

Department of Public Health and Human Services

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Mortality Report for Persons in Montana Receiving Developmental Disability Waiver Services 2010 through 2019

Introduction

The Mortality Review Work Group meets throughout the year to review deaths of individuals receiving services through the Developmental Disabilities Program of Montana.

The group attempts to discover trends as well as causes of death that could possibly be prevented through education and training.

Due to lower population density than many states, Montana has quite low numbers of deaths of people receiving developmental disability services. This makes it more difficult to detect trends and it is not possible to be confident of the statistical significance of the findings. This report will present data covering 10 years to present a number of deaths that is more meaningful when looking for trends. The data collected for Montana presents individuals 18 years of age and older.

The Numbers:

Deaths: 2010 through 2019

Year	Number of deaths
2010	16
2011	22
2012	17
2013	19
2014	26
2015	38
2016	25
2017	30
2018	30
2019	43
10-year Total	266

Age and Gender:

The ages at the time of death were divided into ten-year increments except for the ages of 18 through 29.

Age and Gender 2010 through 2019

Age	'10	'11	'12	'13	'14	'15	'16	'17	'18	'19	10 yr. totals
18-29	3	3	2	1	2	4	2	1	1	4	23
30-39	1	5	5	1	1	4	3	4	2	3	29
40-49	4	3	3	1	3	3	3	2	5	5	32
50-59	4	6	2	7	11	12	8	11	5	8	74
60-69	4	5	3	6	5	9	8	5	13	14	72
70-79	0	0	2	2	4	5	1	5	2	7	28
80+	0	0	0	1	0	1	0	2	2	2	8
Total	16	22	17	19	26	38	25	30	30	43	266
Median	50.5	50	45	59	54	56	51	55.5	63	60	55
Mean (average)	48.0	46.5	46.8	56.4	54.3	53	52	57	59	57	53.9
Age range	22 - 69	23 - 68	23 - 74	18 - 84	22 - 75	18- 87	20 - 70	26 - 93	23 - 91	18 - 91	18 - 93
Male	6	12	9	7	14	22	13	15	20	21	139
Female	10	10	8	12	12	16	12	15	10	22	127

The average age of death for this 10-year span was 53.9 years. There is a clear increase in the average age at death from the first 5-year span (50.4 years) to the second 5-year span (55.6 years).

Compared to data from other states, the average age of death in Montana is lower though increasing. For Connecticut, the average age of death for fiscal years 2014 through 2018 was 60.3 years. For those same years, the average age of death for persons with developmental disabilities in Montana was 55 years.

The life expectancy for the general population of the United States (2018) was 78.7 years and in Montana (2017) 76.9 years.

Gender:

When comparing gender statistics with other states the percentage of male to female deaths is very close except for calendar year 2018 for Montana. For that single year, male deaths accounted for two thirds of the deaths rather than being closer to half as seen in the other years. Exclusive of 2018 for Montana, male deaths accounted for 50 to 58% and female deaths for 42 to 50% in the states shown.

Comparison of the ratio of male to female deaths for 5 states

Gender comparisons	Year	Male	Female
Montana	CY 2015	22 – 58%	16 – 42%
	CY 2016	13 – 52%	12 – 48%
	CY 2017	15 – 50%	15 – 50%
	CY 2018	20 – 67%	10 – 33%
Connecticut	FY 2016	131 – 57%	99 – 43%
	FY 2017	132 – 57%	99 – 43%
	FY 2018	132 – 54%	113 – 46%
Indiana	CY 2015	217 – 54%	183 – 46%
	CY 2016	231 – 53%	205 – 47%
	CY 2017	217 – 56%	173 – 44%
Massachusetts	CY 2015	254 – 55%	209 – 45%
Virginia	FY 2018	114 – 57%	87 – 43%

Causes of Death

Pneumonia, most often aspiration pneumonia, is the leading cause of death for this population in Montana. Cancer, acute heart problems, dementia/failure to thrive, and seizures along with pneumonia, make up the five leading causes of death.

