

2010 & 2011 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 2010-2011. 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 2010 and 2011 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 compile 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,

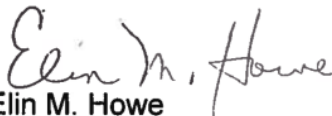

Elin M. Howe
Commissioner

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Executive Summary

This report presents population and mortality information about adult (18 years old and older) service recipients of the Massachusetts Department of Developmental Services (DDS) for the period between January 1 2010 and December 31 2011. Data for the years 2010 and 2011 are presented by year and incorporated in to trend analyses covering 2008 - 2011.

Annual mortality reports are part of the Massachusetts Department of Developmental Services' (DDS), robust quality management and improvement system. The Department's 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 the Department. 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 2010, the Massachusetts DDS served 24,393 adults (over the age of 18 years) with intellectual disabilities. In the middle of calendar year 2011, the Massachusetts DDS served 23,927 adults (over the age of 18 years) with intellectual disabilities.

A total of **406 deaths** occurred for active DDS service recipients in 2010, resulting in a crude adult mortality rate of **16.3 deaths per thousand people**. In 2011, a total of **440 deaths** occurred for active DDS service recipients, for a crude mortality rate of **18.4 deaths per thousand people**. The average age at death of adults in the DDS population was 61.5 years in 2010 and 60.6 years in 2011. Statewide mortality statistics in 2011 do not show a significant change in the rate of death for the population from 2010.

Patterns of mortality in the DDS population are influenced by a number of important 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:** In contrast to previous recent years, mortality by gender closely resembles the population of people served. No statistically significant differences exist between the gender distribution in the DDS population and the deaths that occurred in 2010 and 2011.
- **Residential Setting:** There are substantial differences in mortality between residential settings. Mortality rates are lowest in people living at home or with family, who tend to be younger than people in other residential settings. Mortality rates are highest for people living in nursing homes due to advanced age and/or serious health conditions. The relationship between type of residence and mortality are consistent with expectations and with trends present in other state intellectual disability systems. Between 2010 and 2011, the population supported in the 'DDS Community' setting had a statistically significant increase in the mortality rate, while the population living in nursing homes had a statistically significant decrease in mortality rate. No other settings had statistically significant changes in either 2010 or 2011.

Causes of Death:

- Heart disease was the leading cause of death in 2010 and 2011, consistent with previous years.
- Cancer was the second-ranked cause of death in both years and accounted for about 13% of deaths. This is similar to the proportion in 2009, but this cause has moved up in rankings from 2009 due to a drop in deaths due to Alzheimer's Disease.
- Alzheimer's disease was the third leading cause for both years with 11-13% of deaths. This is lower than the 15% of deaths observed in 2009.
- Aspiration pneumonia was the fourth leading cause of death for both years with 8-12% of deaths. In 2010 this cause was responsible for a higher proportion of deaths than seen in other years.
- Septicemia was the fifth leading cause of death for both 2010 and 2011 representing 8-9% of deaths.
- In 2011, gastrointestinal issues (bowel obstructions, bleeds) were among the top 10 leading causes for the first time.

Other Key Findings in 2010 and 2011:

- In 2010 and 2011, 26 and 24 investigations of abuse or neglect were completed, respectively. Five allegations were substantiated in 2010, and 4 were substantiated in 2011. Three cases remain pending.
- Similar to previous years, crude mortality rates for adults served by the Massachusetts DDS meet many of the Health People 2020 (HP2020) targets.
 - Cancer: While the overall cancer mortality rate does not meet the HP2020 goal, the population meets many of the goals for specific types of cancer, including lung, and uterine cancers and melanoma. Mortality rates for some types of cancer including lung, female breast and colorectal have increased since the last time the 4-year average rates were examined. People with I/DD may have different risk of developing certain types of cancers than the general population due to genetic and lifestyle factors.
 - The rate of deaths from unintentional injuries continues to be above state and national rates on average, particularly for deaths from falls. The majority of deaths from unintentional injury in the population served by the MA DDS are due to choking or aspiration.

2010 and 2011 Mortality Report

INTRODUCTION

This report presents population and mortality data for adults (18 years old and older) eligible for services from the Massachusetts Department of Developmental Services (DDS) during the periods of January 1 and December 31, 2010 (calendar year 2010) and January 1 and December 31, 2011 (calendar year 2011). The mortality information in this report includes all adults who were eligible and active service recipients ("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

As 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 2010, the Massachusetts DDS served 24,393 adults (over the age of 18 years) with intellectual disabilities. A net increase of about 4.0%, or 944 people, was seen in the mid-year adult consumer population from June 2009¹ to June 2010.

¹ 2009 population counts have been revised for comparability due to changes in service coding and data cleaning.

In the middle of calendar year 2011, the Massachusetts DDS served 23,927 adults (over the age of 18 years) with intellectual disabilities. A net decrease of about 0.2%, or 60 people, was seen in the mid-year adult consumer population from June 2010 to June 2011.

Age Characteristics

Figures 1 and 2 present the age distribution for the DDS population by 10 year age groups. The populations in age groups between 18 and 54 years are generally of similar size, each with between 4,000 – 5,000 people. Over the age of 54, the population in each age band decreases with increasing age. Compared to the Massachusetts general population, the MA DDS population of adults is younger with a smaller proportion of the population over the age of 65 years. See Appendix C for data tables.

