

**ARIZONA DEPARTMENT OF ECONOMIC  
SECURITY**

**DIVISION OF DEVELOPMENTAL DISABILITIES**



**Annual Mortality Report**

**October 1, 2003-September 30, 2004**

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## OVERVIEW

The Division of Developmental Disabilities instituted a revised Mortality Review Policy via Administrative Directive No. 80 in October 2002. The Directive supercedes Chapter 2100, Section 2105 of the Policies and Procedures Manual. The Division's new Mortality Review Committee was formed at that time. The Committee is comprised of the Statewide Quality Management Committee while in Executive Session. Members include representatives from urban and rural Districts, Central Office representatives, Arizona Long-Term Care representatives, a Department of Economic Security Risk Management representative, a provider agency representative, a family member, and others. This Administrative Directive has most recently been reviewed and revised in July 2004.

Prior to the formation of the Mortality Review Committee, deaths were reviewed solely by the Medical Director. The Division, however, recognized the value of more timely review as well as the need for careful tracking and trending of all deaths. The first Annual Mortality Review Report analyzed deaths from October 1, 2002 through September 30, 2003. This second Annual Mortality Review Report summarizes and analyzes deaths from October 1, 2003 through September 30, 2004.

The Division's Mortality Review Committee reviews all deaths of Division members, including federally-funded (Title XIX) and state-only funded members. The mortality review process includes all ages across all living environments, including Adult Developmental Homes, Child Developmental Homes, community group homes, long-term-care facilities, family homes, foster homes, private homes and Intermediate Care Facilities for the Mentally Retarded (ICF/MRs).

The review process seeks to answer the following questions: Could the death have been prevented? Are there service system issues identified in the course of the review that need to be addressed? What actions should the Division take to improve the health and safety of the people it serves? How can the Division improve the care and quality of life for others? Recommendations to the Division's Management Team may include new training, education/retraining, policy/procedure development or revision, facility/ equipment improvements, provider corrective action plans, or referral to licensing bodies for investigation.

All member deaths are reported to the Division's Central Office and are also entered into the Risk Incident Management Systems (RIMS) for tracking purposes. Additionally, a separate database has been constructed specifically for tracking and trending mortality issues. The depth of review by the Committee varies depending on the circumstances of the death. For example, when no Division-funded providers are involved, such as when a member resides independently or with family, the Division respects the family's privacy and avoids intruding as much as possible. There may be concerns, however, that the Division was not providing

adequate support to the family, such as respite, especially when Child Protective Services/Adult Protective Services are involved, and a closer review may be warranted. Likewise, when the death was expected (e.g. the member had a terminal condition and hospice was involved), the review may be abbreviated. For some reviews, the Division's Health Care Services may request the sub-contracted health plan to gather medical records for further review, the District may be asked to provide additional information, or autopsy reports may be requested.

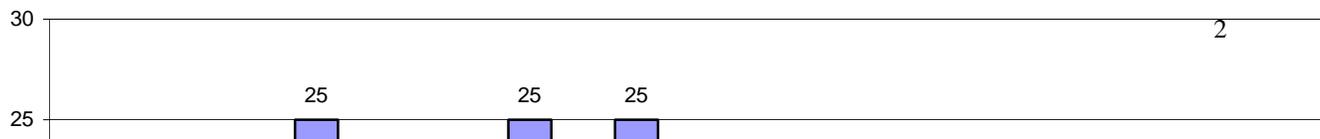
## II. SUMMARY OF RESULTS

As of October 1, 2003, there were **22,208 Division members**. Between October 1, 2003 and September 30, 2004, there were a total of **216 deaths**.

Figure 1 summarizes the total number of deaths per month during the year. The months of June, July and August had the fewest number of deaths at 12, 13 and 10 respectively. December, February, and March had the highest number of deaths at 25. This is consistent with findings from the 2002-2003 year in which the winter months experienced the highest number of deaths, and this is thought to directly relate to the pneumonia/influenza season. The mean (average number of deaths per month) was 18.0 and is indicated by the horizontal line. The median was also 18 deaths per month.

