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Mortality Among People in Vermont Receiving Developmental Disability Services (DDS) FY 2005

Introduction

Every year the Division of Disability and Aging Services (formerly the Division of Developmental Services) publishes a report on the number of people who died during the past year while receiving developmental disability services. An analysis of individual deaths and also of trends in mortality is a component of health and safety oversight for a publicly funded developmental disability services system. The purpose of the report is to provide information about trends, and keep watch for indicators that could help us prevent certain types of death or illness in the future.

Death in and of itself is not an indication that something has gone wrong. If we offer lifelong supports to people, they will eventually die while receiving developmental disability services. Offering care to people who are terminally ill and supporting them to feel safe and cared for while they are in the dying process is an important part of developmental disability services.

In Vermont, the low number of people who die each year makes it difficult to detect trends, and to be confident in their statistical significance even when detected. It is important to look at trends over several years, and to look at data from other states when possible.

The Numbers

In FY 2005, 26 people receiving developmental disability services (DDS) died. This was considerably fewer than the number who died in the previous four years even though the number of people in services has increased. The total number of deaths of people receiving DDS over the past seven years is as follows:

Deaths of People Receiving Developmental Disability Services

	Deaths	Total # in DDS
FY 2005	**26**	**3,095**
FY 2004	37	3,024
FY 2003	40	2,889
FY 2002	37	2,795
FY 2001	36	2,702
FY 2000	25	2,560
FY 1999	30	2,387

County of Residence of People who Died in FY 2005

Addison	0
Bennington	2
Caledonia	1
Chittenden	2
Franklin	1
Orange	2
Orleans	0
Rutland	8
Washington	7
Windham	2
Windsor	1

Type of Living Situation of People who Died in FY 2005

Nursing Home	3
Group home (DDS operated)	2
Other residential care home	2
Shared living/developmental home	13
Respite	2
Independent/apartment	1
Natural Family	4

Note that the residence of a person does not necessarily indicate the location where a person died (*e.g.,* a person may have lived in a group home, but died in a hospital.

Some people with developmental disabilities who live in nursing homes receive DDS supports through the PASARR program; others don't want or need them. In FY 2005 there were three deaths among nursing home residents who received PASARR supports, and two deaths among nursing home residents with DD who didn't get any DDS supports. Only the three who received DDS supports are counted in this report.

The table below shows the age at death of people receiving DDS from FY 2001 - FY 2005.

Age at Death for People in Developmental Services in FY 2001, 2002, 2003

2004 and 2005

Age	FY 2001	FY 2002	FY 2003	I FY 2004	FY 2005
0-14	2	2	2	1	1
15-24	2	1	1	4	3
25-34	3	4	3	6	1
35-44	5	0	2	4	1
45-54	5	6	4	5	4
55-64	7	4	10	6	5
65-74	5	9	5	3	5
75-84	6	10	12	6	3
85+	1	1	1	2	3
Total	**36**	**37**	**40**	**37**	**26**
Median (adults)	**56**	**67**	**62**	**53**	**62.5**
Mean (adults)	**53**	**59**	**60**	**52**	**60.9**

In 2002, 60% of *all Vermonters* who died were 75 or older. In comparison, only 23% of individuals who received DS services lived to be 75 or older. The ***median*** age of death for adults who received DDS supports in FY 2005 was 62.5: half the adults who died were older than 62.5, and half were younger. The ***average***[1] age of death for adults who died in DDS in FY 2005 was 52.[2]

Cause of Death

We analyze cause of death carefully to see if any trends are apparent. Nothing in particular stood out last year.

[1] "Average" (mean) is the sum of the age of death for all adults in services divided by the number of deaths.

[2] Two children under 18 died in FY 2005. One was 4; one was 16. They are not included in these figures.

Detailed Cause of Death for People in DS FY01 - 05

	FY 01	FY 02	FY 03	FY 04	FY 05
Heart Disease/ Heart Failure	7	5	15	4	3
Respiratory Disease Pneumonia	6	7	6	5	6
Cancer	4	7	5	3	3
Accidents	1	3	1	0	1
Unknown	3	2	1	4	1
Adult Onset Dementia (Alzheimer's)	5	2	1	5	3
Stroke	1	2	0	0	0
System Infection	3	2	0	0	0
COPD	0	2	1	1	0
Genetic Disease or Condition	4	1	0	3	1
Bowel Disease	0	1	0	0	0
Pulmonary Embolism	0	1	1	1	0
Post Surgery Aspiration/Pneum.	0	1	0	1	1
Seizure Disorder	0	1	4	4	2
Kidney Disease	1	0	1	0	0
Liver disease	0	0	0	0	1
Diabetes	0	0	0	0	2
GI or Bowel Bleed	1	0	0	2	0
Parkinson's Disease	0	0	1	0	0
Cerebral Palsy (Effects Of aging)	0	0	2	0	1
Suicide	0	0	0	1	0
Other Neurological Disease	0	0	0	2	1
Hepatic Hemagioma	0	0	0	1	0
TOTAL	36	37	40	37	26

