Eunice Kennedy Shriver Center
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2012 & 2013 Mortality Report

Commonwealth of Massachusetts

Executive Office of Health & Human Services

Department of Developmental Services

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Dear Colleagues and Friends:

Enclosed is the Department of Developmental Services Annual Mortality Report for calendar year 2012-2013. The report is compiled by the Center for Developmental Disabilities Evaluation and Research (CDDER), of the University of Massachusetts Medical School. The report analyzes information on all deaths occurring in calendar year 2012 and 2013 for all persons 18 years of age or older who have been determined to be eligible for DDS supports. This is the ninth year in which DDS has commissioned an independent review of all deaths.

The report is a significant component of the Department's quality management system and reflects DDS's ongoing commitment to reviewing and learning from critical information gathered regarding individuals within our system. DDS is committed to a thoughtful and detailed review of deaths of individuals we support and the opportunity such a review presents for organizational learning. Massachusetts is one of but a handful of states that compiles mortality information. We are proud of the fact that data from this report informs the Department's on-going service improvement efforts.

With the assistance of CDDER, DDS has made significant progress in improving our standardized reporting systems, strengthening our clinical mortality review process and improving the comparability of our data to state and national death statistics.

This report is reviewed by the Statewide Mortality Review Committee as well as our Statewide Quality Council to assist DDS in its ongoing commitment to supporting the health and quality of life of the individuals we support. I remain committed to the importance of this independent mortality report as a vital and critical component of the Department's quality management and improvement system and an important step in our shared organizational learning process.

Sincerely yours,

Elin M. Howe
Commissioner

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Executive Summary

This report presents population and mortality information about adult (18 years of age and older) service recipients of the Massachusetts Department of Developmental Services (DDS) for the two year period between January 1, 2012 and December 31, 2013.

Annual mortality reports are part of the Massachusetts DDS' robust quality management and improvement system. DDS' established process for mortality review and death reporting provide the data included in this report. Mortality findings are used to inform quality improvement efforts for supports provided by DDS. The report is written by the University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER), which has prepared annual reports on mortality within this population of Massachusetts citizens since the year 2000.

In the middle of calendar year 2012, the Massachusetts DDS served 22,862 adults (18 years of age and older) with intellectual disabilities. In the middle of calendar year 2013, the Massachusetts DDS served 23,446 adults (18 years of age and older) with intellectual disabilities. Between 2011 and 2012, the population decreased by 4.5% mostly in younger age groups, and between 2012 and 2013 it increased by 2.6%. Shifts may be observed due to people aging into adjoining age bands, consumers relocating out of the state, and consumers that have died.

A total of **438 deaths** occurred for people eligible for DDS services in 2012, resulting in a crude adult mortality rate of **19.2 deaths per thousand people**. In 2013, a total of **409 deaths** occurred for people eligible for DDS services, for a crude mortality rate of **17.4 deaths per thousand people**. The average age at death of adults in the DDS population was 62.5 years in 2012 and 61.1 years in 2013. Statewide mortality statistics in 2013 do not show a significant change in the rate of death for the population from 2012.

Patterns of mortality in the DDS population are influenced by a number of factors:

- **Age**: Mortality rates show a proportional relationship with advancing age – the youngest age groups have the lowest rates of death and the mortality rate increases with age. The average age of death was similar to prior years.
- **Gender**: A statistically significant difference was observed in mortality by gender with females experiencing a higher rate of death than males in 2012 and 2013. This difference was not observed in 2010 and 2011, but was seen in prior years.
- **Residential Setting:** Consistent with expectations, substantial differences in mortality exist between residential settings. Mortality rates are lowest in people living at home or with family (5.7 per thousand and 5.8 per thousand), who tend to be younger than people in other residential settings. Mortality rates are highest for people living in nursing homes (112.6 per thousand and 120 per thousand) and DDS Facilities (57.9 per thousand and 43.6 per thousand) due to advanced age and/or serious health conditions. In both 2012 and 2013, the average age of death for people living in nursing homes fell slightly to 59 years due to multiple deaths of young adults with substantial medical needs living in pediatric nursing homes. The relationship between type of residence and mortality are consistent with prior years and with trends present in other state intellectual disability systems. Rates of death in the 'DDS Community' were similar across years (29.8 per thousand and 26.7 per thousand).

Causes of Death:

- Heart disease was the leading cause of death in 2012 and 2013, in alignment with prior years and national patterns. However, the rate of death from this cause fell in 2013 to 2.4 per thousand. In fact, only 1 death separated it from the next ranked cause, cancer.

- Cancer was the second leading cause of death in 2012 and 2013, accounting for 13.4-13.7% of deaths each year. The top causes of cancer deaths include lung cancer, colon cancer and female breast cancer. Findings suggest a greater opportunity for the use of preventive screenings for breast and colorectal cancers. People with intellectual and developmental disabilities may require support to overcome barriers to screening, which include individual-level, interpersonal and environmental challenges.
- Alzheimer's disease was the third leading cause in both years with 12.2-13.0% of deaths. There proportion of deaths and the rate of deaths from this cause increased in 2012 compared to previous years, but the rate fell slightly in 2013. Of the 2012 deaths due to this cause, 58% of people had Down Syndrome. Also, 48% of all deaths in people with Down Syndrome were due to Alzheimer's disease.
- Aspiration pneumonia was the fourth leading cause of death in 2013 and the fifth leading cause in 2012. Each year it was the underlying cause of death for 8.6% to 9.4% of deaths; additionally a substantial proportion of the deaths due to Alzheimer's disease, chronic lower respiratory diseases and septicemia also involved aspiration pneumonias.
- Septicemia was the fourth leading cause of death in 2012 and 2013 (tied with aspiration pneumonia). It was the underlying cause of death for 10% of deaths in 2012 and 7.1% in 2013. Most cases of septicemia began as aspiration pneumonias and/or urinary tract infections (UTIs).
- Chronic Lower Respiratory Diseases were the fifth leading cause of death in 2013 and the seventh in 2012. In many cases, chronic aspiration pneumonias have contributed to the long-term lung damage of people dying from this condition.
- By Residential Setting: The distribution of causes of death within residential settings was generally similar to previous years. In the DDS Community, top causes remained Alzheimer's disease, heart disease, and cancer. For people living on their own or with family, top causes were cancer and heart disease; notably septicemia was the second leading cause of death in 2012, and diabetes is the fourth ranked cause in 2013 for this subgroup.
- Benchmarking: Leading causes of death, including cancer and heart disease, are similar in both rank and cause-specific adult mortality rates to the general population of Massachusetts. Certain leading causes differed from the general population, with higher mortality rates from influenza and pneumonia, aspiration pneumonia, and septicemia in the population served by MA DDS. Compared to other state systems serving people with similar, attributable mortality was similar in causes such as heart disease, pneumonias and septicemia, and higher for Alzheimer's disease and cancer. The population also met many of the Healthy People 2020 mortality-related targets, except for certain types of cancer, stroke and unintentional injuries.

2012 and 2013 Mortality Report

INTRODUCTION

This report presents population and mortality data for adults (18 years of age and older) eligible for services from the Massachusetts Department of Developmental Services (DDS) during the periods of January 1 and December 31, 2012 (calendar year 2012) and January 1 and December 31, 2013 (calendar year 2013). The mortality information in this report includes all adults who were eligible to receive services ("consumers") in the Meditech Consumer System during these periods and who died during the calendar year.

The Massachusetts DDS utilizes a formal process for reviewing and reporting instances of mortality. This process, instituted in 1999, is an integral component of the Department's robust quality management and improvement system. Through this process, DDS reviews the causes and circumstances of the deaths of people it supports, and uses the findings to inform quality improvement efforts of the Department. As part of this effort, the University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER) has prepared annual reports on mortality of this population of Massachusetts citizens since the year 2000. In order to prepare each annual report, CDDER compiles mortality information from DDS records as well as other external sources and performs mortality and population analyses contained in this report.

DDS Clinical Mortality Review

Clinical mortality reviews are conducted by the DDS Mortality Review Committee for deaths of people served by DDS who:

- **Are at least 18 years of age;**
- **Receive a minimum of 15 hours of residential support that is provided, funded, arranged or certified by DDS;**
- **Died in a day support program funded or certified by DDS;**
- **Died in a day habilitation program; or**
- **Died during transportation funded or arranged by DDS.**

Not all of the people served by DDS who die meet the criteria for a clinical mortality review. See the section on mortality review for a more detailed description of the process. This report includes both deaths of people that received a clinical review, and those that did not.

OVERVIEW OF POPULATION SERVED BY DDS

Since the population served by DDS fluctuates over the course of the year, the midyear population is used as an estimate of the annual population in this report. In the middle of calendar year 2012, the Massachusetts DDS served 22,862 adults (18 years of age and older) with intellectual disabilities. A net decrease of about 4.5%, or 1,065 people, was seen in the mid-year adult consumer population from June 2011 to June 2012.

In the middle of calendar year 2013, the Massachusetts DDS served 23,446 adults (18 years of age and older) with intellectual disabilities. A net increase of about 2.6%, or 584 people, was seen in the mid-year adult consumer population from June 2012 to June 2013. See Appendix B for more details annual population changes.

The population served by DDS tends to be younger than the general population, with a smaller proportion of people living into older age groups (e.g. 65 years and older). About 50% of the population lives in their own home independently or with family, about 40% living in community-based supported residential settings, and the remainder live in other settings including nursing homes, facilities and other staff-supported locations. See Appendix B for more details on age, gender and residential setting distributions.

MORTALITY DURING 2012 & 2013

This section contains information on the deaths of people with intellectual disabilities who were 18 years of age or older at the time of death and who were eligible for DDS services during calendar years 2012 and 2013. Appendix A describes the methodology used to collect and analyze the information and data contained in this section.

Mortality Statistics

A total of **438 deaths** occurred for people eligible for DDS services in 2012, resulting in a crude adult mortality rate[a] of **19.2 deaths per thousand people**.[1] In 2013, a total of **409 deaths** occurred for people eligible for DDS services, for a crude mortality rate of **17.4 deaths per thousand people**. Changes in mortality rate were not significantly different between 2011 and 2012, and between 2012 and 2013.[b]

The average age at death of adults in the DDS population was 62.5 years in 2012 and 61.1 years in 2013. The median age at death[c] of adults in the DDS population was **63.3 years in 2012** and **62.2 years in 2013.**

Table 1
Mortality Trends in DDS, 2009 - 2013

Year	No. Deaths	Mortality Rate (No. Deaths/1000)	Ave. Age at Death (in years)
2009	421	17.6	58.7
2010	406	16.6	61.5
2011	440	18.4	61.1
2012	438	19.2	62.5
2013	409	17.4	61.1

[a] The crude death rate is a measure of how many people out of every thousand served by DDS died within the calendar year. It is determined by multiplying the number of people who died during the year times one thousand and dividing this by the total number of people served by DDS during the same year. The crude death rate can be useful when comparing deaths across populations of varying sizes.