FIGURE 1

Deaths Per Month  
FFY 04



As mentioned above, as of October 1, 2003, there were 22,208 Division members. These were distributed among the various Districts as follows:

District	Total served
I (Maricopa County)	12,215
II (Pima County)	4374
III (Yavapai, Coconino, Navajo, and Apache Counties)	2345
IV (Yuma, La Paz, and Mohave Counties)	973
V (Pinal and Gila Counties)	1268
VI (Santa Cruz, Cochise, Graham, and Greenlee Counties)	888
VIII (Arizona Training Program at Coolidge; ATPC)	145
	<b>22,208</b>

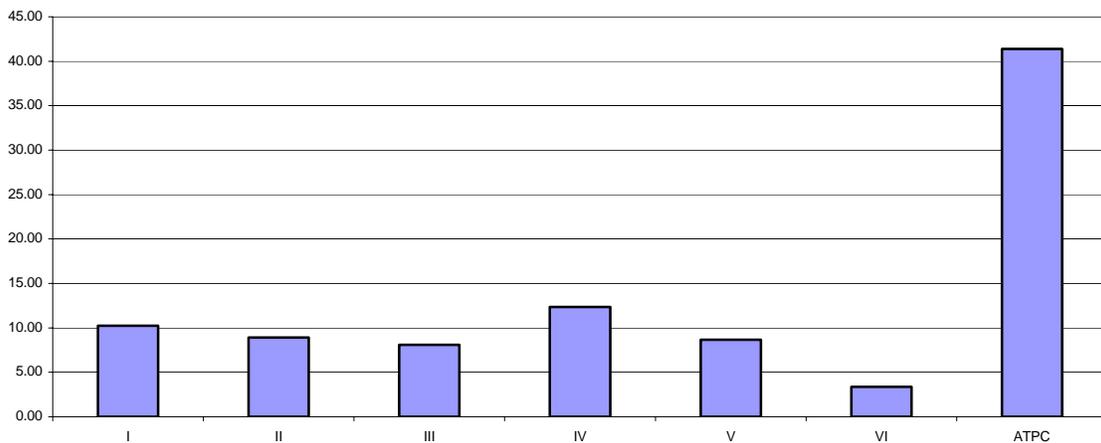
Figure 2 summarizes the total number of deaths per District during the year. As expected, the Districts serving the most consumers reported more total deaths.

FIGURE 2

Figure 3 illustrates the total number of deaths per 1000 members per District in order to account for the variability in populations between Districts. Excluding the larger ICF/MR setting in Coolidge (ATPC), the deaths/1000 members ranges from a low of 3.38 deaths/1000 members in District VI to a high of 12.33 deaths/1000 members in District IV.

**FIGURE 3**

**Deaths Per 1000 Members Per District  
FFY 04**



The Arizona Training Program at Coolidge (ATPC; District VIII) is the state's largest ICF/MR setting and is analyzed separately, as it consists of Division members residing in the state's sole remaining, large congregate setting. Current residents (or their guardians) have specifically chosen to remain in this setting. This group of consumers is aging, and the average age of the 145 consumers residing at the Arizona Training Program at Coolidge (ATPC) currently is 47-years-old (youngest is 35-years-old; oldest is 74-years-old). The following tables provide the demographics of this sub-population at this time:

<b>Age Range</b>	<b>Total</b>
30-40	9
41-50	50
51-60	61
61+	19

<b>Disability Level</b>	<b>Total</b>
Profound Mental Retardation	74
Severe Mental Retardation	52
Moderate Mental Retardation	12
Mild Mental Retardation	1

The consumers living at the Training Program are highly medically involved individuals.

<b>Needs</b>	<b>Total</b>
Wheelchair for mobility	68
Regular nursing oversight	51
Feeding tube	18
100% dependent for daily living needs	52

There were six deaths during the October 1, 2003-September 30, 2004 year at the Training Program, which equaled 41.38 deaths/1000 members.