For the general population of Montana, the five leading causes of death are heart disease, cancer, chronic lung disease, accidents, and strokes. For the United States, the leading causes of death are heart disease, cancer, unintentional injuries, chronic lung disease and strokes.

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Cause of Death for the Years 2010 through 2019

Cause of Death*	'10	'11	'12	'13	'14	'15	'16	'17	'18	'19	10-year totals
Pneumonia	1	6	3	9	12	5	10	11	8	8	73
Cancer deaths, total	4	3	2	0	5	7	2	3	6	3	35
Cardiac arrest/MI	3		1	4	2	9	1	1	3	7	31
Dementia/failure to thrive		1	1	1	1	4	4	2	3	9	26
Seizures	1	2	3	1	3	4	1		1	2	18
Chronic heart disease	2	1	1		1	4	2	2	2		15
GI/bowel disease			1	1		1		1	3	2	9
Stroke/brain aneurysm		3				1	1	1		1	7
Sepsis/infection	1				1		1	4			7
Pulmonary embolus	1	1	1					1	1	1	6
Choking			1						1	4	6
Accidental				3				1		1	5
Chronic lung disease		1					2			1	4
Parkinson's					1	2					3
Anaphylaxis	1	1									2
Genetic disease/condition			2			1			2	2	7
Other	2	3	1				1	3		2	12
TOTALS	16	22	17	19	26	38	25	30	30	43	266

*Explanations

Cancer includes: Colon, gastric, lung, lymphoma, kidney, metastatic with unknown primary, brain, bladder, breast, liver, and skin cancers.

GI/bowel disease includes: pancreatitis, bowel obstruction or perforation, gastric necrosis, GI bleed.

Accidental includes: drug overdose, hypothermia, subdural hematoma from a fall, anaphylaxis, and asphyxia.

Genetic includes: ventriculoseptal defect, myotonic dystrophy, muscular dystrophy, and Sanfilippo syndrome.

Chronic lung disease includes COPD, pulmonary embolus, pulmonary hypertension, but does not include pneumonia.

Other includes: meningioma, complications from surgery, multisystem organ failure, tracheal hemorrhage, and unknown.

Cancer Deaths:

The number of cancer deaths increased by a small amount from the first five years reported (14) to the second five years reported (21), but not significantly. The types of cancer varied though any type of GI cancer was the most common type seen.

Cancer deaths by type	'10	'11	'12	'13	'14	'15	'16	'17	'18	'19	Total
Brain						2					2
Breast		1									1
Lung									1		1
Throat, esophageal, gastric	1					1		1	4	1	8
Colon/rectal	1				1	2	1	1	1	2	9
Liver	1										1
Pancreatic			2		1						3
Ovarian/uterine					2	1					3
Bladder/renal/prostate					1	1	1	1			4
Melanoma	1	1									2
Unknown primary		1									1
Total cancer deaths/year:	4	3	2	0	5	7	2	3	6	3	35

Cancer deaths by type of cancer over 10 years

Hospice Use:

Hospice use has increased over the past 10 years and especially since 2014. The use of hospice services allows Providers and the Developmental Disabilities Program of Montana to support people through the final stages of a terminal or chronic irreversible progressive illness while remaining in their current residence.

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**Number of persons receiving hospice services
and causes of death 2010 through 2019**

