



STATE OF VERMONT
AGENCY OF HUMAN SERVICES
Department of Aging and Independent Living
Division of Disability and Aging Services
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Mortality Among People in Vermont Receiving Developmental Disability Services (DDS) in Vermont FY 2004

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 2004, 37 people receiving developmental disability services (DDS) died. The total number of deaths of people receiving DDS over the past six years is as follows:

Deaths of People Receiving Developmental Disability Services

	Deaths	Total # in DDS
FY 2004	37	3024
FY 2003	40	2889
FY 2002	37	2795
FY 2001	36	2702
FY 2000	25	2560
FY 1999	30	2387

County of Residence of People who Died in FY 2004

Addison	2
Chittenden	5
Franklin	6
Orange	1
Orleans	1
Rutland	5
Washington	9
Windham	4
Windsor	4

Type of Living Situation of People who Died in FY 2004

Nursing Home	2
Group home (DDS operated)	6
Other residential care home	2
Shared living/developmental home	19
Respite	1
Independent/apartment	1
Natural Family	6

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). Three situations in FY 2004 were hard to classify: we coded as "natural family" a young man who died unexpectedly while on one of his frequent visits home with his natural family, even though he lived in a developmental home.; we coded as developmental home individuals who had lived in a developmental home but returned to their natural family home for hospice care during their final illness. One individual had been living in an apartment, and a roommate had just moved in at the time of his death. We coded this individual as "apartment".

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 2004 there were two deaths among nursing home residents who received PASARR supports, and one death among nursing home residents with DD who didn't get any DDS supports. Only the two who received or were waiting for DDS supports are counted in this report.

In 2002, about 25% of *all Vermont deaths* occurred in a nursing home (most of the others were in hospitals, or at home). In contrast, only 2 of 37 deaths of Vermonters who received developmental disability services occurred in nursing homes. The rate of placement in a nursing home for a final illness (5%) was dramatically lower for people with DD than for the Vermont population as a whole and much improved over FY 2003, when 30% of DDS deaths occurred in nursing homes. ***In FY 2004 the Developmental Disability Services system excelled in its ability to serve people through final illness in non-institutional settings.***

As in previous years, more people who died were being served in shared living/developmental homes than in any other type of residence. This does not indicate that shared living/developmental homes are more dangerous than other types of supports. In Vermont's developmental disability services system, shared living/developmental homes are the most prevalent type of residential support outside the natural family.¹

Tables on pages 3 and 4 show the age at death of people receiving DDS from FY 2001- FY 2004.

Age at Death for People in Developmental Services in FY 2001, 2002, 2003 and 2004

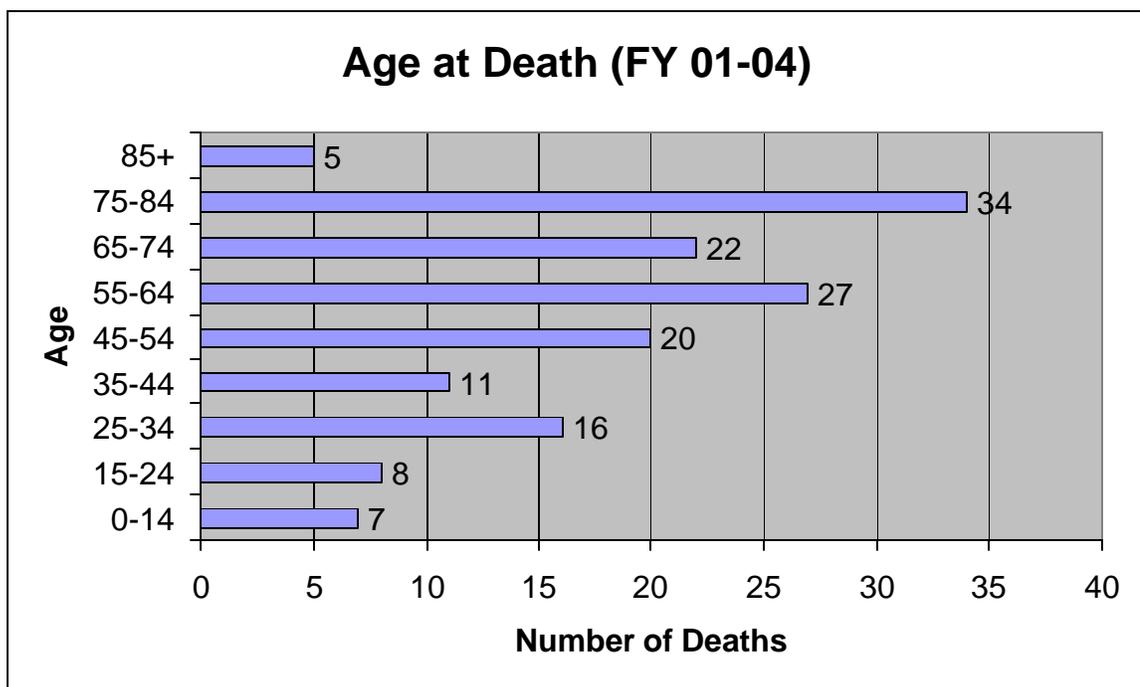
<u>Age</u>	<u>No. of Deaths in FY 2001</u>	<u>No. of Deaths in FY 2002</u>	<u>No. of Deaths in FY 2003</u>	<u>No. of Deaths In FY 2004</u>
0-14	2	2	2	1
15-24	2	1	1	4
25-34	3	4	3	6
35-44	5	0	2	4
45-54	5	6	4	5
55-64	7	4	10	6
65-74	5	9	5	3
75-84	6	10	12	6
85+	1	1	1	2
Total	36	37	40	37
Median (adults)	56	67	62	53
Mean (adults)	53	59	60	52