Cause of Death by Major Class FY 2001 - FY 2005

Nervous system (including Parkinson -1, Alzheimer's -16 Neurological disease– 3, Genetic– 9, Seizure -11)	=	40
Heart	=	33
Lung disease/pneumonia	=	35
Cancer	=	22

We chose a single cause of death for each person. Where there was a known underlying disease process (such as cancer) we listed that, rather than the immediate cause (such as pneumonia). Many people had several conditions which contributed to their failing health, and the choice of a single primary cause of death is sometimes rather arbitrary. For instance, diabetes was considered the cause of death for two people, but there were other factors as well.

Pneumonia is particularly difficult to classify. Where a person had another active disease process such as cancer or Alzheimer's, which caused the person to be in frail health, we would pick the other process, even though the person may have had pneumonia at the end. Where a person had health problems which had caused weakened health, such as a genetic disease, but had not been considered to be terminally ill, we generally identify pneumonia if they had pneumonia at the time of death.

Chronic lower pulmonary disease (CLRD) is now reported as the 4th leading cause of death in Vermont and in the nation. Prior to 1999, CLRD was known as chronic obstructive pulmonary disease (COPD). CLRD is a group of diseases that cause airflow blockage and breathing-related problems; it includes emphysema, chronic bronchitis, and asthma and is not yet used in our reporting statistics. Our reporters do not seem to be familiar with this term and thus the older categories of COPD and other respiratory disease are retained in this report.

One death is classified as "unknown". This was a young child who lived and died at home; the family chose not to share the cause of death.

All three of this year's Alzheimer's victims had Down Syndrome. Their ages at death were 53, 55, 68.

Medico/legal Death

There were no homicides, suicides, or deaths from weapons-related cause.

Accidental Death

There was one accidental death: an elderly gentleman who died after falling down stairs.

Prevention

Vermonters with developmental disabilities generally die from the same causes as other Vermonters, and the same prevention activities which are effective for all Vermonters can reduce mortality among people with developmental disabilities.

Smoking, obesity, and lack of physical activity continue to be prevalent among people with developmental disabilities. Concerted efforts at smoking cessation, weight-reduction, and

opportunities for physical activity can make a tangible difference in extending the lives of Vermonters with developmental disabilities.

On-going monitoring

Better understanding of the proximate and underlying causes of death continues to be a tool for prevention. Prompt notification of every death is key to this process. Prompt reporting of deaths makes possible timely screening to determine whether to seek an autopsy or investigation of care surrounding death. In several cases one to several days elapsed before DDAS was notified of the death. In most of these cases, the delay occurred because the individual lived with family and the family did not notify the agency of the death.

DDAS actively seeks an autopsy in any death where the death was unexpected and the cause of death is not clearly established. The Medical Examiner initiates an autopsy where there is a possibility that the death did not occur from natural causes or neglect may have been a factor. Approximately 10% of all Vermont deaths are investigated by autopsy. The rate of autopsy among individuals in DDS was 19 per cent. A recent survey found that the rate of autopsies nationwide for individuals in developmental services programs is about 11%.[3] In Connecticut, 21% of deaths of people in developmental services were followed up by autopsy. [4] In some cases where we might recommend an autopsy, it is not possible because of late reporting or because of family objection. In one case this year a family member became very distressed because we urged the Medical Examiner to do an autopsy though the family objected. Following that case, the Medical Examiner and DDAS are more reluctant to seek an autopsy over family objection.

Any death report which raises a concern that abuse or neglect of care may have occurred is reported to Adult Protective Services (for adults) and SRS (for children). To our knowledge, no deaths of individuals in DDS were reported to APS or SRS in FY 05.

[3] The Columbus Organization. Mortality Review Survey: Survey of the States. Submitted to the California Department of Developmental Services. May, 2002.
[4] State of CT DMR, Health & Mortality Report (Oct. 2003)