Figure 1
Distribution of the Population Served by DDS
by Age and Gender, 2010

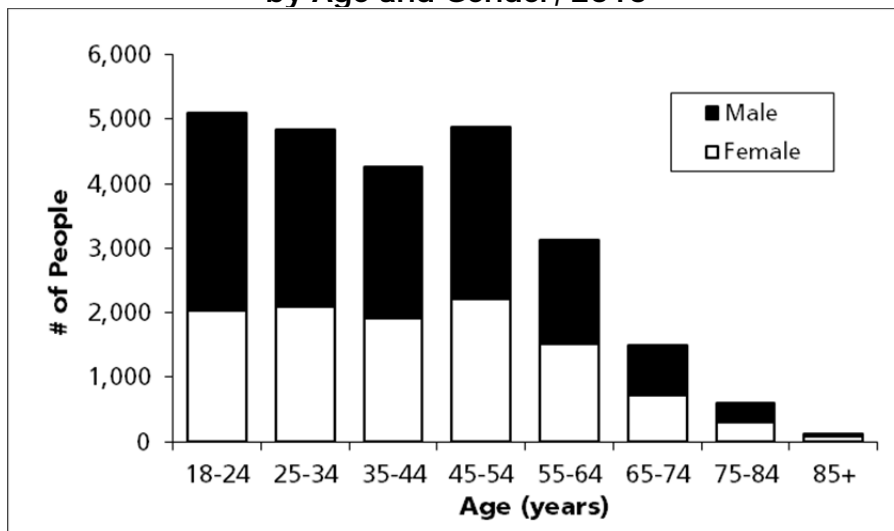


Figure 2
Distribution of the Population Served by DDS
by Age and Gender, 2011

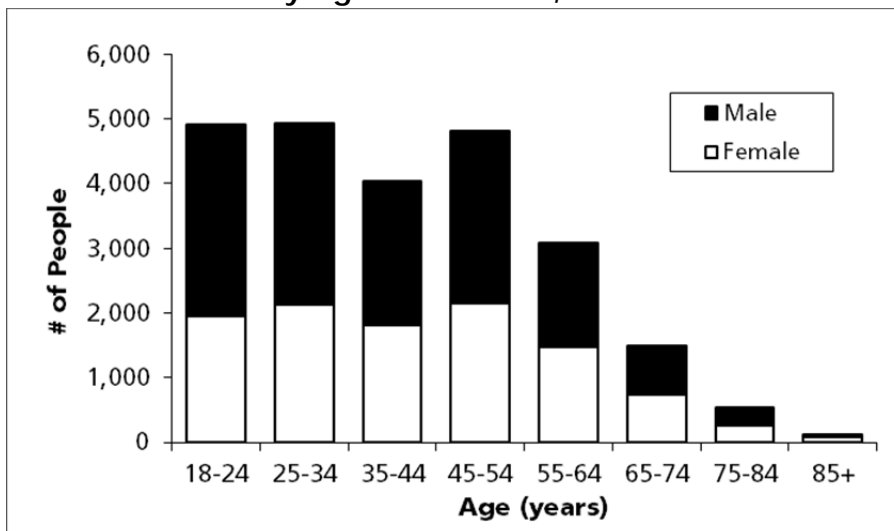


Figure 3 presents the change in the DDS population between calendar years 2009¹ and 2010. All age groups except the 35-44 year old age group showed an increase. This shift is similar to the shift from 2008-2009 which had a decline in the 25-24 age group, but generally showed increases in the other age groups. The population increases by age band typically result from new consumers entering the DDS system as a result of aging into adult services, moving into the state, or seeking services for the first time. Shifts are also seen as individuals age in to the next age band. These increases are balanced by consumers relocating out of the state, and consumers that have died.