[b] For 2011 to 2012, χ=0.36, d.f.=1; for 2012 to 2013, χ=0.97, d.f.=1

[c] Median = the middle age if all deaths were ranked by age

The number of deaths for people served by DDS was slightly lower in 2012 and 2013. Table 1 shows the deaths, mortality rates and average age at death for the DDS population for 2009 through 2013. The mortality rate and average age at death increased slightly in 2012 (19.2 per thousand and 62.5 years) and then decreased to numbers consistent with previous years.

CAUSES OF DEATH

The following section presents information about the causes of death for adults served by the Massachusetts DDS during 2012 and 2013. The World Health Organization's International Classification System for Diseases (ICD-10) is used in this report to assign the basis for death.[d] Appendix C contains the specific ICD-10 codes included in each cause of death category. Consistent with the current standard in mortality reporting, this report assigns cause of death with a focus on underlying causes. This methodology is used in national and state reports, and has been used in Massachusetts DDS mortality reports since 2001.

> *"A cause of death is the morbid condition or disease process, abnormality, injury, or poisoning leading directly or indirectly to death. The underlying cause of death is the disease or injury which initiated the train of morbid events leading directly or indirectly to death or the circumstances of the accident or violence which produced the fatal injury."*[2]

The information used to determine the causes of death was obtained from the DDS Death Report (an electronic system) and the Death Certificate. In the case of people subject to clinical mortality review, the cause may have been confirmed by the DDS Mortality Review Committee.[e] Table 2 shows cause-specific mortality rates for the major causes of death in the DDS population for the four year time period between 2010 and 2013.[f]

Table 2
Cause-specific DDS Mortality Rates, 2010-2013

2013 Rank	2012 Rank	Previous (2011) Rank	Cause of Death	DDS Rates of Death (per thousand)			
				2010	**2011**	**2012**	**2013**
1	1	1	Heart Disease	3.0	3.2	3.1	2.4
2	2	2	Cancer	2.3	2.3	2.6	2.5
3	3	3	Alzheimer's Disease	2.1	2.0	2.5	2.1
4	5	4	Aspiration Pneumonia	2.0	1.5	1.8	1.5
	4	5	Septicemia	1.4	1.4	1.9	1.5

[d] It is the same classification system used by the Massachusetts Department of Public Health (DPH) Vital Statistics and the Federal Centers for Disease Control and Prevention National Center for Health Statistics (NCHS). These agencies prepare the Massachusetts state mortality report and the national mortality report, respectively.

[e] In some cases, additional reports were available, such as toxicology, autopsy or medical examiner reports. See the Mortality Review Process and Committee section of this report for clinical review criteria.

[f] Rates are subject to annual fluctuations based on minor changes in the number of deaths in this small population.

6	7	8	Chronic Lower Respiratory Disease	0.8	0.7	0.9	1.2
7	8	6	Influenza and Pneumonia	0.7	1.3	0.7	0.9
8	9	8	Gastrointestinal	0.3	0.7	0.6	0.6
9	6	7	Unintentional Injury	0.4	0.9	0.9	0.6
10	14	12	Stroke	0.7	0.4	0.3	0.5

Table 3
Top 10 Leading Causes of Death

Rank	U.S. 2012[3]	MA 2012[4]	DDS 2008	DDS 2009	DDS 2010	DDS 2011	DDS 2012	DDS 2013
Age inclusion	**All ages**	**15+**	**18+**					
1	Heart Disease *23.6%*	Cancer *24.3%*	Heart Disease *18.7%*	Heart Disease *16.6%*	Heart Disease *18.0%*	Heart Disease *17.5%*	Heart Disease *16.0%*	Heart Disease *13.7%*
2	Cancer *22.9%*	Heart Disease *21.9%*	Alzheimer's Disease *14.1%*	Alzheimer's Disease *15.2%*	Cancer *13.8%*	Cancer *12.7%*	Cancer *13.7%*	Cancer *13.4%*
3	CLRD *5.6%*	CLRD *4.8%*	Aspiration Pneumonia *11.2%*	Cancer *13.3%*	Alzheimer's Disease *12.8%*	Alzheimer's Disease *10.9%*	Alzheimer's Disease *13.0%*	Alzheimer's Disease *12.2%*
4	Stroke *5.1%*	Stroke *4.5%*	Cancer *8.7%* Septicemia *8.7%*	Aspiration Pneumonia *7.6%*	Aspiration Pneumonia *12.3%* Septicemia *8.6%*	Aspiration Pneumonia *8.0%*	Septicemia *10.0%*	Aspiration Pneumonia *8.6%* Septicemia *8.6%*
5	Unintentional Injuries *5.0%*	Unintentional Injuries *4.1%*	CLRD *5.7%*	Influenza & Pneumonia *6.9%*		Septicemia *7.7%*	Aspiration Pneumonia *9.4%*	
6	Alzheimer's Disease *3.3%*	Alzheimer's Disease *3.2%*	Influenza & Pneumonia *6.3%*	Septicemia *6.4%*	CLRD *4.7%*	Influenza & Pneumonia *7.0%*	Unintentional Injury *4.8%*	CLRD *6.6%*
7	Diabetes *2.9%*	Influenza & Pneumonia *2.6%*	CLRD *4.9%* Stroke *4.0%*	CLRD *6.2%*	Influenza & Pneumonia *4.4%*	Unintentional Injury *4.8%*	CLRD *4.6%*	Influenza & Pneumonia *5.4%*
8	Influenza & Pneumonia *2.0%*	Nephritis *2.4%*		C-P Arrest/ Seizure *5.2%*	Stroke *3.9%*	C-P Arrest/ Seizure, CLRD, Gastro-intestinal Conditions *3.9% each*	Influenza & Pneumonia *3.9%*	Gastro-intestinal Conditions *3.4%*
9	Nephritis & Other Renal Diseases *1.8%*	Ill-defined conditions, signs, and symptoms *2.1%*	Unintentional Injuries *3.7%*	Unintentional Injuries *4.3%*	Congenital anomalies, Nephritis & Other Renal Diseases *3.0%*		Gastro-intestinal Conditions *3.0%*	Unintentional Injury *3.2%*
10	Suicide *1.6%*	Diabetes *2.1%*	C-P Arrest/ Seizure *3.3%*	Nephritis & Other Renal Diseases 2.9%	C-P Arrest/ Seizure *3.3%*		Congenital anomalies *2.7%*	Stroke 2.9%

**CLRD = Chronic Lower Respiratory Disease; C-P Arrest = Cardiopulmonary Arrest

The top ten causes of death in the DDS client population for 2012 and 2013 are compared with data from previous years and with state and national data in Table 3.

The cause of death for six 2012 decedents and seven 2013 decedents was unknown. In these cases, the causes were listed as unknown on death certificates or the certificate was unavailable due to an out of state death.

Table 4 compares the adult mortality rates for leading causes of death between the Massachusetts general population, and the population served by MA DDS.

Table 4
Comparison of Adult[g] Cause-specific Mortality Rates[28]
Between MA DDS and MA General Population

Cause of Death	State of MA 2013	MA DDS			
		2010	2011	2012	2013
Heart Disease	2.2	3.0	3.2	3.1	2.4
Cancer	2.3	2.3	2.3	2.6	2.3
Alzheimer's Disease	0.30	2.1	2.0	2.5	2.1
Aspiration Pneumonia	unknown	2.0	1.5	1.8	1.5
Septicemia	0.15	1.4	1.4	1.9	1.5
Influenza & Pneumonia	0.28	0.7	1.3	0.7	0.9
Unintentional Injury	0.44	0.4	0.9	0.9	0.6

This comparison shows that the rate of deaths due to cancer in the MA DDS population is very similar to that of the general population of the state. Additionally, the rate of heart disease in 2013 for those served by MA DDS approaches that of the general population, but was higher in previous years. Mortality rates for MA DDS due to influenza and pneumonia, septicemia and aspiration pneumonia substantially exceed the adult mortality rates in the general population. In some years, the rate of unintentional injuries is greater than the general population, and in some years it is below.

Heart Disease. Heart disease was the leading cause of death in both 2012 and 2013, consistent with previous years. In 2013, there was a decrease in the rate due to this cause (2.4 per thousand, compared with 3.1 per thousand in 2012); it was only separated into the top cause by the difference of one death from the next most prevalent cause, cancer. This decrease is in line with state findings. Heart disease as the second leading cause is consistent with the Massachusetts general population which experienced a similar shift in prior years. However, the U.S. general population still experiences heart disease as the leading cause.

Cancer. Cancer accounted for 13.7% of deaths in 2012 and 13.4% in 2013, and had an adult cause-specific mortality rate of 2.3-2.6 per thousand. The primary sites of cancers causing death in 2008 are ranked in Table 5. In both 2012 and 2013, lung cancer and colorectal cancer were among the top causes. Deaths related to female breast cancer were lower in 2012 than in previous years, and the second most frequent cause of cancer in 2013. Annual fluctuation in other causes is typical for this small population; interestingly pancreatic cancer has been among the most frequent primary site in both

[g] MA General population includes people aged 15 years and older, MA DDS population includes people aged 18 years and older.

years. Adult mortality rates of lung cancer (0.2 – 0.4 per thousand) are similar to the all-age mortality rate for the general population of Massachusetts (0.4 per thousand)[28], despite lower rates of smoking in the population served by DDS. However, adult mortality rates of colorectal cancer are higher in the population served by DDS (0.3 -0.5 per thousand) than all-age mortality rate for the MA general population (0.13 per thousand).

