hours, and Level III providing supervision at an intensity less than Level I or II. Data 74% of those who have died received Level I support. Level II and Level III supports showed nine deaths each.

**Funding Source**

Sixty-six of those who died were receiving funding through HCBS-adult, accounting for 96% of deaths. Three were receiving funding through CTS, accounting for 4% of deaths.
Thirty-eight or 55% of deaths were male and thirty-one or 45% were female.

The age group with the highest number of deaths was 61-70 years old, followed by 51-60 years old.
SYSTEMS IMPROVEMENTS FOR 2008

As a result of careful review of the data as well as substantive dialogue with a variety of stakeholders, a number of systems improvements are being put into place this year. The UIR process is an important aspect of DDD’s quality management system and as such is iterative in nature. One of the primary functions of this annual report is to provide all interested parties with a summary of these improvements. They are as follows:

1. Pursuant to a recommendation by CMS in response to an evidentiary review as well as a recent meeting with the South Dakota Association for Community Based Services, the UIR/QA Team will be expanded to include a DDD nurse and individuals not affiliated with DDD. These additions will include a person receiving community-based services, family members and representatives from the South Dakota Developmental Center and two ATCs. This change will occur over the course of the next six months and should strengthen the objectivity of the review process;
2. The Division’s HCBS waiver managers will also take a more active role in reviewing UIR data, consistent with their responsibility to monitor DDD’s compliance with CMS’s basic assurance requirements for health and welfare; and
3. DDD requested technical assistance from CMS on data and trend analysis to improve its ability to analyze the UIR data and be more proactive in identifying patterns of concern.
4. The victim of assault category will be removed and this information will be captured in the abuse/neglect/exploitation section of the UIR category.
5. The abuse category will be expanded to record the type of abuse:
   a. Physical;
   b. Verbal; or
   c. Sexual.

It is hoped that these improvements increase the overall quality of the UIR process as well as the analysis capacity at both the state and local levels.

Please direct any comments and questions about this report to John New, Program Specialist, at 605-773-3438 or john.new@state.sd.us.