Figure 3
DDS Population Change, 2009¹-2010

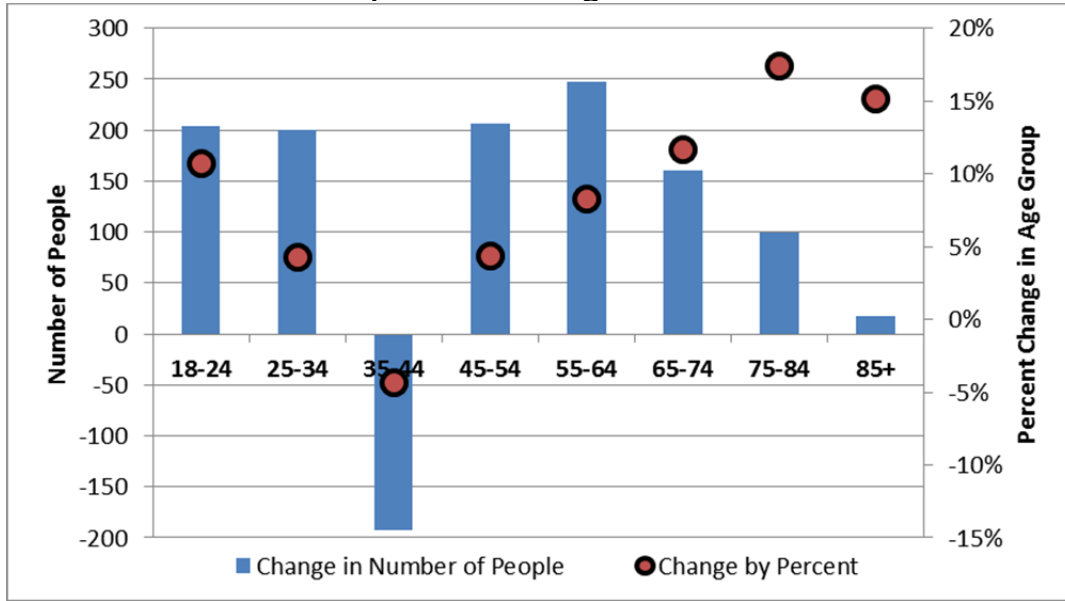


Figure 4
DDS Population Change, 2010-2011

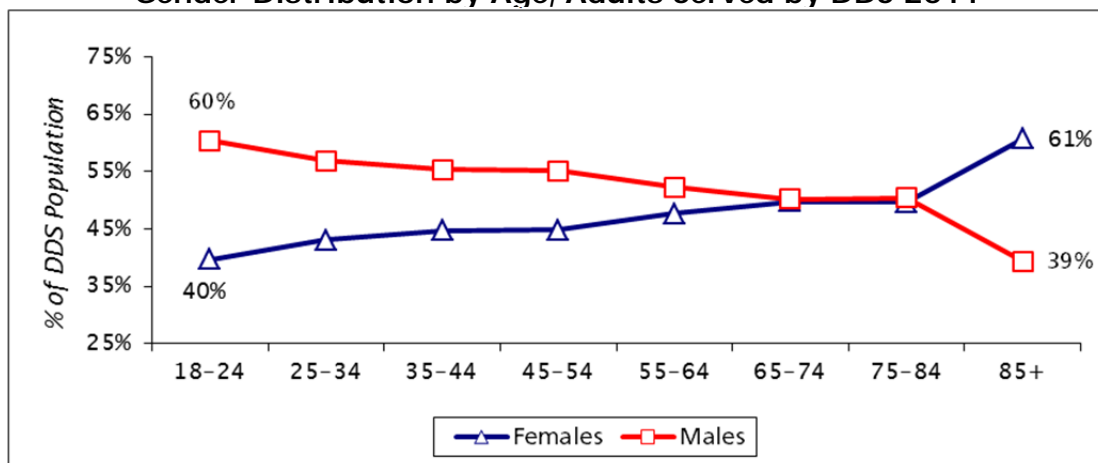


Figure 4 presents the change in the DDS population between calendar years 2010 and 2011. In contrast to previous years, the population has declined slightly between 2010 and 2011, particularly in the 18-24 and the 35-44 age groups. Typically in previous years when an age group such as the 35-44 year old group declined, the next higher age group would increase. In this period, there was instead a small decrease in the 45-54 age group, suggesting that a period of lower enrollment is moving across the age groups. This pattern is reflective of patterns in the general population where Generation X which partially falls into the 35-44 age band is smaller than the previous 'Baby Boom' generation, and also smaller than Generation Y which was affected by an upswing in births after 1983. See Appendix C for data tables.

Gender Characteristics

The gender distribution in the 2010 and 2011 adult DDS populations is similar to previous years. As Figure 5 shows below, the proportion of men and women served by DDS varies with age. Younger age groups have a larger proportion of men. The shift in gender distributions in the elderly population is similar to reports from other states and that seen in the general population.² Over the past few years, the gender distribution in the oldest age group has grown more similar between genders.

Figure 5
Gender Distribution by Age, Adults Served by DDS 2011



Residential Setting Characteristics

Adults receiving services from DDS reside in a variety of different settings. Many people served by DDS live independently in their own homes or with their family, while others receive residential supports directly from DDS or from another state agency. In this report, the residential settings are grouped into six categories. The percent of people served by DDS living in each residential category is presented in Figure 5.

In 2011, just over half of the adults served by DDS reside in their own home, which includes people living independently or with their family. Residential programs operated,

² Gruman, C. and Fenster, J. *A Report to the Department of Mental Retardation: 1996 through 2002 Data Overview*, April 2002.

licensed/certified or funded by DDS are shown in the sections shaded in solid grey in Figure 6. Just over 40% of adults served by DDS live in community residential programs, and 3% live in 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.

About 10% of adults served by DDS reside either in programs that are funded privately or by other agencies, represented by the "Non-DDS" category in Figure 6, or in nursing homes. 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.

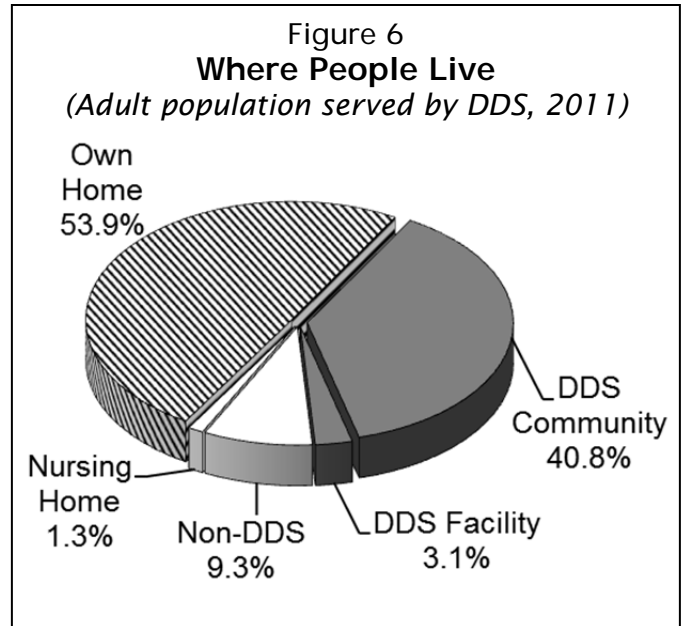
The population living in the DDS community has seen an increase in older people with medical needs, particularly as more Rolland vs. Patrick class members are moved from nursing home settings into the DDS community. Often these older adults are placed into medical homes and may be on hospice.