Table 5
Top Primary Sites for Cancer Deaths in the DDS Population, 2012-2013

2012			2013		
Primary Site	**Number of Deaths**	**Mortality Rate (per thousand)**		**Number of Deaths**	**Mortality Rate (per thousand)**
Trachea, bronchus & lung	10	0.4	Colon, rectum & anus	11	0.5
Colon, rectum & anus	7	0.3	Female Breast	7	0.3
Pancreas	5	0.2	Leukemia; Ovary; Pancreas; and Trachea, bronchus & lung	4 each	0.2
Esophagus; Lymphoma	4 each	0.2			

Causes ranked by Rate per 1,000

Numerous studies show that people with developmental and intellectual disabilities experience a range of barriers to preventive screenings for cancers including colorectal and female breast cancer.[5] **People with intellectual and developmental disabilities may require support to overcome these barriers to screening, which include individual-level, interpersonal and environmental challenges**. Rates of preventive screening for adults served by DDS are below those of the general population for colorectal cancer screening and female breast cancer.[6] Strong social support systems are associated with people with intellectual and developmental disabilities reporting "better understanding of the importance of cancer screening and… more desire to engage in preventive health measures".[5] Additionally, provider communication about the importance of screenings, and how to prepare for and access the screenings is an important factor in successful screening.[7,8,9]

More research is needed on cancer incidence and prevalence among individuals with intellectual disabilities.[10] Medical literature suggests that people with intellectual disabilities of certain etiologies may be predisposed to certain types of cancers[11,12,13,14] (such as colorectal cancer) and that cancer may develop at significantly younger ages in this population (e.g. colorectal cancer around age 35[11]). This is particularly true for people who have genetically-caused disabilities. For example, people with Down Syndrome (a genetically caused syndrome) have a greater risk of leukemia and testicular and ocular tumors, but appear to have a lower risk for many other types of cancers.[15,16] Recent research suggests that changes in the genes that cause certain syndromes may also cause conditions in the body that increase the risk of specific cancers.[17] Beyond genetics, there may be other lifestyle factors or associated conditions that can change risk of cancer. For example, people with chronic gastrointestinal problems, including infection with certain bacteria commonly found in group settings, may also be at increased risk for stomach

and colorectal cancer.[18,19] People with these disability may be at lower risk of developing certain cancers because they are not exposed to the cause of the cancer, such as cancers related to occupational chemical exposure. Women who do not engage in sexual activity will have a lower risk of cervical cancer, and people who do not use tobacco products will have lower risks of lung cancer and oropharyngeal (mouth/neck) cancers.

Alzheimer's Disease. Alzheimer's disease was the third leading cause of death in both 2012 and 2013 with 12.2-13.0% of deaths. In order for a death to be listed as due to Alzheimer's Disease, the person must have had the disease for 2 or more years and be in an advanced stage of the disease. In the past 5 years, the rate of death for this cause has ranged from 2.0 per thousand to 2.5 per thousand.

There is also evidence to suggest that the prevalence of Alzheimer's disease in those with intellectual disabilities, especially Down Syndrome, is higher than in those with no intellectual disabilities,[20] and may develop at younger ages (as early as 35) for people with Down Syndrome.[21,22,23] It is estimated that at least half of all people with Down Syndrome who live into their sixties will develop Alzheimer's disease.[24,25] The higher prevalence and earlier onset of Alzheimer's disease in people with Down Syndrome, together with the degenerative nature of the disease are part of the reason this is a more frequent cause of death in this population. In fact, the majority of deaths from Alzheimer's disease in the MA DDS population are in people with Down Syndrome (e.g. 58% in 2012).

Pneumonia

As with past reports, deaths due to pneumonia are distinguished as either (a) pneumonia due to acute infection (Influenza and Pneumonia) or (b) pneumonia due to aspiration of liquids and solids (Aspiration Pneumonia).

Aspiration Pneumonia. Aspiration pneumonia was the fourth leading cause of death in 2013, tied with septicemia, with 8.6% of deaths and the fifth leading cause in 2012 with 9.4% of deaths. Mortality rates ranged from 1.5 to 1.8 per thousand for this cause, consistent with previous years.

Aspiration, choking and resultant pneumonias are a substantial source of morbidity and mortality in people with I/DD that is not seen to the same extent in the general population. The benchmarking section, later in this report, discusses the impact of these issues in other I/DD systems. This form of pneumonia is the result of the entry of unwanted substances (secretions, food, vomitus) into the lungs, which can occur from coughing or choking while eating or may occur 'silently' as reflux from the stomach. The entry of these substances into the lung irritates the tissue and can lead to infection. People with abnormal swallowing mechanisms from neurological conditions, physical deformities, long-term medication side effects, gastro-esophageal reflux (GERD), chronic lung disease, or mealtime respiratory distress are at risk to develop aspiration pneumonia.[26] Current treatment options, such as modified food consistency, assessments for appropriate positioning or surgical interventions (like G- or J-tubes), are available to help people who are unable to swallow effectively, although they may provide incomplete protection from recurrence of illness. Aspiration pneumonia is also often a contributing factor in deaths categorized as due to Alzheimer's disease or septicemia.

Table 6
Distribution of Deaths by Age Group, 2012-2013

Age Range	2012			2013		
	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)
18-24	9	2.1%	1.9	16	3.9%	3.3
25-34	24	5.5%	5.1	20	4.9%	4.1
35-44	24	5.5%	6.6	28	6.8%	7.8
45-54	67	15.3%	14.9	80	19.6%	17.7
55-64	114	26.0%	36.7	89	21.8%	27.5
65-74	103	23.5%	65.0	84	20.5%	51.5
75-84	65	14.8%	115.2	56	13.7%	94.4
85 yrs & older	32	7.3%	231.9	36	8.8%	260.9
Total	438	100.0%	19.2	409	100.0%	17.4

The relationship between age and rate of death for adults served by DDS is displayed in Figure 1. The line in Figure 1 illustrates the increase of mortality rate with age. In the elderly age groups (age 65+) mortality rates are the highest, showing sharp increases compared to younger age groups. These higher rates reflect the expected increase in risk of mortality for adults of advanced age. A very similar pattern between rate of death and age was seen in 2011, 2012 and previous years.

GENDER

Gender proportions vary with age in the population served by DDS, and a complex relationship exists between gender and mortality. While females tend to live slightly longer (2.1 years in 2012 and 3.7 years in 2013), females served by DDS experience higher death rates than their male counterparts. As noted earlier, there are a higher proportion of females in older age groups which have a higher death rate. These trends are consistent with previous years.

Table 7
No. Deaths, Average Age at Death and Death Rate by Gender, 2012

Gender	Adult Population	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	10,014	201	45.9%	63.6	20.1
Male	12,848	237	54.1%	61.5	18.4

Tables 7 and 8 display the adult population, number of deaths, percent of overall deaths, average age at death and rate of death for each gender. The adult mortality rate for females is 20.1 per thousand in 2012 and 18.2 per thousand in 2013. For males, the adult mortality rate was 18.4 per thousand in 2012 and 16.9 per thousand in 2013.

Table 8
No. Deaths, Average Age at Death and Death Rate by Gender, 2013

Gender	Adult Population	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	10,233	186	45.5%	63.1	18.2
Male	13,213	223	54.5%	59.4	16.9

RESIDENCE

Adults eligible for DDS services live in one of five general types of residential settings: their own home independently or with family; community settings operated, funded or certified by DDS; residential programs that are not part of the DDS system; facilities operated by DDS; and nursing homes or other long-term care settings. Specific definitions, including residential codes, are contained in Appendix B. Mortality statistics for these residential categories are displayed in Tables 4 and 5.

Age and Residence

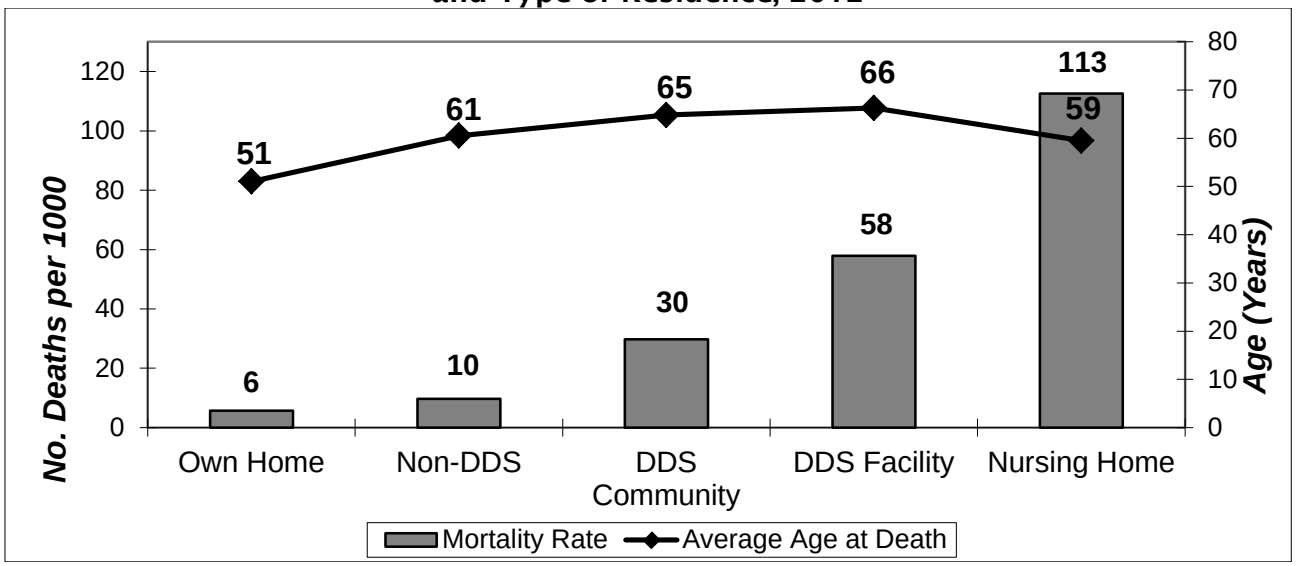
The average age at death varies across residential settings. Generally, the average age at death for each residential setting is reflective of the relative age and the health status of the population that resides in each setting. Historically, in the DDS population, the rate of death is higher in residential settings which have a higher average age at death. This is an expected finding since age is highly correlated with risk of mortality. However, the average age of death in nursing homes decreased from 71 in 2011 to 59 in both 2012 and 2013. This pattern differs from previous years when the average age of death trend line increased across care settings by order of intensity of services provided. In both years, the average age of death in nursing homes was lowered due to more deaths of young adults with complex health needs residing in pediatric nursing homes. The decrease in average age of death among DDS clients residing in nursing homes may be reflective of the increase of health complexity among individuals residing in nursing homes as individuals with less intensive needs transition to community settings[27], and may also be affected by more children with complex health needs living into early adulthood.

As shown in Tables 9 and 10, the average age at death was lowest for people living in their own home (51.1 years in 2012 and 49.4 years in 2013). The average age at death was highest for those living in DDS Community (64.8 years in 2012 and 64.6 years in 2013) and DDS Facility settings (66.3 years in 2012 and 62.8 years in 2013). The average age of adults served by DDS who reside in their own home and in DDS Community settings is often younger than those who reside in DDS Facilities or nursing homes. Because of this discrepancy, average age of death is often lower for individuals residing in their own homes and in community settings.