¹ In FY 04, 911 people lived in shared living/developmental homes. mortality report fy 04

In 2002, 60% of *all Vermonters* who died were 75 or older. Individuals in DDS continue to die at a much younger age than Vermonters as a whole.

The **median** age of death for adults who received DDS supports in FY 2004 was 53. Half the adults who died were older than 53, and half were younger. This is considerably lower than the median age of death in FY 2002, which was 67, and quite a bit lower than the median age of death in FY 2003, which was 62. The **average**² age of death for adults who died in DDS in FY 2004 was 52, as compared with an average age of death in FY 2003 of 60 and FY 2001 of 59.³

There was a dramatic increase in the number of younger people who died (14 between ages 18 and 44) compared with 6 individuals in this age group in FY 03 and 5 individuals in FY 02. Further analysis of this group is found on page 5 under Cause of Death.



Cause of Death

Cause of death for people who received developmental disability services and died in FY 2001-4 was as follows:

² "Average" (mean) is the sum of the age of death for all adults in services divided by the number of deaths.

³ One child under 18 died in FY 2004. He was 3. He is not included in these figures.

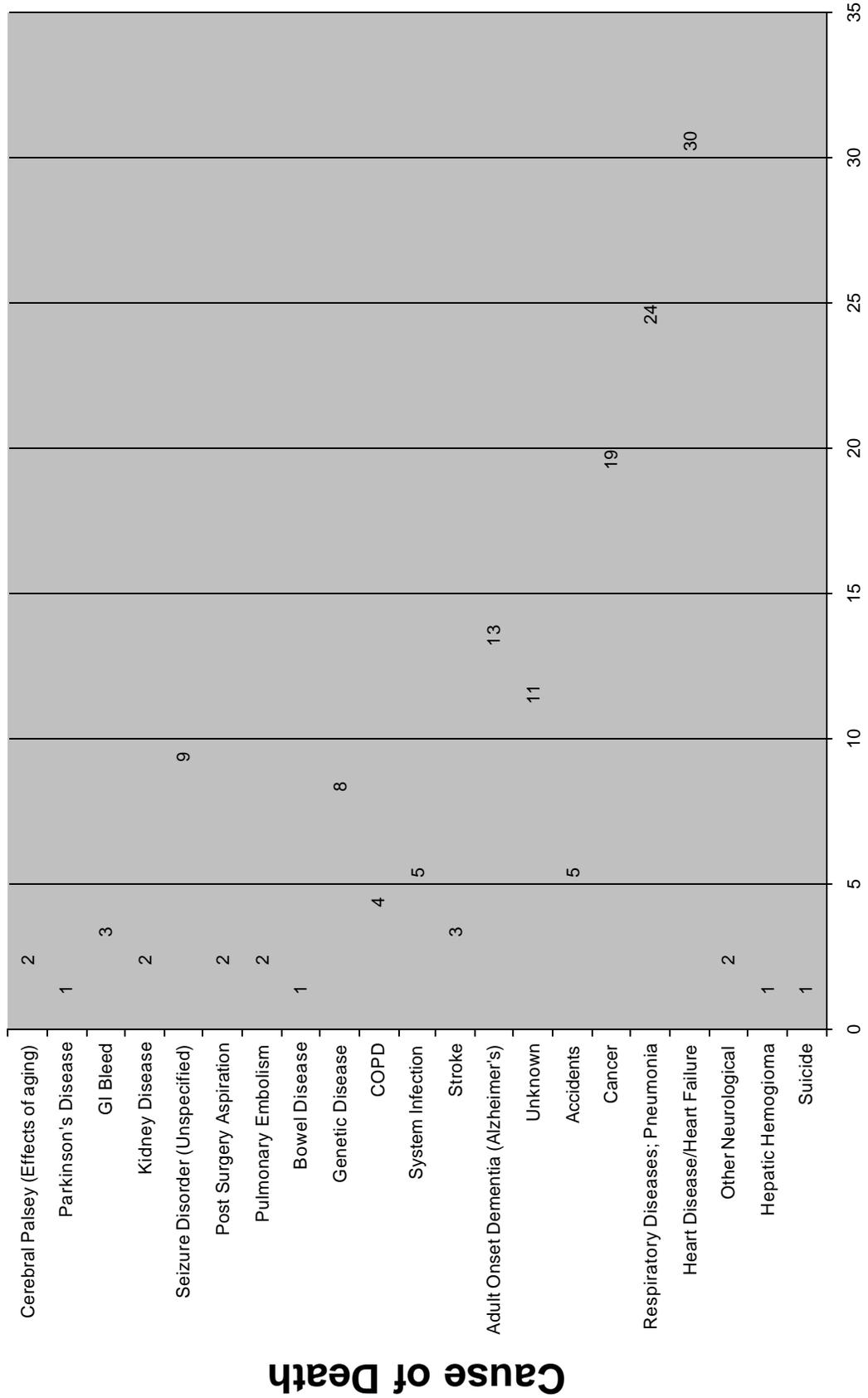
Cause of Death by Major Class FY 2001 - FY 2004