The six deaths at the Arizona Training Program at Coolidge are summarized below:

<b>Consumer</b>	<b>Age</b>	<b>Cause of Death</b>
1	55	end-stage liver disease
2	51	metastatic colon cancer
3	55	uncontrolled seizures; respiratory failure
4	45	cardiac arrest
5	52	sepsis leading to acute renal failure and cardiac arrest
6	52	pneumonia

The mean for Districts I-District VI is 9.52 deaths per 1000 members. This is notably higher than in 2002-2003 in which the mean was 7.75 deaths per 1000 members. Nationally, however, mortality rates average 15-16 deaths per 1000 members, and Arizona consistently appears to be lower than the national average.

The overall number of deaths per 1000 members statewide, including those from the Coolidge setting, is 9.73. This is based on the 216 deaths during the study period and the total number of members as of October 1, 2003 (22,208). Again, this is notably higher than in 2002-2003 when the overall number of deaths per 1000 members statewide was 7.947.

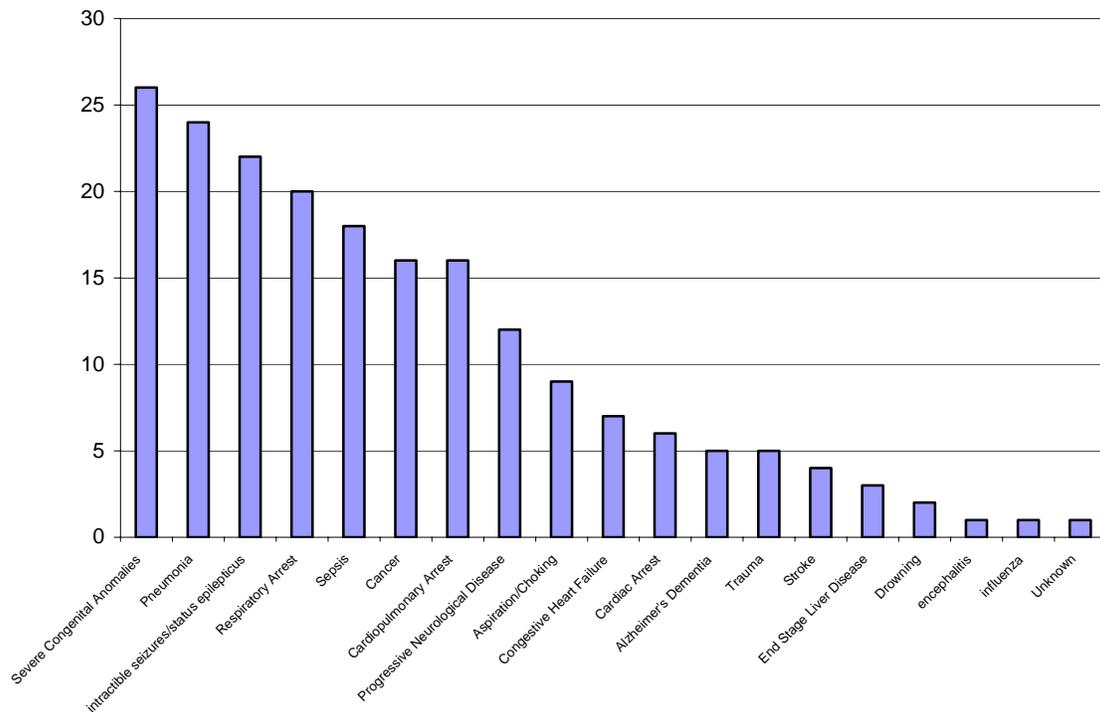
According to the Arizona Health Status and Vital Statistics, 2003 information (2004 information is not yet available), the statewide mortality rate in the general population in 2003 was 7.84 per 1000 individuals. This is consistent with the rate in 2002: 7.964 per 1000 individuals. It is concerning that the average number of

deaths per 1000 members for the Division, (9.73) is higher than the average number of deaths per 1000 individuals for the general population in Arizona (7.84). In 2002-2003, the Division was pleased to find the average number of consumer deaths were almost equal to that found in the general population. It is not clear why the death rate for individuals with disabilities is higher than the general population in 2003-2004. There has been ongoing concern at the national level regarding health care disparities in this population. Although Arizona did not find this to be true in the 2002-2003 mortality report, findings for 2003-2004 would suggest that these disparities continue to exist.