Table 9
Age and Mortality by Type of Residential Setting, Adults Served by DDS, 2012

Residential Setting	Adult Population (No. People)	% of DDS population[h]	% of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home	11,034	48.3%	5%	63	14.4%	51.1	**5.7**
DDS Community	9,767	42.7%	15%	291	66.4%	64.8	**29.8**
Non-DDS	2,268	9.9%	11%	22	5.0%	60.5	**9.7**
DDS Facility	622	2.7%	32%	36	8.2%	66.3	**57.9**
Nursing Home	231	1.0%	27%	26	5.9%	59.5	**112.6**
Total (Statewide)	22,862	100.0%	11%	438	100.0%		**19.2**
Average						62.5	

Figure 2
Relationship between Mortality Rate, Average Age at Death, and Type of Residence, 2012

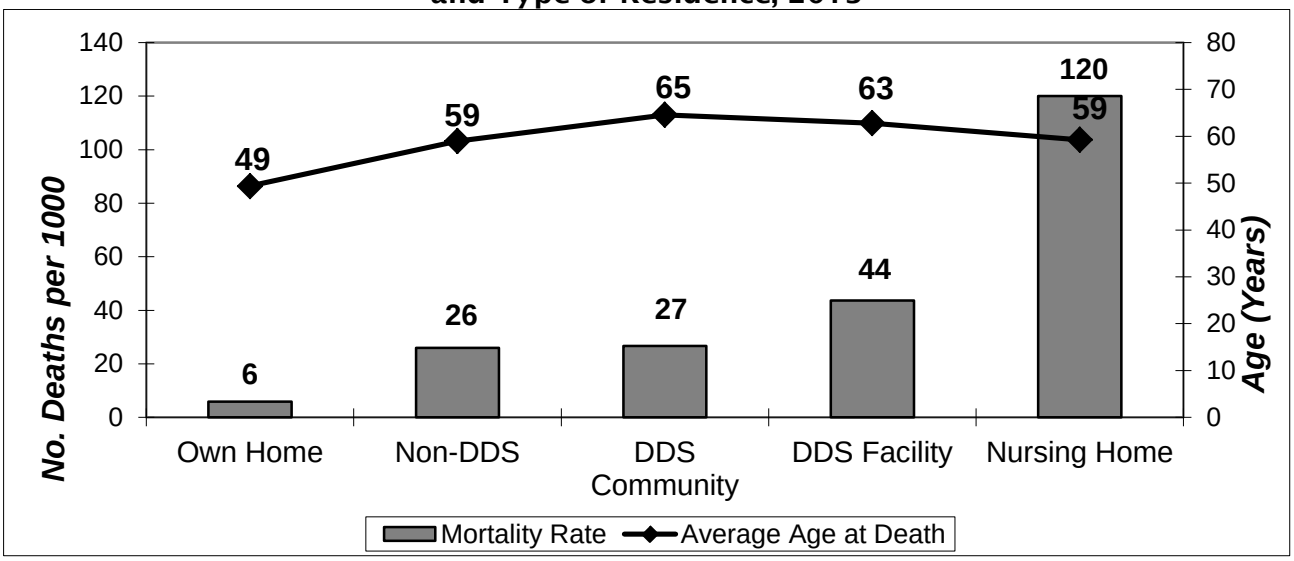


[h] Total may sum to greater than 100% due to duplication in enrollment data.

Table 10
Age and Mortality by Type of Residential Setting, Adults Served by DDS, 2013

Residential Setting	Adult Population (No. People)	% of DDS population[i]	% of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home	11,822	50.4%	5%	69	17%	49.4	5.8
DDS Community	9,528	40.6%	16%	254	62%	64.6	26.7
Non-DDS	1,466	6.3%	14%	38	9%	59.0	25.9
DDS Facility	550	2.3%	32%	24	6%	62.8	43.6
Nursing Home	200	0.9%	25%	24	6%	59.2	120.0
Total (Statewide)	23,446	100.0%	11%	409	100%		17.4
Average						61.1	

Figure 3
Relationship between Mortality Rate, Average Age at Death, and Type of Residence, 2013



The settings with the highest mortality rates for 2012 and 2013 were nursing homes, DDS Facilities, and DDS Community settings. These patterns are consistent with previous years. From 2012 to 2013, there was an increase in mortality rate among individuals residing in Non-DDS settings (9.7 per thousand to 25.9 per thousand). These settings include inpatient facilities run by other state agencies, Adult Foster Care settings, homeless shelters, and assisted living settings. The wide variety of Non-DDS settings and

[i] Total may sum to greater than 100% due to duplication in enrollment data.

the small proportion of the population residing in these settings may account of inconsistencies in mortality data from year to year. Additionally, shifts in how residential settings are classified over the years likely contributed to rate differences.

Own Home

People served by DDS living independently in their own home or with family comprised more than half of the individuals served by DDS and had the lowest mortality rates in 2012 and 2013, similar to previous years. The crude adult rate of death for those living in their own home was 5.7 and 5.8 per thousand in 2012 and 2013, respectively. These rates are slightly lower than previous years. The crude adult mortality rates for people living in their own home are lower than the crude mortality rate of 8.2 per thousand for all ages of the general population of Massachusetts.[28] The subgroup of people living in their own homes is the youngest on average of all residential subgroups and has the smallest percentage of people over the age of 65 (5%); this is reflected in the relatively low average age at death of 51.1 and 49.4 years.

DDS Community

'DDS Community' describes a diverse residential subgroup both in terms of age and level of service need. This is the second-largest residential subpopulation of DDS consumers in Massachusetts. The crude adult mortality rate for people served by DDS living in the DDS Community was 29.8 per thousand in 2012 and 26.7 per thousand in 2013. The mortality rate was significantly higher in the DDS Community in 2012 compared to 2011, and was not significantly different in 2013.[j] The mortality rate among individuals in the DDS Community population is consistent with 2011 data and continues to be higher than data prior to 2011. It is possible that recent changes in the population living in the DDS community, including those with high medical needs who were previously living in nursing homes, may contribute to this increase. At the time of transition, a portion of the group of people moving out of nursing homes and into the community has been in hospice. The average age at death (64.8 and 62.4 years) is similar to the average age for this population.

Other Residential Settings

The remaining three residential settings, Non-DDS funded supported settings, DDS facilities and nursing homes, represent in total about 10% of the entire DDS population. It is important to note that such small population numbers can result in large annual fluctuations in the rate of death when compared by residential setting. Changes in rate should therefore be interpreted with caution as small changes will have a relatively large impact on mortality rates.

Non-DDS. The Non-DDS category includes a variety of residential settings, some of which are paid for by other Health and Human Services Agencies as well as some special programs. Because of this, demographics among this group tend to vary greatly. The population grew in 2010, 2011, and 2012 largely due to increases in adult foster care use. However, the population decreased in 2013 to numbers consistent with years prior to 2010, and this change may be due to changes in how enrollments are categorized in DDS systems. Twenty-two people in 2012 and 38 people in 2013 served by DDS living in

[j] Z-test between proportions of residential-specific deaths and populations, z = 3.2 2011 to 2012; z=-1.32 2012 to 2013

Non-DDS residences died. The adult mortality rate for this setting was 9.7 per thousand in 2012 and 25.9 per thousand in 2011.

DDS Facilities. The population in this setting is shrinking as efforts are made to shift facility-based residential supports to community-based supports. Between 2012 and 2013, the total population decreased by over 10% from 622 individuals to 550 individuals. The population remaining in facilities is the oldest of all residential settings, with more than 30% over the age of 65. In 2012, 36 people who were residing in DDS facilities died; the crude adult mortality rate for this setting was 57.9 per thousand. In 2013, 24 people died for a crude adult mortality rate of 43.6 per thousand. The mortality rates in 2012 and 2013 were not significantly different.[k] Because of the changes to the underlying population in this setting, comparisons between years should be made with caution.

Nursing Homes. Since the Supreme Court's *Olmstead vs. L.C.* (1999) decision, states are required to screen all applicants to a Medicaid-certified nursing facility for intellectual disabilities to help ensure that people receive the assistance they require in the least restrictive setting and are not inappropriately placed in nursing facilities.[29] As a result, people living in this setting have some of the highest care needs of all DDS consumers and one quarter are over the age of 65 years. The population of people served by DDS living in nursing homes is the smallest population overall and represents only 1% of all individuals served. In 2012, 26 people who were residing in nursing homes (for more than 30 days) died; 24 died in 2013. This setting had a crude adult mortality rate of 112.6 per thousand in 2012 and 120 per thousand in 2013, representing the highest rate of death of all residential settings. The 2012 mortality rate for this setting was significantly higher than the 2011 rate; no significant difference was observed between 2012 and 2013.[l] The mortality rate for this setting is likely affected by increased efforts to divert people from living in nursing homes when possible, resulting in a greater proportion of people in these settings being at the end of their lives. Deaths in this setting represented 6% of all deaths for people served by DDS.

Cause of Death by Residence

Mortality statistics tend to vary across the DDS subpopulations living in different residential settings. This is likely because factors associated with mortality, such as average age and health characteristics, also vary across these subpopulations. Mortality causes with the highest frequency for people living in the DDS Community are presented in Table 11.

The top three causes of death in people residing within the DDS community are chronic conditions in 2012 and 2013: Alzheimer's disease, heart disease, and cancer, consistent with previous years. Aspiration pneumonia and septicemia, in some cases resulting from aspiration pneumonias, represent the next two most frequent causes.

[k] Z-test between proportions of residential-specific deaths and populations, z = 0.91 2011 to 2012; z=-0.27 2012 to 2013
[l] Z-test between proportions of residential-specific deaths and populations, z = 4.0 2011 to 2012; z=0.24 2012 to 2013

Table 11
Top Causes of Death for DDS Community[m]

2013 Rank	Cause of Death	2012		2013	
		Number of Deaths	Rate of Death (per thousand)	Number of Deaths	Rate of Death (per thousand)
1	Alzheimer's Disease	43	4.4	42	4.4
2	Heart Disease	50	5.1	36	3.8
3	Cancer	39	4.0	25	2.6
4	Aspiration Pneumonia	24	2.5	23	2.4
5	Septicemia	28	2.9	21	2.2

The top causes of death for people residing in their own home or with family, shown in Table 12, are generally similar to the common causes of mortality in the Massachusetts general population. The information available to use in the assignment of a cause of death can be limited for people who die at home.[n] Cancer, heart disease and influenza and pneumonia represented the top causes of death in 2013. Congenital anomalies contribute to a substantial proportion of deaths in this setting in 2012, and are typically associated with etiology of the person's disability. Diabetes was a top cause of death in 2012 and 2013, and the rate of death due to septicemia (0.63 per thousand) was higher in 2012 than in previous years.

Table 12
Top Causes of Death for Adults Served by DDS and Residing in Their Own Home[o]

2013 Rank	Cause of Death	2012		2013	
		Number of Deaths	Rate of Death (per thousand)	Number of Deaths	Rate of Death (per thousand)
1	Cancer	11	1.0	16	1.4
2	Heart Disease	5	0.5	9	0.8
3	Influenza and Pneumonia	2	0.2	6	0.5
4	Diabetes	4	0.4	4	0.3

Populations and numbers of death are small for remaining residential settings. Causes of death not shown.