Cause of death	'10	'11	'12	'13	'14	'15	'16	'17	'18	'19	10 yr. totals
Pneumonia				2	3	1	2	1	2	2	13
Cancer deaths, total	2	2	2		5	4	2	1	5	2	25
Dementia/failure to thrive		1	1		1	4	4	1	3	9	24
Chronic heart disease			1			4		1	1		7
GI/bowel disease								1		1	2
Stroke/brain aneurysm						1					1
Septicemia/infection					1		1	1			3
Accidental (post fall)				1							1
Chronic lung disease							1				1
Parkinson's					1	1					2
Genetic (cerebral palsy)			1								1
Renal failure										2	2
Hydrocephalus								1			1
TOTALS	2	3	5	3	11	15	10	7	11	16	83
Gender: Male	1	3	3	0	6	8	5	3	7	7	40
Female	1	0	2	3	5	7	5	4	4	9	36
Percent of total deaths/year	12.5	13.6	29.4	15.8	42.3	39.5	40	23.3	36.7	37.2	31.2/ 10 yr.
Age range	54 - 56	35 - 68	40 - 75	53 - 60	30 - 74	31 - 87	49 - 70	52 - 93	38 - 91	43 - 79	30 - 93

Comparisons:

Data from other states was found and comparisons to Montana are shown below. Since limited information was available, the table was adjusted to show only the calendar and fiscal years 2016 through 2018 depending upon how the states reported their data. States may report the cause of death in slightly different categories.

Comparisons of causes of death among four states

Cause of Death	Connecticut* FY 2016- 2018	Georgia CY 2016- 2018	Virginia FY 2016- 2018	Montana CY 2016- 2018	Montana CY 2010 - 2019
Pneumonia**	7.8%	15.3%	15.4%	34.1%	27.4%
Cancer	7%	6.6%	9.4%	12.9%	13.2%
Dementia/ failure to thrive	6%		3.2%	10.6%	9.8%
Cardiac arrest/MI	29.8%	21.6%	11.7%	7.1%	11.7%
Chronic heart disease			7.8%	7.1%	5.6%
Septicemia/infection	4.5%	12%	7.1%	5.9%	2.5%
GI/bowel disease	1.5%		2.3%	4.7%	3.4%
Seizures		5.4%	2.9%	2.4%	6.8%
Stroke/ brain aneurysm	3.2%		2.0%	2.4%	2.6%
Chronic lung disease	23.4%	10.8%	7.0%	2.4%	1.5%
Genetic disease or condition		12.4%	3.6%	2.4%	2.6%
Renal disease	3.0%	3.7%	3.5%		1.1%
TOTAL DEATHS	696	546	818	85	266

FY = Fiscal Year. CY = Calendar Year

*Connecticut covers all ages including children

**Pneumonia includes aspiration pneumonia

Summary:

Due to small numbers and differences in reporting among the states, the data presented may not be statistically significant, however it is worth reviewing. To impact deaths, especially at the young ages often seen, it is imperative to promote lifestyles that will prevent underlying health issues, such as obesity, which contribute to developing chronic lung disease and heart disease. It is important to review ways in which aspiration can be prevented. It is also imperative that persons in services obtain evaluation and treatment in a timely manner.

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The number of deaths due to choking increased significantly in 2019. To help prevent further choking deaths, a Choking Risk Screening Tool was developed based on one in use in Ohio. This screening tool will help Providers identify clients at an increased risk for choking. A Power Point Presentation “Choking Prevention” was also developed and presented to Providers on a Contractor call. This is available on the DDP website. The Providers who had deaths due to choking in 2019 worked with QIS staff and the DDP Medical Director to improve or develop eating protocols. Clients at increased risk for choking were identified and swallowing evaluations were done as indicated.

When reviewing investigations, it is often noted that clients have a POLST in place without a terminal illness. For a POLST with a do not resuscitate order in it to be valid, there must be a proper terminal illness diagnosis. Once a terminal illness is established, the POLST must be signed by either a family member, someone with appropriate medical power of attorney, or a guardian with end of life making decision authority granted by the court. That authority is separate from the authority granted by a full guardianship.

Invalid Advance Directives are also sometimes seen. Some clients who do not have the capacity to understand what an Advance Directive means, have had one signed by a family member or guardian. Those Advance Directives are invalid as the only person who should and can sign an Advanced Directive is the person for whom it pertains. The person signing must have capacity to understand it's meaning.