(See Appendix B for detail of the residential setting categories).

MORTALITY DURING 2010 & 2011

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 2010 and 2011. Appendix A describes the methodology used to collect and analyze the information and data contained in this section.

A total of **406 deaths** occurred for active DDS service recipients in 2010, resulting in a crude adult mortality rate³ of **16.3 deaths per thousand people**.⁴ In 2011, a total of **440 deaths** occurred for active DDS service recipients, for a crude mortality rate of **18.4 deaths per thousand people**.



³ 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.

⁴ Standard recommended by the U.S. Centers for Disease Control and Prevention, National Vital Statistics Report, *Age Standardization of Death Rates: Implementation of the Year 2000 Standard*, Vol. 47, No. 3, 1998.

The average age at death of adults in the DDS population was 61.5 years in 2010 and 60.6 years in 2011. The median age at death⁵, of adults in the DDS population was **61.8 years in 2010** and **60.5 years in 2011**. Mortality statistics in 2011 do not show a significant change in the rate of death for the population from 2010⁶.

Age

Mortality statistics for the adult population by age group are presented in Table 1. The use of a mortality rate (deaths per thousand people) controls for differences in the population size between age groups, and allows for age groups of different size to be compared to each other.

Table 1
Distribution of Deaths by Age Group, 2010-2011

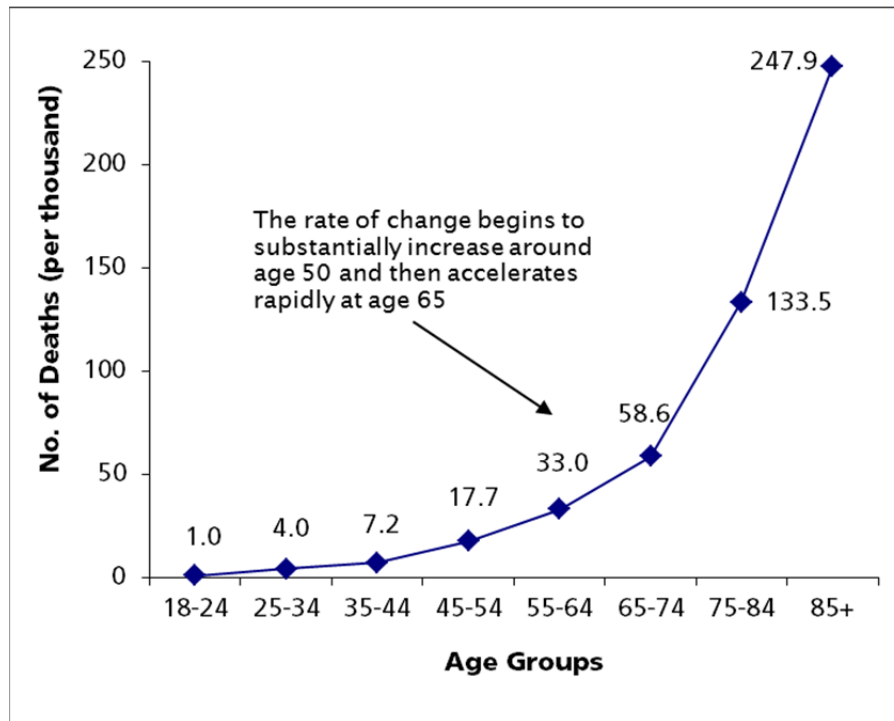
Age Range	2010			2011		
	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)
18-24	20	4.9%	3.9	17	3.9%	1.0
25-34	16	3.9%	3.3	20	4.5%	4.0
35-44	31	7.6%	7.3	29	6.6%	7.2
45-54	61	15.0%	12.5	85	19.3%	17.7
55-64	98	24.1%	31.3	102	23.2%	33.0
65-74	83	20.4%	55.9	87	19.8%	58.6
75-84	63	15.5%	105.9	71	16.1%	133.5
85 yrs & older	34	8.4%	278.7	29	6.6%	247.9
Total	406	100%	16.6	440	100%	18.4

The relationship between age and rate of death for adults served by DDS is displayed in Figure 7. The line in Figure 7 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 2010 and previous years.

⁵ Median = the middle age if all deaths were ranked by age

⁶ T-test assuming unequal variance: $t = 0.25$, $d.f. = 829$

Figure 7
Mortality Rate by Age Group
Adults Served in 2011



Gender

Gender proportions vary with age in the population served by DDS, and a complex relationship exists between gender and mortality.

Table 2
No. Deaths, Average Age at Death and Death Rate by Gender, 2010

Gender	Adult Population	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	10,856	185	45.6%	62.5	17.0
Male	13,537	221	54.4%	60.7	16.3

No. Deaths, Average Age at Death and Death Rate by Gender, 2011

Gender	Adult Population	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	10,590	207	47.0%	62.5	19.6
Male	13,337	233	53.0%	59.9	17.5

Table 2 displays 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 17.0 per thousand in 2010 and 19.6 per thousand in 2011. For males, the adult mortality rate was 14.9 per thousand in 2010 and 17.5 per thousand in 2011.