[m] The person may have passed away in a setting other than the DDS Community, however, people are listed by their primary residential setting.

[n] Cause of death assignments for people living at home with family typically depend on information from family and the death certificate, which may not list the underlying cause of death.

[o] The person may have passed away in a setting other than their own home, however, people are categorized by their primary residential setting.

Place of Death

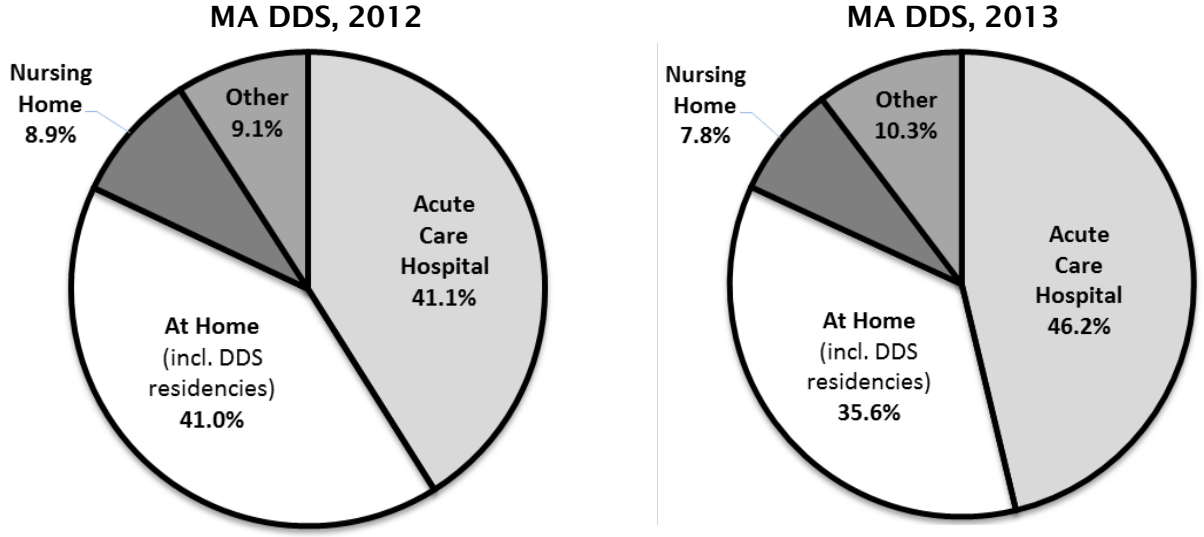
In 2012, an equal amount of deaths occurred in acute care hospitals and in the person's home. In 2013, the greatest proportion of deaths among individuals served by DDS occurred at a hospital. The percent of deaths (41.1% in 2012) that occurred in hospitals is slightly higher than the percent of deaths (38% in 2012) that occurred in hospitals among the general Massachusetts population. The difference between these two populations increased in 2013 during which the percent of deaths that occurred in hospitals were 46.2% and 37%, respectively.

Among the DDS population, the second most common place of death was at home. At home refers to a setting outside of a hospital or nursing home and includes Adult Foster Care settings, DDS residences and facilities, and an individuals or their family's own home. In 2012, a near equal percent of deaths, 41%, occurred at home and hospital settings. A substantially higher percentage of the DDS population (41%) died at home compared to the general Massachusetts population (27%)[35]. In 2013, the percent of deaths that occurred at home among the DDS population decreased to 35.6%, however remained higher than the general Massachusetts population (28%)[28].

Table 13
Distribution of Deaths by Location, 2012-2013

Location	2012		2013	
	No. Deaths	Percent of Deaths	No. Deaths	Percent of Deaths
Acute Care	**180**	**41.1%**	**189**	**46.2%**
At Home	**179**	**41.0%**	**146**	**35.6%**
Adult foster	7	1.6%	10	2.4%
DDS Facility	16	3.7%	5	1.2%
DDS Residence	136	31.1%	110	26.9%
Own/Family	20	4.6%	21	5.1%
Nursing Home	**39**	**8.9%**	**32**	**7.8%**
Other	**40**	**9.1%**	**42**	**10.3%**
Total	**438**	**100.0%**	**409**	**100.0%**

Figure 4
Places of Death, 2012-2013



A small proportion of deaths among DDS members occurred in nursing homes. The proportion decreased from 8.9% in 2012 to 7.8% in 2013. These proportions are substantially lower than the Massachusetts general population, among whom 29% died in nursing homes in 2012 and 2013. Deaths that occurred outside of hospital, home or nursing home setting made up 9.1% of deaths among DDS members in 2012 and 10.3% of deaths that occurred in 2013.

Hospice Use

In 2012, hospice support was provided to 201 or 45.9% of individuals served by DDS who died. The proportion of deceased individuals who received hospice support decreased to 162 or 39.6% in 2013. The rate of hospice use is very similar to the general population where 44.6% of deaths in the US were reported to use hospice services,[30] which is in line with expectations given the frequency of end stage conditions observed in causes of death.

Table 14
Number of Individuals Receiving Hospice Support

Hospice	2012		2013	
	No. Deaths	Percent of Deaths	No. Deaths	Percent of Deaths
Yes	201	45.9%	162	39.6%
No	218	49.8%	231	56.5%
Unknown	19	4.3%	16	3.9%
Total	438	100.0%	409	100.0%

MORTALITY REVIEW PROCESS AND COMMITTEE

Clinical mortality reviews are completed by DDS for all deaths involving people who meet the following criteria:

1. 18-yrs of age and older,
2. receive a minimum of 15-hrs of residential support provided, funded, arranged or certified by DDS, or
3. died in a day support program funded or certified by DDS, or
4. died while participating in a day habilitation program, or
5. died during transportation funded or arranged by DDS.

Mortality reviews for this population are submitted to the Regional and/or Central Review Committee for analysis, confirmation of cause of death and follow-up if indicated. All reviews required by DDS policy were completed in 2012 and 99% of reviews were completed in 2013. A total of 313 required mortality reviews plus 4 requested were completed for 2012 deaths and 269 required reviews plus 9 requested were completed for 2013 deaths.

Mortality Review Procedure

A Clinical Mortality Review is conducted by the DDS Area Nurse or Facility Nurse utilizing the standardized Clinical Mortality Review Form. Clinical Mortality Review Forms are submitted to Central Office upon completion and review by the Regional Director, Facility Director or their designee within 30 days of the death.

A review of each case is conducted by the Regional Mortality Review Committee which consists of at least 1 Registered Nurse, 1 Risk Manager and 1 representative from the Central Mortality Review Committee. Other members may be assigned at the discretion of the Region. When reviewing a case, the Regional Committee considers if there are any unanswered questions with respect to timely diagnosis or identification of health issues, appropriate treatment or intervention, standards of care, advocacy, staff training, medication regimen, or clinical oversight. The Regional Committee seeks answers to any questions raised in the review process before determining if the case can be closed or must be referred to the Central Mortality Review Committee based on a list of criteria provided.

The Central Mortality Review committee is made up of the DDS Director of Health Services, DDS Director of Risk Management, DDS Director of Investigations, at least one representative from each of the Regional Mortality Review Committees, two physicians (one DDS and one a community practitioner), a representative each from the Department of Public Health and the Disabled Person's Protection Commission, a clinical pharmacist, two DDS nurse practitioners, one from a facility and one from an area office, and a DDS ethicist. Cases referred to the Central Mortality Review Committee are reviewed, information is clarified and cases are closed as appropriate.

A random review of at least 10% of the cases closed at the regional level is conducted annually by the Central Committee in order to determine if cases are being closed appropriately and to identify any new criteria for referral to the Central Committee.

INVESTIGATIONS

All death reports received by DDS are reported to the DDS Investigations Division which forwards all reports to the Disabled Persons Protection Commission (DPPC). Whenever there is a suspicion that the death of a person with intellectual disabilities was the result of abuse, neglect or omission, the Disabled Persons Protection Commission (DPPC), and/or the DDS Investigations Division, and/or the Department of Public Health (DPH) conducts an investigation into the causes, manner, and circumstances of the death. Also subject to investigation are any deaths that meet medico-legal requirements in the Massachusetts General Laws, chapters six and thirty-eight.[p]

Some deaths may involve more than one investigation by more than one state agency. For example, DPH is charged with investigating allegations of abuse, mistreatment or neglect in certain licensed health facilities including hospitals, rehabilitation hospitals and

[p] "Any death in which the Chief Medical Examiner takes responsibility for determining the cause and manner of death, to include all cases of suspected homicide, suicide, accidental drug overdose, or sudden and unexpected natural deaths."

nursing facilities. Therefore DPPC or DDS may conduct an investigation of issues in a DDS funded or licensed setting and DPH may conduct a separate, non-duplicative investigation of the care the person received while in an acute care hospital.

Table 15 displays investigation information for 2006 – 2013. There were slightly fewer deaths investigated in 2012 and 2013 than in the previous three years with a total of 20 and 21 investigations, respectively. DDS conducted about 10 investigations and DPPC conducted 3 investigations per year in 2012 and 2013. Law enforcement reviewed 13 cases in 2012 and 9 cases in 2013.

Table 15
Summary of Investigations, 2006 to 2013

Type of Activity	2006	2007	2008	2009	2010	2011	2012	2013
DDS Investigation	2	9	8	13	5	3	10	9
DPPC Investigation	3	10	5	3	3	1	3	3
Refer to Other Agency	2	7	0	3	4	4	2	6
District Attorney/Law Enforcement Investigation	2	9	10	3	10	12	13	9
Other/dismissed[q]	3	5	4	2	3	2	4	2
Resolved Fairly and Efficiently		1	0	1	1	0	1	0
Total Number of Deaths Investigated	9	34	18	25	26	24	20	21

Table 16 presents the findings of investigations by either DDS or DPPC. Investigations regarding 5 of the deaths that occurred in 2012 and 3 of the deaths that occurred in 2013 found the allegations were substantiated, meaning the death was the result of abuse, neglect or omission. One investigation by DPPC from 2013 is still pending. Fifteen investigations in 2012 and seventeen in 2013 were found to be unsubstantiated allegations.

Table 16
Findings in Cases Investigated by DDS or DPPC, 2006 to 2013
(Includes cases deferred to law enforcement)

Findings	2006	2007	2008	2009	2010	2011	2012	2013
Number of Substantiations	2	3	1	3	5	4	5	3
Pending	3	3	2	1	1	2	0	1

[q] Complaint was Dismissed, Resolved w/o Investigation or Referred to the Regional Office for administrative review.

BENCHMARKS

This section of the report compares information on mortality among MA DDS service recipients to other benchmark data in order to provide a context to inform whether findings are substantially different from or similar to expectations for a population of persons with intellectual disabilities and/or developmental disability.