Figure 4 illustrates the causes of death from most frequent to least frequent.

**FIGURE 4**

Cause of Death

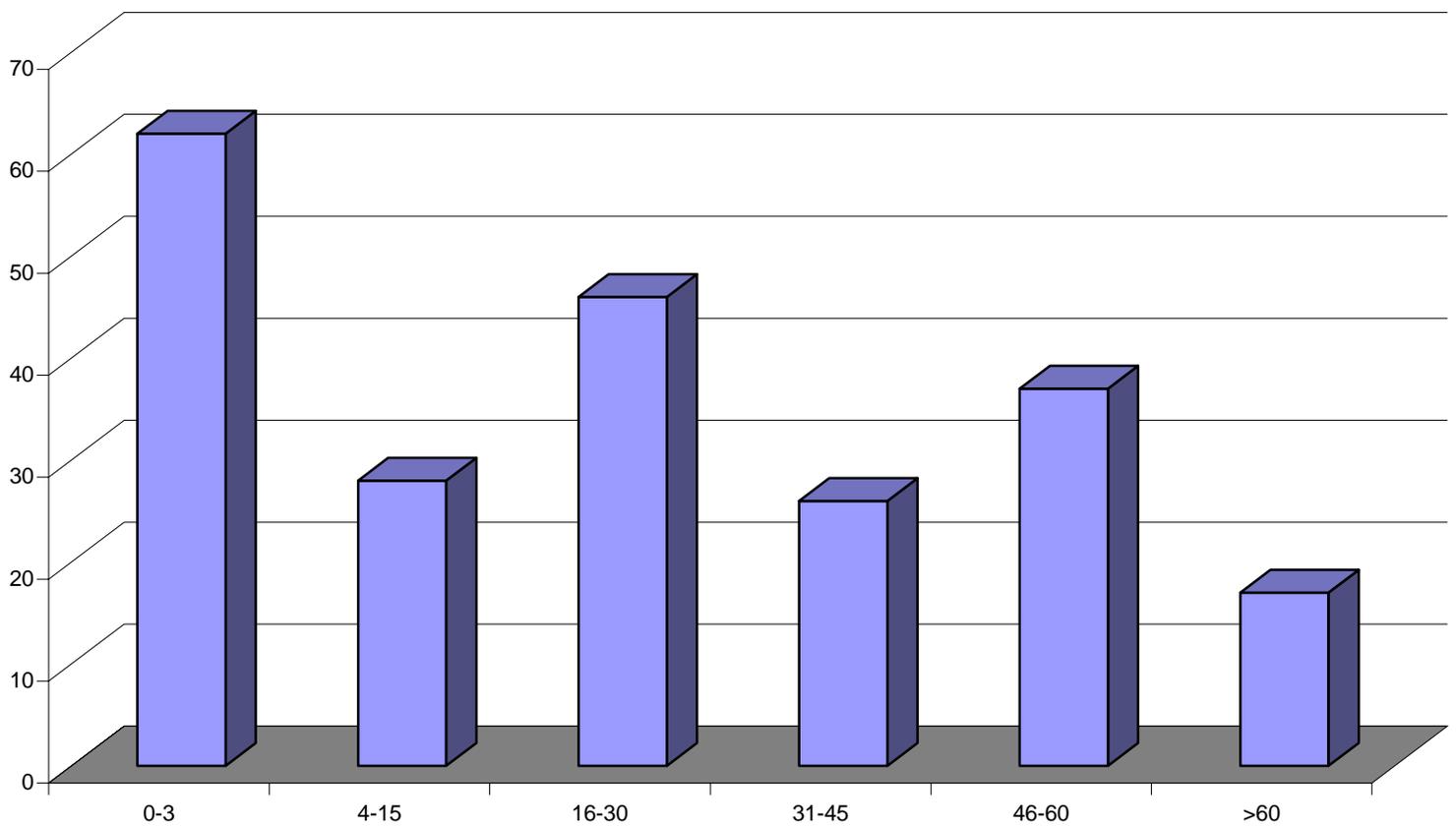


The top three causes of death included Severe Congenital Anomalies (26), Pneumonia (24), and Intractible Seizures/Status Epilepticus (22). It can be assumed that deaths related to severe congenital anomalies cannot be prevented. When these deaths are removed from the overall analysis, the death rate for Arizona's consumers more closely matches that of the general population but is still higher: 190 deaths/22,208 consumers is 8.56 deaths/1000 consumers.

Figure 6 breaks out the total number of deaths by age groups for the year.

**FIGURE 6**

**Deaths by Age Group**  
**Oct 1, 2003 - Sept 30, 2004**



When all deaths ages 0-3 are excluded (62), the death rate becomes 154 deaths/22,208 consumers, or 6.93 deaths per 1000 consumers.

Table 1 lists the top three causes of death for each age group.

<b>0-3 Age Group</b>	<b>Totals</b>
Severe Congenital Anomalies	25
Respiratory Arrest	8
Pneumonia	6
<b>4-15 Age Group</b>	
Progressive Neurological Disease	4
<b>Tie:</b> Cardiopulmonary Arrest/ End-stage Renal Disease/Respiratory Arrest	3
<b>16-30 Age Group</b>	
Intractable Seizures/Status Epilepticus	11
Pneumonia	7
Respiratory Arrest	5
<b>31-45 Age Group</b>	
Intractable Seizures/Status Epilepticus	5
Pneumonia	4
Cardiopulmonary Arrest	3
<b>46-60 Age Group</b>	
Sepsis	11
Cancer	5
Dementia	4
<b>61+ Age Group</b>	
Pneumonia	3
<b>Tie:</b> Congestive Heart Failure/Cardiopulmonary Arrest/ Cardiac Arrest/Cancer	2

Figure 7 illustrates the primary residence of the consumers. The vast majority resided in their family homes.