Residence

Adults eligible for DDS services live in one of six 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 3 and 4.

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 reside in each setting. Historically, in the DDS population, the rate of death is higher in residential settings that have a higher average age at death, an expected finding since age is highly correlated with risk of mortality. Mortality statistics in 2010 and 2011 continued to follow this general pattern as shown in Figures 8 and 9.

As the average population age and health tend to vary by setting⁷, the relationship between type of residence and mortality are consistent with expectations and with trends present in other state intellectual disability systems.⁸

Table 3
Age and Mortality by Type of Residential Setting,
Adults Served by DDS, 2010

Residential Setting	Adult Population (No. People)	% of DDS population	% of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home	12,735	52%	5%	91	22%	49.4	7.1
DDS Community	9,373	38%	14%	210	52%	64.8	22.4
Non-DDS	2,103	9%	11%	31	8%	59.3	14.7
DDS Facility	853	3%	31%	40	10%	70.0	46.9
Nursing Home	363	1%	38%	34	8%	65.5	93.7
Total (Statewide) ⁹	24,393	100%	10%	406	100%		16.6
Average						61.5	

⁷ The population that lives at home or with family is substantially younger than the population that lives in nursing homes. The population that lives in community settings falls in the middle in terms of average age.

⁸ State of Connecticut. *Mortality Annual Report FY11*

⁹ 1,034 consumers had duplicate residential enrollments in 2010. Therefore, the total reflected here will be 1,034 less than the sum of each residential setting.

Figure 8
 Relationship between Mortality Rate, Average Age at Death,
 and Type of Residence, 2010