People with intellectual disabilities, such as those supported by the Massachusetts DDS, often present with a variety of potentially complex co-morbidities (secondary health and behavioral conditions) that can elevate their relative mortality risk compared to the general population. Therefore, while comparative benchmarks from the general population can be valuable, relying solely on these benchmarks can be misleading because people with I/DD may experience important factors that can substantially alter the risk of mortality (e.g., health-related issues that are more prevalent in persons with significant disability). Therefore, it is useful to examine mortality statistics in adult populations with I/DD from other state systems that provide support to populations similar to the Massachusetts DDS and that issue reports based on similar data and methods. Unfortunately, very few state agencies that serve people with intellectual or developmental disabilities routinely publish annual mortality information. Where public reporting is available, there exists significant variability in the type of information that is shared and the methods for organizing the data that is made available.

It is therefore very important to recognize these limitations when reviewing the comparative benchmark data presented below. Benchmark data should be viewed with caution and should only be used as a very general guide for understanding the 2012 and 2013 Massachusetts findings. Direct comparisons of specific data should NOT be made, especially where important differences are noted.

Mortality and Age Benchmarks

Crude mortality rates by age group show similar patterns to MA DDS in other state I/DD systems including Connecticut[31] and Louisiana.[32] Mortality rates tend to increase gradually in the younger age groups and demonstrate a sharper increase after age 60-65 years.

Cause of Death Benchmarks

A comparison of the top five leading causes of death as reported by I/DD state agencies in Connecticut, Ohio, and Louisiana are presented in Table 17.

It is important to note that the Connecticut DDS does not and other states may not use underlying causes of death in their reporting. This may affect rankings by lowering the rate of causes such as Alzheimer's disease, and may increase the ranking of more immediate causes of death.

While rank order is only a relative comparison, the most common causes of death for the populations served by these state agencies have many similarities. The percent of deaths for adults served by MA DDS due to heart disease (13.7% - 16.0%) was similar to the

percent of deaths of all ages in Ohio and Louisiana (12.4%), but much lower than in Connecticut (28.6%). Because heart disease typically has an onset in adulthood, it would be expected that other state systems maybe observe a lower percent of deaths due to this cause because they include all ages in their reports.

Cancer showed similar patterns across states and was responsible for 13.4-13.7% of deaths in MA, compared with 10% of deaths in CT, 9.1% in OH and 10.1% in LA.

Table 17
Comparison of the Top 5 Leading Causes of Death
As Reported by Four State I/DD Agencies

Rank	MA DDS CY2012 (adults)	MA DDS CY2013 (adults)	CT DDS FY2013[31] (all ages)	OH DDD 2012[33] (all ages)	LA OCDD FY2012[32] (all ages)
Method	**Underlying**		**Primary**	**Unknown**	**Unknown**
1	Heart Disease 16.0%	Heart Disease *13.7%*	Heart Disease 28.6%	Heart Disease 14.7%	Pneumonia 15.0%
2	Cancer 13.7%	Cancer *13.4%*	Respiratory Disease 22.4%	Congenital Diseases 13.0%	Heart Disease 12.4%
3	Alzheimer's Disease 13.0%	Alzheimer's Disease *12.2%*	Cancer 10.0%	Cancer 9.1%	Cancer 10.1%
4	Septicemia 10.0%	Aspiration Pneumonia *8.6%* Septicemia *8.6%*	Aspiration Pneumonia 7.9%	Aspiration Pneumonia 6.9%	Congenital Diseases 10.1%
5	Aspiration Pneumonia 9.4%		Septicemia 7.9%	Pneumonia 6.8%	Septicemia 8.8%

While Alzheimer's disease appears as a common cause of death in the Massachusetts state I/DD system**, it may not appear in listed causes for other state systems due to the way the causes are determined**. Alzheimer's disease is rarely listed as an immediate cause of death, and may not be listed on death certificates as an underlying cause of death. It may instead be related to deaths of respiratory disease and aspiration pneumonia in other states.

Table 18
Relative Percent of Annual Deaths by Pneumonia Type

% of annual deaths	MA DDS CY2012 (adults)	MA DDS CY2013 (adults)	CT DDS FY2013[31] (all ages)	OH OMRDD 2012[33] (all ages)	LA OCDD FY2012[36] (all ages)
Aspiration Pneumonia	9.4%	8.6%	7.9%	6.9%	Unknown
Influenza and Pneumonia	3.9%	5.4%	7.5%	6.8%	Unknown
Total	13.4%	14.0%	15.4%	13.7%	15.0%

Some states report different types of pneumonia separately and others report all pneumonias together in one category. In order to provide a more accurate comparison of the relative percentage of deaths caused by difference causes of pneumonia, Table 18 presents pneumonia organized by type and in total across the states. Aspiration pneumonia is a significant cause of mortality in Massachusetts, Connecticut and Ohio, representing between 6.9% and 9.4% of deaths. While these three states count aspiration pneumonia separately from influenza and pneumonia (consistent with ICD-10 classification), the Louisiana OCDD mortality report appears to combine all pneumonias into the category of 'pneumonia'.

HEALTHY PEOPLE 2020 OBJECTIVES

The U.S. Department of Health and Human Services' Healthy People 2020 (HP2020) initiative contains a series of health-related, science-based goals and objectives for the nation to achieve by the year 2020. The initiative builds upon previous decades of Healthy People targets. Within the objectives are mortality rate targets for the nation and individual states. Comparison of a five-year average of DDS data with the objectives contained in HP2020, in combination with other benchmarks and literature, can help inform planning for future improvement initiatives and assist in identifying priorities for further research, review, and/or strategic intervention.

Table 19 below displays data associated with 20 of the mortality targets. These mortality targets were selected because they are related to a series of underlying causes of death that are consistent with the Massachusetts DDS and Massachusetts state mortality reports. It is also important to note that the crude mortality rates presented here for the population served by the MA DDS are for adults only. In contrast, the HP2010 targets, as well as the age-adjusted mortality rates for MA and the US are for all ages, except where noted. In general, adult-only mortality rates are higher than the mortality rates for all ages because the risk of mortality, and certain conditions, increases with age. **Therefore, while the adult-only mortality rates for the MA DDS population may be higher than HP2020 targets or other populations, part of the difference will likely be due to the different age distributions of the base population.**

The mortality rates objectives in HP2020 are based upon a standard rate (no. deaths per 100,000 people). It is important to note that the Massachusetts DDS serves a small population relative to state and national populations, and is therefore subject to substantial variability from year to year in a measure such as mortality rate. For example, one additional death can inflate the DDS annual death rate over 4 points when using a scale based on 100,000 people. To compensate for this variability, death rates in this section of the report were averaged over the past five years (2009-2013). This method allows for a broader view of the status of the population and helps to minimize random effects on the cause-specific rates. As an additional precaution, target status is not reported for causes of death with only 1 or 2 reported deaths across the five years.

Similar to previous years, crude mortality rates for adults served by the Massachusetts DDS meet many of the HP2020 targets. While the overall cancer mortality rate does not meet the HP2020 goal, it is important to distinguish that the target and US and state rates are based on a mortality rate for all ages, while the average DDS rate is based only on adults. Because there is an association between age and the onset of cancer, it may be

expected that the adult rate for DDS would exceed the other figures. The population served by DDS does meet many of the goals for specific types of cancer, including lung and uterine cervix, oropharyngeal and prostate cancers. Average mortality rates have increased since the last report for some types of cancer including lung, female breast, colorectal and melanoma. The mortality rate for colorectal cancer and female breast cancer continues to substantially exceed the HP2020 goals as well as state and national rates. In many of these types of cancer, early detection can improve survival rates; therefore continued efforts are recommended to advocate for mammography and colorectal screening in this population.

The average of the rate of deaths in 2009 to 2013 from unintentional injuries continues to be above state and national rates on average, particularly for deaths from falls and drownings. The majority of deaths from unintentional injury in the population served by the MA DDS are due to choking or aspiration, consistent with prior years.

Table 19
Target Status for Selected Healthy People 2020 Mortality Objectives
Rates per 100,000 population

Objective Number	HEALTHY PEOPLE 2010 OBJECTIVE	TARGET 2020[34]	DDS 2009-2013 Avg. Crude Adult Rate	DDS 2009-2013 Target Status	MA 2013[35]	US 2012[34]
C-1	Overall Cancer death rate	160.6	239.0	●	159.7	166.5
C-2	Lung Cancer	45.5	27.9	✓	41.4	44.9
C-3	Female Breast Cancer (per 100,000 females)	20.7	42.5	●	18.4	21.3
C-4	Uterine cervix (per 100,000 females)	2.2	2.0	✓	1.0	2.3
C-5	Colorectal Cancer	14.5	35.5	●	13.0	15.0
C-6	Oropharyngeal Cancer	2.3	1.7	✓	2.4	2.5
C-7	Prostate Cancer (per 100,000 males)	21.8	13.7	✓	18.5	19.5
C-8	Malignant Melanoma	2.4	3.4	●	3.2	2.7
HDS-3	Stroke deaths	34.8	43.7	●	31.8	36.9
HIV-12	HIV-infection deaths	3.3	0.0	✓	1.0	2.2
	Injuries					
IVP-11	Unintentional injuries (Accidents)	36.0	70.3	●	33.9	39.1
IVP-13.1	Motor vehicle crashes	12.4	5.9	✓	5.2	10.9
IVP-23.1	Falls	7.2	17.0	●	7.8	8.3
IVP-30	Firearm-related	9.3	0.0	✓	3.2	10.5
IVP-9.1	Poisonings	13.2	1.7	✓	18.4	14.6
IVP-24.1	Hanging, strangulation or suffocation	1.8	0.0	✓	5.4	1.9
IVP-28	Residential fire deaths	0.86	1.7	●	0.2	0.64
IVP-25	Drowning	1.1	4.2	●	1.3	1.2
IVP-29	Homicide	5.5	3.4	✓	2.3	5.4
MHMD-1	Suicide	10.2	0.9	✓	8.5	12.6

✓ = YES, met target O = NO, but within 25% of target ● = NO, > 25% from target

Appendix A

Methodology for Mortality Review and Analysis

This mortality report analyzes information on all deaths occurring in calendar year 2012 and 2013 for all people with intellectual disabilities, 18 years of age or older, who have been determined to be eligible for DDS supports.

The source data for this report comes from DDS Death Records that must be completed within 24 hours of an person's death according to DDS policy. This report includes statistics on all deaths of people who died in calendar year 2012 and 2013 and whose Death Report was received by DDS by the writing of this report.