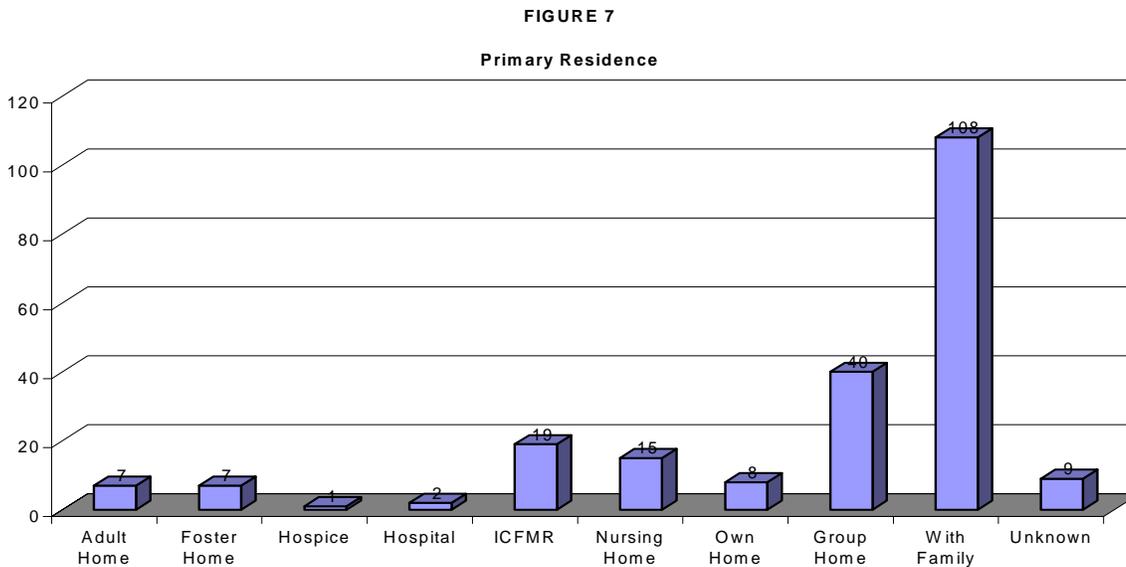
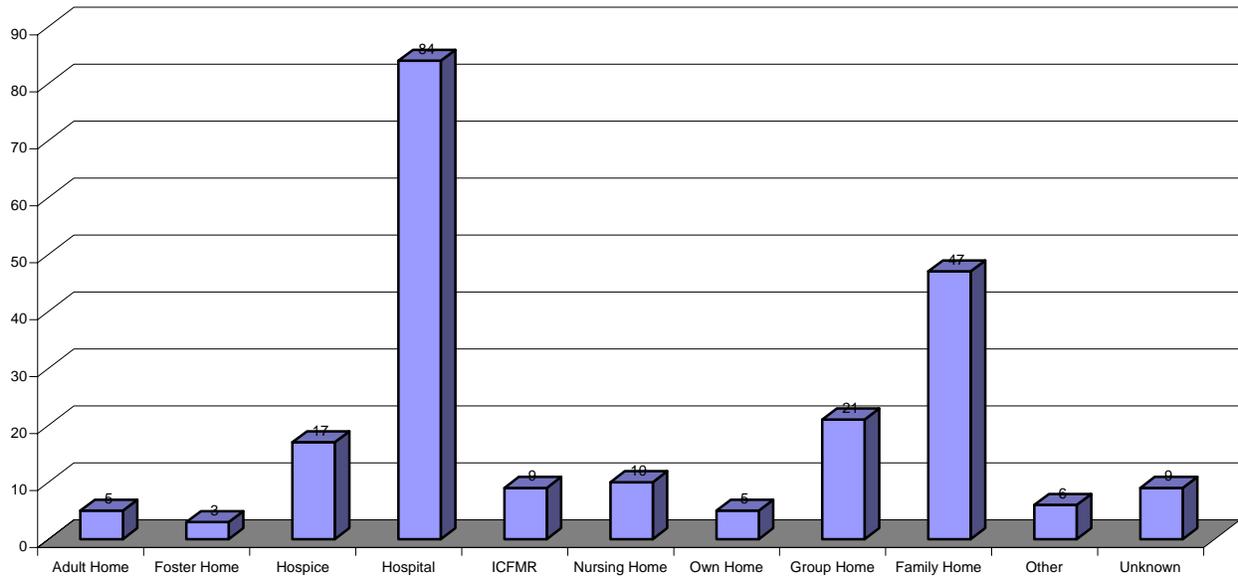


Figure 8 indicates the location of the death. If a consumer became unconscious or was found unresponsive at their home or group home and then transported to the Emergency Department where they were pronounced deceased, the location of death is listed as “Family Home,” “Group Home,” etc. Only consumers who had been admitted to a hospital bed prior to passing away would be captured in the “Hospital” category. “Hospice” refers to actual hospice facilities. Consumers who passed away at home may have been receiving Hospice services.