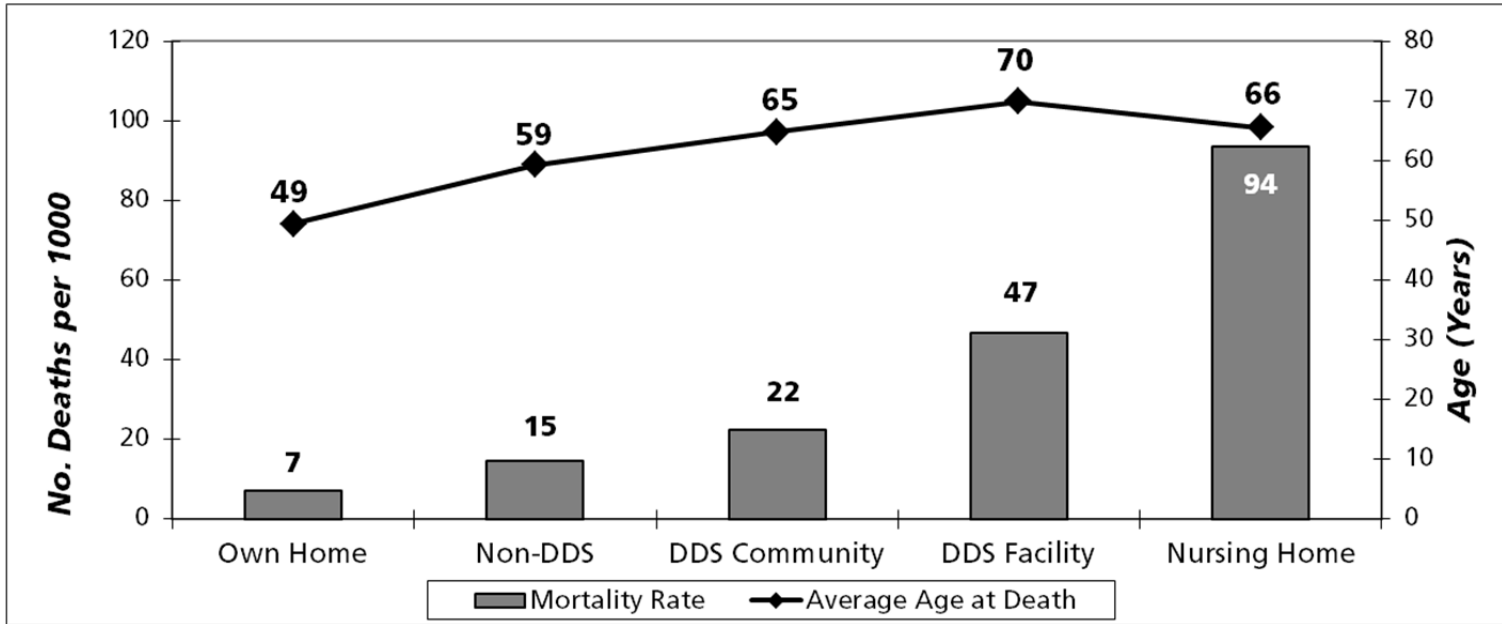


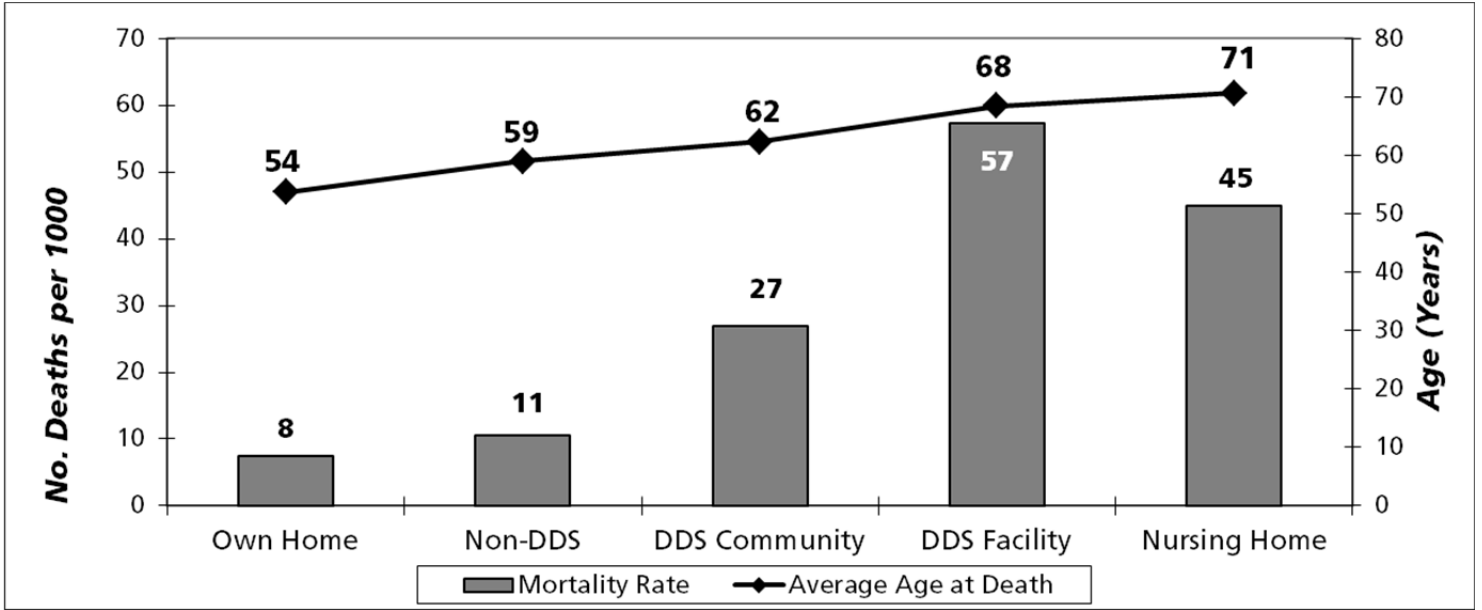
Table 4
 Age and Mortality by Type of Residential Setting,
 Adults Served by DDS, 2011

Residential Setting	Adult Population (No. People)	% of DDS population	% of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home	12,900	54%	5%	97	22%	53.7	7.5
DDS Community	9,710	41%	14%	262	60%	62.4	27.0
Non-DDS	2,270	9%	12%	24	5%	59.0	10.6
DDS Facility	750	3%	30%	43	10%	68.5	57.3
Nursing Home	312	1%	34%	14	3%	70.7	44.9
Total (Statewide)¹⁰	23,927	100%	10%	440	100%		18.4
Average						61.1	

Average age at death was lowest for people living in their own home (53.7 years). The average age at death is highest for those living in nursing homes (70.7 years). The average age of death in the population living in DDS facilities was similar to that of nursing homes at 68.5 years. The average ages of death for individuals living in the DDS community (62.4 years), and non-DDS settings (59.0 years) were similar.

¹⁰ 2015 consumers had duplicate residential enrollments in 2011. Therefore, the total reflected here will be 2015 less than the sum of each residential setting.

Figure 9
**Relationship between Mortality Rate, Average Age at Death,
 and Type of Residence, 2011**



Own Home

People served by DDS living independently in their own home or with family had the lowest mortality rates in 2010 and 2011, similar to previous years. The crude adult rate of death for those living in their own home was 7.1 per thousand in 2010 and 7.5 per thousand in 2011. These rates are very similar to previous years. The crude adult mortality rates for people living in their own home is lower than both the crude mortality rate of 8.1 per thousand for all ages of the general population of Massachusetts.¹¹ 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 49.4 and 53.7 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 22.4 per thousand in 2010 and 27.0 per thousand in 2011. The change in rate between 2010 and 2011 was statistically significant.¹² 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, some of the people moving out of nursing homes and into the community have been on hospice. The average age at death (64.8 and 62.4 years) is similar to the average age for this population.

¹¹ *Massachusetts Deaths 2010*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, January 2013. Table 1: Trends in Mortality Characteristics, Massachusetts: 2000 – 2010.

¹² Z-test between proportions of residential-specific deaths and populations, $z = 2.04$

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 Service Agencies as well as some special programs. Because of this, demographics among this group tend to vary greatly. As discussed previously, this population has grown in 2010 and 2011 compared to previous years, largely due to increases in adult foster care use. Thirty-one people in 2010 and 24 people in 2011 served by DDS living in Non-DDS residences died. The adult mortality rate for this setting was 14.7 per thousand in 2010 and 10.6 per thousand in 2011. No significant change in the mortality rate was seen from 2009 or 2010.¹³

DDS Facilities. The population in this setting is shrinking as efforts are made to shift facility-based residential supports to community based supports. The population remaining in facilities is one of the oldest of all residential settings, with 30% over the age of 65. In 2010, 40 people who were residing in DDS facilities died; the crude adult mortality rate for this setting was 46.9 per thousand. In 2011, 43 people died for a crude adult mortality rate of 57.3 per thousand. The mortality rates in 2010 and 2011 were not significantly different.¹⁴ Because of the changes to the underlying population in this setting, comparisons between years should be made with caution.