The data used to calculate death rates per 1000 by age group and type of residence was supplied by the DDS Meditech System of July 1, 2012 and July 1, 2013.[r] The Meditech system contains information on every person eligible for DDS supports, including those who may not be receiving DDS services currently. In addition, DDS made Mortality Review forms and clinical notes available to CDDER for verification of information about the consumers subject to Clinical Mortality Review.

DDS provided the following information for deaths:

- Name of the person
- Date of birth
- Date of death
- Social security number
- Cause of death, if known
- Residence type
- DDS region
- Whether death was referred for investigation
- Whether a Mortality Review form was received
- Ricci class membership status
- Rolland class membership status
- Boulet class membership status

Crude mortality rates were calculated for the entire DDS population. Death rates were also calculated by age category, region and residence type. The specific methodology employed by CDDER for calculating death rates per 1000 for each of the categories is as follows:

$$\text{Crude Death Rate} = \frac{(\text{Number of people who died in calendar year} \times 1000)}{(\text{No. of people in Meditech systems in middle of calendar year})}$$

[r] CDDER relies on the accuracy of information about the number of people eligible for DDS services, their ages, region and type of residential placement. Inaccuracies in DDS information systems, if any, will be reflected in the numbers used to compute death rates in the DDS population.

Appendix B

Demographic Data

Age Characteristics

Figure 5 presents the age distribution for the DDS population in 2013. With the exception of population groups under 25 and over 84, populations are in 10 year age groups. The largest populations are in age bands between 18 and 34, and 45-54, with over 4,500 per age band. There is a decrease in population for adults ages 35-44 which drops to approximately 3,600. Over the age of 54, the population in each age band decreases with increasing age. Compared to the Massachusetts general adult population, a greater proportion of adults served by MA DDS are under age 65 (90% compared to 82%)[36]. Also, while only 0.6% of the MA DDS population is age 85 or older, almost 3% of the Massachusetts general adult population is within this age group.

Table 20
2012 DDS Population

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1793	1999	1616	2001	1457	786	278	84	10014
Male	2873	2672	2028	2490	1647	798	286	54	12848
Total	4666	4671	3644	4491	3104	1584	564	138	22862

Table 21
2013 DDS Population

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1817	2114	1609	2026	1499	796	290	82	10233
Male	3009	2790	1994	2494	1733	834	303	56	13213
Total	4826	4904	3603	4520	3232	1630	593	138	23446

Figure 5
Distribution of the Population Served by DDS by Age and Gender, 2013

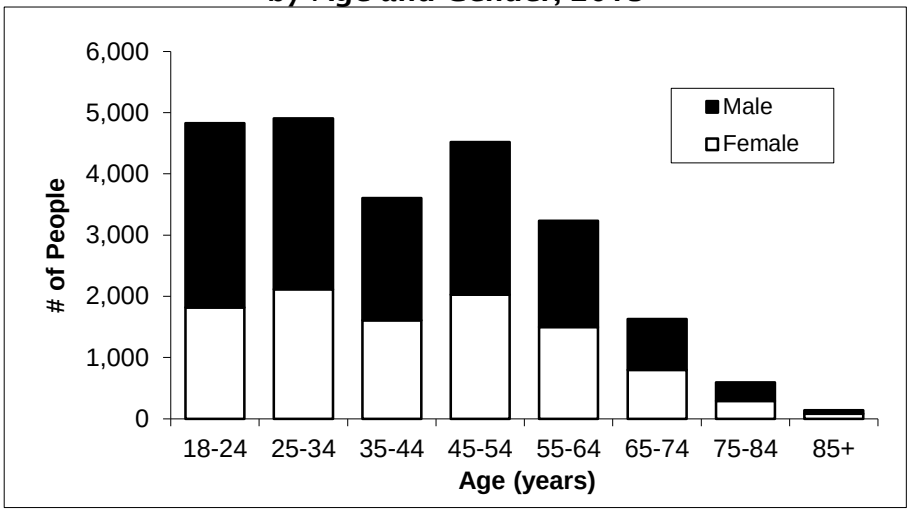


Figure 6 presents the change in the DDS population between calendar years 2011 and 2012. Between 2011 and 2012, there were fewer people served in all younger age groups (<54 years) and more people served in age groups 55 and older. Shifts may be observed due to people aging into adjoining age bands, consumers relocating out of the state, and consumers that have died. Patterns were similar across genders.

Figure 6
DDS Population Change, 2011-2012

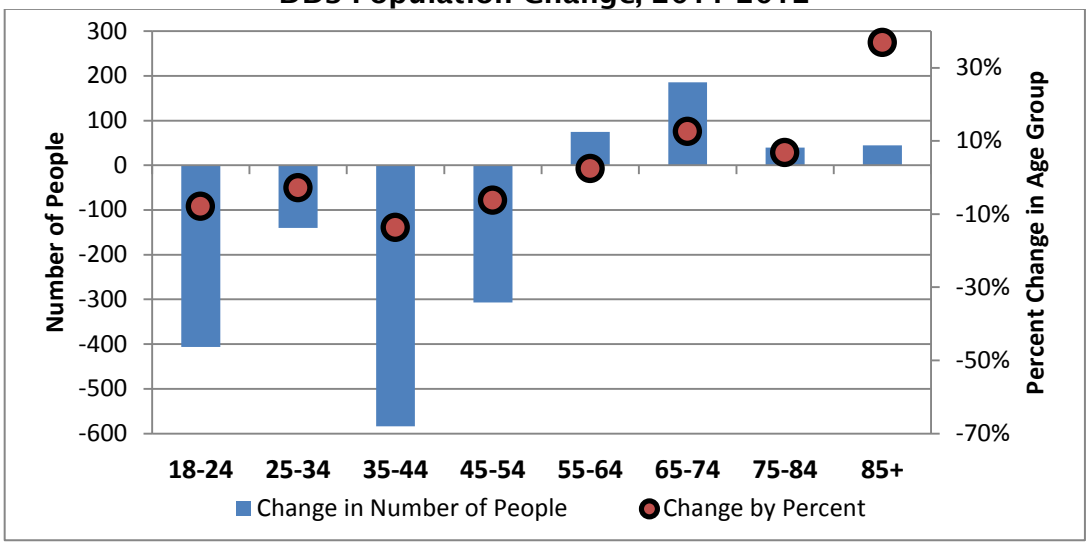


Figure 7 presents the change in the DDS population between calendar years 2012 and 2013. Between 2012 and 2013, there were more people served in almost all age groups, but the largest gains were in the older age groups. As shown in Figure 8, patterns differed slightly by gender with larger proportional increases in the male population 18-24 and at 55-64.

Figure 7
DDS Population Change, 2012-2013

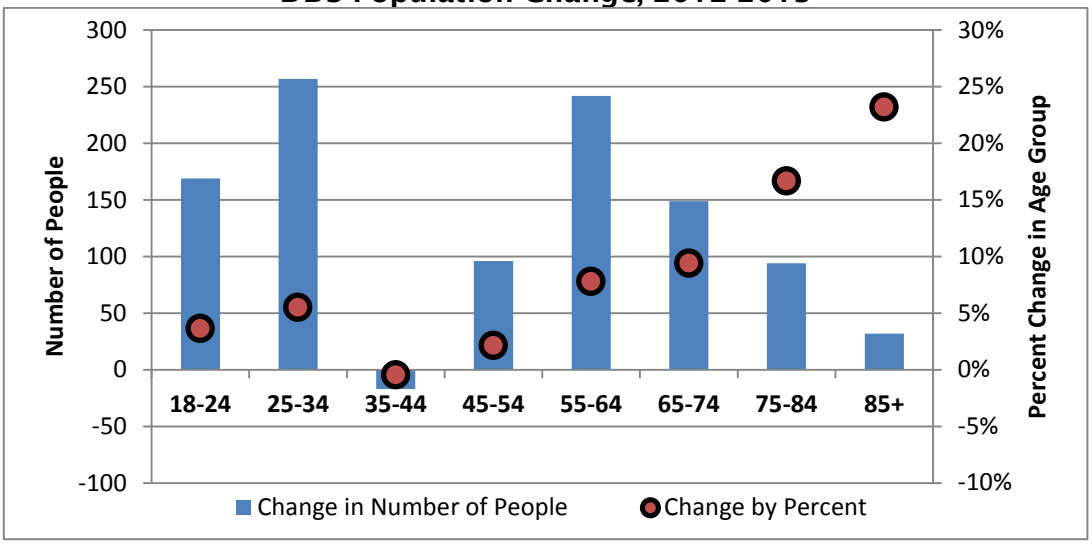
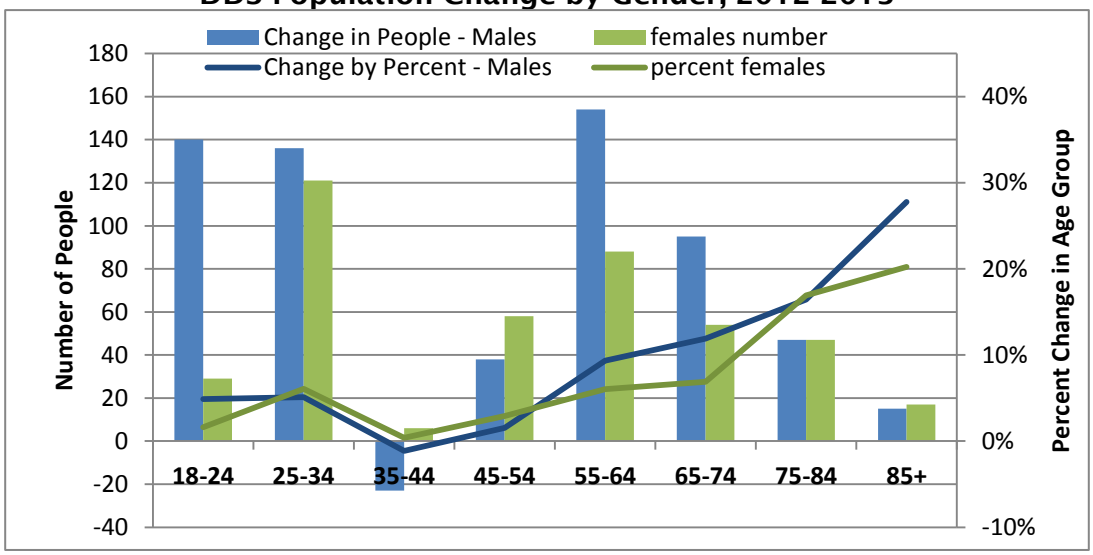


Table 22
Annual DDS Population Change within Age Group
A Comparison of 2012 and 2013

Age Group	Gross Population Fluctuation[s]		
	People	% Change within Age Group	Resulting % Change in DDS Consumer Population from 2012
18-24	160	3.4%	0.7%
25-34	233	5.0%	1.0%
35-44	-41	-1.1%	-0.2%
45-54	29	0.6%	0.1%
55-64	128	4.1%	0.6%
65-74	46	2.9%	0.2%
75-84	29	5.1%	0.1%
85+	0	0.0%	0.0%
Total	584	2.6%	2.6%