**Figure 8**  
**Location of Death**



## DISCUSSION

### Aspiration and Choking

The Mortality Review Committee closely tracks all cases related to choking and aspiration in order to identify additional training needs. The July 2004 edition of the Division’s Clinical Quality Bulletin included an article about aspiration and pneumonia. Risk factors were discussed. Consumers were encouraged to seek medical attention as soon as possible when symptomatic, especially if they have a history of aspiration. Providers were encouraged to consider chest x-rays and blood work sooner and to offer the pneumococcal vaccine. The Division has approved and distributed a Risk Assessment Form, which Support Coordinators use for all members living outside of the family home. It is also used as needed for members living independently or with their family. It helps identify potential risks to consumers, including risks for choking and aspiration, such as pica, eating too quickly or without chewing, and having a previous history of aspiration. Preventive approaches can then be initiated to decrease risk. The Division enlisted the assistance of a national expert, Karen Green McGowan, to provide additional training in August 2003. Ms. McGowan conducted a “train the trainer” session and each District sent representatives. The Division is currently reviewing the effectiveness of the Risk Assessment Form and will be modifying it as needed. During the 2003-2004 year, there were nine deaths categorized as “Aspiration/Choking” as detailed below:

Age	Details
22 months	Found by parents in the morning; thought to have aspirated; no autopsy; no providers present; consumer used oxygen as needed
7	Recurrent aspiration pneumonia/choking; had G-tube placed and fundoplication in 1998 but family continued to feed orally at times; no CPS involvement; result: article in Clinical Quality Bulletin advising physicians to discuss options with family, such as speech therapy evaluation, careful documentation, CPS referrals for medical neglect
18	Found by caretaker in the morning; history of self-induced vomiting; felt that she made herself vomit during the night and choked; Autopsy report listed cause of death as “aspiration pneumonia due to congenital abnormalities/ natural.” Pathological diagnoses included congenital spina bifida, pulmonary edema and congestion (acute), and aspiration pneumonia. There was concern about the quality of the autopsy report and autopsy reports will be tracked to identify any particular medical examiners who would benefit from further contact.
27	Per Primary Care Provider records, consumer died from choking on a hot dog. He was with his mother at the time; no providers present; no previous history of choking reported.
21	Consumer diagnosed with Duchene's Muscular Dystrophy; had begun to cause swallowing difficulties, dysphagia, and respiratory problems; went out to eat with mother and had a choking episode but recovered; in car

	going home, however, stopped breathing; taken to ER and placed on life support
44	Consumer diagnosed with severe mental retardation; while at day program, consumer choked on his lunch; providers called 911 and initiated CPR; no history of choking or pica in the past
46	Medically fragile consumer diagnosed with diabetes, asthma, history of bowel obstruction, Congestive heart failure, chronic yeast infections, osteoporosis, and port-o-cath problems; admitted to hospital and reportedly died from aspiration pneumonia
52	Consumer with history of ulcerating esophagitis, upper gastrointestinal bleeding, G-tube, recurrent aspiration pneumonia, abnormal blood counts (low platelets); had Do Not Resuscitate order since Sept. 2002; had been slowly and progressively declining; no concerns with quality of care provided
76	Consumer from the state's institution; diagnosed with asthma, dementia, history of polio, gastric reflux; she had been congested for the previous 1-2 weeks and was receiving routine nursing care; a risk assessment had been completed due to coughing when consumer would drink liquids; diagnosed with aspiration of Metamucil and fruit that progressed to respiratory difficulties/congestion and respiratory arrest

### **Nursing Home Guidelines**

The Mortality Review Committee continues to review deaths of members receiving care in a skilled nursing facility. The Division now forwards reports from the Centers for Medicare and Medicaid Services (CMS) Nursing Home Compare to the District nurse and the District Program Manager whenever a consumer is placed in a skilled nursing facility. The report summarizes all deficiencies for the specific nursing home.

### **Cancer**

There were 16 deaths due to cancer during the study period. The following types were diagnosed: leukemia (3), pancreatic/biliary/liver (3), brain/brainstem (2), esophageal/throat (2), lung (2), colon (1), bone (1), kidney (1), and breast (1). They spread across all age ranges. In several cases, the cancer was diagnosed very late and treatment was not initiated. In other cases, the cancer was diagnosed and aggressively treated. The October 2004 edition of the Division's Clinical Quality Bulletin included an article stressing screening exams and the importance of early detection of cancer.