Nursing Homes. In 2010, 34 people who were residing in nursing homes (more than 30 days) died; 14 died in 2011. This setting had a crude adult mortality rate of 93.7 per thousand in 2010 and 44.9 per thousand in 2011. The 2011 mortality rate for this setting was significantly lower than the 2010 rate.¹⁵ Deaths in this setting represented 3-8% of all deaths for people served by DDS. The population residing in nursing homes tends to experience the highest rate of death of all residential settings, despite accounting for only about 1% of the total DDS population. However, in 2011 this setting had the second-highest rate behind facilities. People residing in nursing homes are much older than those living in other settings, with 38% of residents over the age of 65, and have substantial health care needs.

¹³ Z-test between proportions of residential-specific deaths and populations, $z = 0.23$, $z = -1.23$

¹⁴ Z-test between proportions of residential-specific deaths and populations, $z = 0.94$

¹⁵ Z-test between proportions of residential-specific deaths and populations, $z = -2.53$

TRENDS OVER TIME

Mortality Statistics

The number of deaths and mortality rate for people served by DDS were slightly lower in 2010 than in previous years, and about the same in 2011 as in 2008 and 2009 as shown in Table 5. Figure 10 shows the deaths, mortality rates and average age at death over time for the DDS population.

Table 5
Mortality Trends in DDS, 2008 - 2011

Year	No. Deaths	Mortality Rate (No. Deaths/1000)	Ave. Age at Death (in years)
2008*	427	18.1	61.5
2009*	421	17.6	58.7
2010	406	16.6	61.5
2011	440	18.4	61.1

The average age of death is presented in Figure 11 for 2008 through 2011. Averages for both 2010 and 2011 are within the range of previous years.

CAUSES OF DEATH

The following section presents information about the causes of death for adults served by the Massachusetts DDS during 2010 and 2011. The World Health Organization's International Classification System for Diseases (ICD-10) is used in this report to assign the basis for death. 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.

The information used to determine the cause of death for each person was obtained from the DDS Death Report (an electronic system) and in some cases, 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.¹⁶ [See the Mortality Review Process and Committee section of this report for clinical review criteria.]

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.

¹⁶ In some cases, additional reports were available to confirm the cause of death, such as toxicology, autopsy or medical examiner reports.

“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.”¹⁷

To allow for more accurate comparisons with other state and I/DD agency reports, this report contains an appendix that lists the specific ICD-10 codes included in each cause of death category (see Appendix D).

Table 6 shows cause-specific mortality rates for the major causes of death in the DDS population for the four year time period between 2008 and 2011.¹⁸

The top ten causes of death in the DDS client population for 2010 and 2011 are compared with data from four previous years and with state and national data in Table 7.

The cause of death for one 2010 decedent and three 2011 decedents was unknown. In these cases, the causes were listed as unknown on death certificates. In at least two of these cases, an autopsy was performed and the cause remained unknown post-autopsy.

Table 6
Cause-specific DDS Mortality Rates, 2008-2011

2011 Rank	2010 Ranking	Previous (2009) Ranking	Cause of Death	DDS Rates of Death (per thousand)			
				2008 ¹⁹	2009 ¹⁹	2010	2011
1	1	1	Heart Disease	3.4	2.9	3.0	3.2
2	2	3	Cancer	1.6	2.3	2.3	2.3
3	3	2	Alzheimer’s Disease	2.5	2.7	2.1	2.0
4	4	4	Aspiration Pneumonia	2.0	1.3	2.0	1.5
5	5	6	Septicemia	1.6	1.1	1.4	1.4
6	7	5	Influenza and Pneumonia	1.1	1.2	0.7	1.3
7	11	9	Unintentional Injury	0.7	0.8	0.4	0.9
8	13	8	CP Arrest/Seizure	0.6	0.9	0.2	0.7
	6	7	Chronic Lower Respiratory Disease	0.9	1.1	0.8	0.7
10	12	14	Gastrointestinal	0.3	0.2	0.3	0.7
11	9	10	Nephritis and Other Renal Diseases	0.5	0.5	0.5	0.5
12	8	13	Stroke	0.7	0.3	0.7	0.4
13	9	11	Congenital Anomalies	0.4	0.3	0.5	0.3

¹⁷ National Center for Health Statistics. "NCHS Instruction Manual, Part 2a, Vital Statistics, Instructions for Classifying the Underlying Cause of Death." Hyattsville, Maryland: Public Health Service, published annually.

¹⁸ This analysis is based on relatively small numbers of people and is therefore subject to rate fluctuations based on minor changes in the number of deaths from year to year for any given cause.