Nervous system (including Parkinson -1, Alzheimer's -13 Neurological disease- 2, Genetic- 8, Seizure -9)	= 33
Heart	= 30
Lung disease/pneumonia	= 28
Cancer	= 19

Detailed Cause of Death for People in DS FY01 - 04

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

Cause of Death (FY 01-04)



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 a contributing cause of death for some people, but it is not listed as the primary cause of death for anyone.

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.

Four deaths are classified as "unknown". Two were individuals who died in the care of their family and the family chose not to share cause of death. One person died unexpectedly, but no autopsy was done due to local errors or misunderstandings. In the fourth case the individual had been in declining health of unknown cause and the family declined autopsy.

In FY 02 we had seen a spike in cancer-related deaths (7), including a possible trend of increased cancers related to smoking. That trend did not continue and we saw instead a marked decline in cancer deaths in FY 03 (5 of 40) and FY 04 (3 of 37). In Vermont, cancer is the second leading cause of death and the rate has been increasing. We have no way of counting the number of people with DDS supports who were successfully treated for cancer, but we have anecdotal knowledge that there are many such people.

Alzheimer's type dementia was a leading cause of death (5 of 37). Three of these individuals died relatively young for Alzheimers (60, 61, 53). These three all had Down Syndrome. The other two Alzheimer's victims were 79 and 76 and did not have Down Syndrome.

Because of specific concern about the increase in deaths among young people, we analyzed the causes of death for the 16 people who died between age 3 and 50 with the following results.

Cause of Death of Individuals in DDS: Age 3 to 50 (FY 2004)

Seizure disorder	4
Cancer	1
Cardiac	1
Neurological or genetic	3
Unknown family didn't share)	2
Unknown (no autopsy)	1
Bowel perforation & hepatic	
Hemangioma	2
Post surgery infection	1
Pneumonia	2

Of specific concern are the four young people who died as a result of seizure disorder. Follow-up on quality of care for people with severe seizure disorders is recommended.

Medico/legal Death

One person died from suicide (drug overdose); there were no homicides or deaths from weapons-related cause.

Accidental Death

There were no accidental deaths.

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.

The identification of a primary physician and cancer screening can reduce mortality and are tracked by the Department of Health as part of their Healthy Vermonters 2010 program.⁴ In these two areas, people in DDS rank well.

Additional attention to quality of monitoring and medical care of people with severe seizure disorders is recommended.

⁴ Access to a primary care physician is Objective No. One of Healthy Vermonters 2010, and regular screening for colorectal, breast and cervical cancer are also primary objectives. In FY 2000 94% of adult Vermont women had had a Pap smear within the past 3 years, and 78% had had a mammogram within the past 2 years.

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 about the same (5 of 40). A recent survey found that the rate of autopsies nationwide for individuals in developmental services programs is about 11%.⁵ In Connecticut, 21% of deaths of people in developmental services were followed up by autopsy.⁶ In some cases where we would have recommended an autopsy, it was not possible because of late reporting or because of 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 04.

⁵ The Columbus Organization. Mortality Review Survey: Survey of the States. Submitted to the California Department of Developmental Services. May, 2002.

⁶ State of CT DMR, Health & Mortality Report (Oct. 2003)