Figure 8
DDS Population Change by Gender, 2012-2013



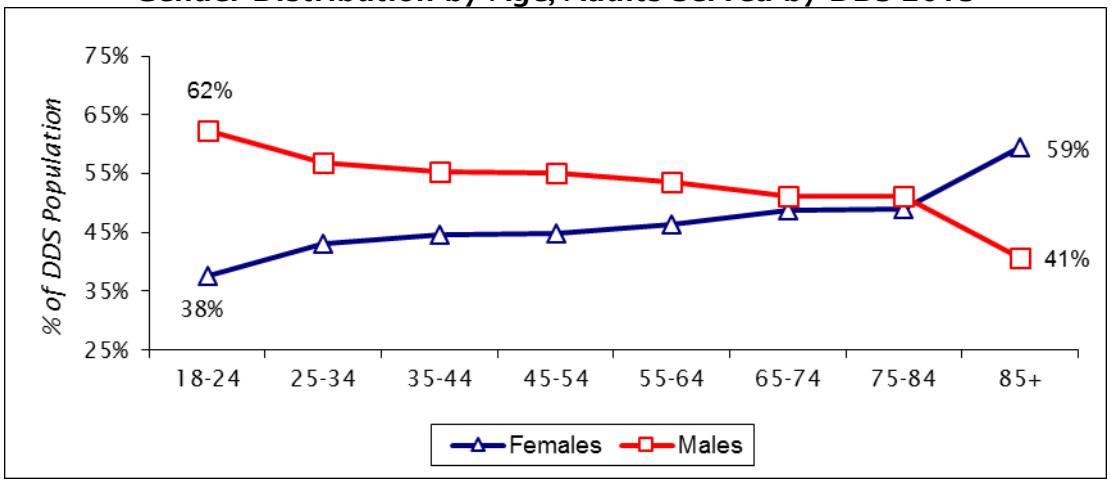
Gender Characteristics

The gender distribution in the 2012 and 2013 adult DDS populations is similar to previous years. The proportion of men served by DDS is highest for individuals age 18-24 and decreases by age group, as illustrated in Figure 9. The proportion of men is higher for all adult age groups except for older adults ages 65-84. For those ages 85 and above, there are a much higher proportion of women. The shift in gender distributions in the elderly population is similar to reports from other states and that seen in the general

[s] Gross population change reflects the migration of living people between age groups. The figures take into account the people that must have entered the age group to compensate for death over the course of the year. The percent increase in the population will not match the net population increase.

population. Since 2010, the gender distribution in the oldest age group has consistently been more similar between genders.

Figure 9
Gender Distribution by Age, Adults Served by DDS 2013



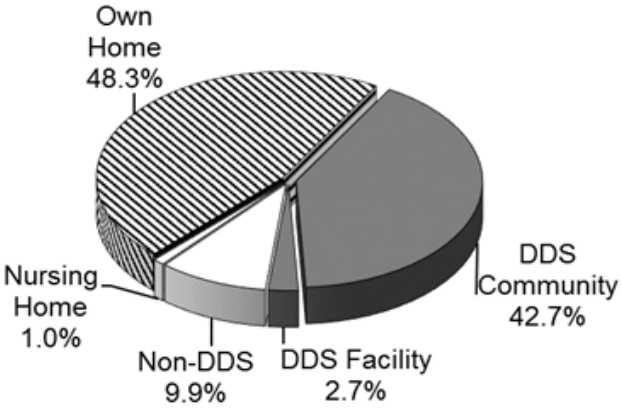
Residential Setting Characteristics

Adults receiving services from DDS reside in a variety of different settings. In this report, the residential settings are grouped into five categories: their own home, either independently or with family; community settings operated, funded or certified by DDS; residential programs that are not part of the DDS system; facilities operated by DDS; and nursing homes or other long-term care settings. The percent of people served by DDS living in each residential category is presented in Figure 10.

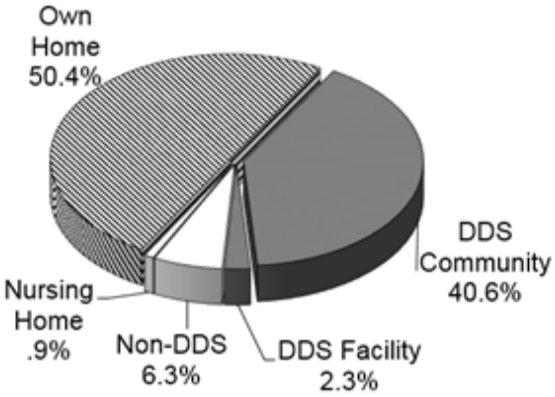
In 2012, 48.3% of the adults served by DDS resided in their own home, which includes people living independently or with their family. By 2013, this increased to over half.

Residential programs operated, licensed/certified or funded by DDS make up the second most common residential setting as seen in the dark grey sections in Figure 6. In 2012, about 43% of adults served by DDS lived in a community residential program, and over 2% lived in

Figure 10
Where People Live
Adult population served by DDS, 2012



Adult population served by DDS, 2013



DDS facilities. The number of people living in DDS facilities continues to decline annually largely due to DDS's efforts to plan transitions to community settings for these residents. Several initiatives in Massachusetts have contributed to the declining number of individuals served by DDS residing in facility-based settings. These include the Rolland vs. Patrick lawsuit, which was dismissed in 2013 after 640 class members transitioned out of facilities[37], the closure of several DDS Residential Care facilities, and the Money Follows the Person Demonstration. All of these initiatives align with the Massachusetts Community First Olmstead Plan, which includes as one of its goals to "help individuals transition from institutional care."[38]

In 2012, about 11% of adults served by DDS resided either in programs that are funded privately or by other agencies or in nursing homes. In 2013, this portion decreased to 7.2% of the DDS population who resided in Non-DDS or nursing home settings, as seen in Figure 10. The portion of the population living in the "Non-DDS" setting has increased from 5.3% of the population in 2009, largely due to growth in the use of Adult Foster Care services.

Appendix C

ICD-10 Codes Used in this Publication

(Sorted by ICD-10 Codes)

Cause of Death	ICD-10 Code
Infectious and parasitic diseases	A00-B99
Septicemia	A40-A41
Human Immunodeficiency Virus (HIV) disease	B20-B24
Cancer (Malignant Neoplasms)	C00-C97
of esophagus	C15
of stomach	C16
of colon, rectum, rectum and anus	C18-C21
of pancreas	C25
of trachea, bronchus and lung	C33-C34
of female breast	C50
of cervix uteri	C53
of corpus uteri and uterus, part unspecified	C54-C55
of ovary	C56
of prostate	C61
of kidney and renal pelvis	C64-C65
of bladder	C67
of meninges, brain & other parts of central nervous system	C70-C72
Hodgkin's Disease	C81
Non-Hodgkin's lymphoma	C82-C85
Leukemia	C91-C95
Multiple myeloma and immunoproliferative neoplasms	C88, C90
Diabetes Mellitus	E10-E14
Alzheimer's Disease	G30
Heart Disease	I00-I09, I11, I13, I20-I51
Stroke (Cerebrovascular Disease)	I60-I69
Influenza and Pneumonia	J10-J18
Chronic Lower Respiratory Diseases	J40-J47
Chronic Liver Disease and Cirrhosis	K70, K73-K74
Nephritis and other renal diseases	N00-N07, N17-N19, N25-N27
Congenital malformations, deformations, and Chromosomal abnormalities	Q00-Q99
External causes of injuries and poisonings (intentional, unintentional and of undetermined intent)	V01-Y89
Accidents (Unintentional Injuries)	V01-X59, Y85-Y86
Suicide	X60-X84, Y87.0
Homicide	X85-Y09, Y87.1
Injuries of undetermined intent	Y10-Y34,Y87.2,Y89.9

Appendix D

ICD-10 Codes Used in this Publication

(Sorted by Category)

Cause of Death	ICD-10 Code
Accidents (Unintentional Injuries)	**V01-X59, Y85-Y86**
Alzheimer's Disease	G30
Aspiration Pneumonia	J69
Cancer (Malignant Neoplasms)	C00-C97
Cardiopulmonary Arrest/ Seizure	G40, R09.2, J96.0
Chronic liver disease and cirrhosis	K70, K73-K74
Chronic Lower Respiratory Diseases	J40-J47
Congenital malformations, deformations, and Chromosomal abnormalities	Q00-Q99
Diabetes Mellitus	E10-E14
Heart Disease	I00-I09, I11, I13, I20-I51
Influenza and Pneumonia	J10-J18
Nephritis and other renal diseases	N00-N07, N17-N19, N25-N27
Septicemia	A40-A41
Stroke (Cerebrovascular disease)	I60-I69
Unknown	R96-R99

Appendix E

ICD-10 Codes for Selected Healthy People 2020 Mortality Objectives Used in this Publication

(Sorted by Objective Number)

Objective Number	Cause of Death	ICD-10 Identifying Codes
C-1	Cancer (all sites)	C00-C97
C-2	Lung cancer	C33-C34
C-3	Female breast cancer	C50
C-4	Uterine Cervix cancer	C53
C-5	Colorectal cancer	C18-C21
C-6	Oropharyngeal cancer	C00-C14
C-7	Prostate cancer	C61
C-8	Malignant melanoma	C43
HDS-3	Stroke	I60-I69 (including underlying or multiple causes)
HIV-12	HIV infection	B20-B24
IVP-30	Firearm-related deaths	U01.4, W32-W34, X72-X74, X93-X95, Y22-Y24, Y35.0.
IVP-9	Poisoning	X40-X49, X60-X69, X85-X90, Y10-Y19, Y35.2
IVP-24.1	Hanging, strangulation or suffocation	W75-W84, X70, X91, Y20
IVP-11	Unintentional injuries (Accidents)	V01-X59, Y85-Y86
IVP-28	Residential fire deaths	X00, X02
IVP-23.1	Falls	W00-W19
IVP-25	Drowning	W65-W74, X71, X92, Y21, V90, V92
IVP-29	Homicides	X85-Y09, Y87.1
MHMD-1	Suicide	X60-X84, Y87.0

These Healthy People 2020 objectives use data on underlying causes of death.

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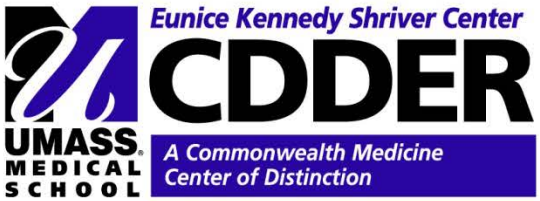

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