¹⁹ Rates for 2008-2009 adjusted with population figures that are aligned to 2010/2011 methodology

Table 7
Top 10 Leading Causes of Death

Rank	U.S. 2009 ²⁰	MA 2010 ²¹	DDS					
			2006	2007	2008	2009	2010	2011
Age inclusion	All ages	15+	18+					
1	Heart Disease 24.6%	Cancer 24.9%	Heart Disease 21.9%	Heart Disease 16.8%	Heart Disease 18.7%	Heart Disease 16.6%	Heart Disease 18.0%	Heart Disease 17.5%
2	Cancer 23.3%	Heart Disease 23.1%	Alzheimer's Disease 14.4%	Cancer 13.7%	Alzheimer's Disease 14.1%	Alzheimer's Disease 15.2%	Cancer 13.8%	Cancer 12.7%
3	CLRD 5.6%	Stroke 4.8%	Cancer 9.9%	Septicemia 13.0%	Aspiration Pneumonia 11.2%	Cancer 13.3%	Alzheimer's Disease 12.8%	Alzheimer's Disease 10.9%
4	Stroke 5.3%	CLRD 4.6%	Aspiration Pneumonia 8.4%	Alzheimer's Disease 11.3%	Cancer 8.7% Septicemia 8.7%	Aspiration Pneumonia 7.6%	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 8.0%
5	Unintentional Injuries 4.8%	Unintentional Injuries 3.9%	CLRD 5.7%	Aspiration Pneumonia 10.6%		Influenza & Pneumonia 6.9%	Septicemia 8.6%	Septicemia 7.7%
6	Alzheimer's Disease 3.2%	Alzheimer's Disease 3.4%	C-P Arrest/Seizure 5.5%	Unintentional Injuries 6.5%	Influenza & Pneumonia 6.3%	Septicemia 6.4%	CLRD 4.7%	Influenza & Pneumonia 7.0%
7	Diabetes 2.8%	Nephritis & Other Renal Diseases 2.7%	Stroke 5.2% Septicemia 5.2%	C-P Arrest/Seizure 3.6%	CLRD 4.9%	CLRD 6.2%	Influenza & Pneumonia 4.4%	Unintentional Injury 4.8%
8	Influenza & Pneumonia 2.2%	Influenza & Pneumonia 2.5%		Influenza & Pneumonia 3.4%	Stroke 4.0%	C-P Arrest/Seizure 5.2%	Stroke 3.9%	C-P Arrest/Seizure, CLRD, Gastro-intestinal Conditions 3.9% each
9	Nephritis & Other Renal Diseases 2.0%	Diabetes 2.0%	Influenza & Pneumonia 3.9%	Stroke 2.9%	Unintentional Injuries 3.7%	Unintentional Injuries 4.3%	Congenital anomalies, Nephritis & Other Renal Diseases 3.0%	
10	Suicide 1.5%	Septicemia 1.5%	Unintentional Injuries 3.7%	CLRD 2.6% Congenital anomalies 2.6%	C-P Arrest/Seizure 3.3%	Nephritis & Other Renal Diseases 2.9%		

**CLRD = Chronic Lower Respiratory Disease

²⁰ Table D. Deaths and percentage of total deaths for the 10 leading causes of death, by race: United States, 2009. National Vital Statistics Reports, Vol. 61, No. 7, October 26, 2012

²¹ Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2010, *Massachusetts Deaths 2010*. Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, January 2013. (Most recent data available)

Heart Disease. Heart disease was the leading cause of death in both 2010 and 2011 for people served by DDS, consistent with data from previous years and with data from the Massachusetts and U.S. general populations. The adult rate of death from Heart disease was 3.0 per thousand in 2010 and 2.3 per thousand in 2011.

Cancer. Cancer accounted for 12.7-13.8% of deaths, and had an adult cause-specific mortality rate of 2.3 per thousand in both 2010 and 2011. Since 2005, the rate of death from cancer has fluctuated in the DDS population. However, 2010 and 2011 rates are similar to mortality rates seen in 2009. The primary sites of cancers causing death in 2008 are ranked in Table 8.

In both 2010 and 2011 cancer of the trachea, bronchus and lung was the most common primary site, followed by cancer of colon, rectum and anus. Female breast was the third most frequent primary sight, followed by the pancreas.

Medical literature suggests that people with intellectual disabilities of certain etiologies may be predisposed to certain types of cancers^{22,23,24,25} (such as colorectal cancer) and that cancer may develop at significantly younger ages in this population (e.g. colorectal cancer around age 35²²). This predisposition is particularly true for people who have a genetically-caused intellectual disability, and the relationship with specific cancer varies by each genetic cause. 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.^{26,27,28} People with Rett's syndrome are at greater risk for certain types of bone cancer and tuberous sclerosis is associated with kidney and brain tumors.²⁹ Recent research suggests that changes in the genes that cause these syndromes may also cause conditions in the body that increase the risk of the particular cancers.³⁰ 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.^{31,32} Some

²² Lucci-Cordisco E, Zollino M, Baglioni S, Mancuso I, Lecce R, Gurrieri F, Crucitti A, Papi L, Neri G, Genuardi M. A novel microdeletion syndrome with loss of the MSH2 locus and hereditary non-polyposis colorectal cancer. *Clin Genet*. 2005 Feb;67(2):178-82.

²³ Ross JA, Blair CK, Olshan AF, et al. Periconceptional vitamin use and leukemia risk in children with Down syndrome: a Children's Oncology Group study. *Cancer*. 2005 Jul 15;104(2):405-10.

²⁴ Smith DI, Zhu Y, McAvoy S, Kuhn R. Common fragile sites, extremely large genes, neural development and cancer. *Cancer Lett*. 2006 Jan 28;232(1):48-57. Epub 2005 Oct 10.

²⁵ Patja K, Eero P & Livanainen M. Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research*. 2001 Aug 45(4):300-307.

²⁶ Satge D, Sommelet D, Geneix A, et al. (1998) A tumor profile in Down syndrome. *Am J Med Genet* 78: 207-216.

²⁷ Hill DA, Gridley G, Cnattingius S, et al. (2003) Mortality and cancer incidence among individuals with Down syndrome. *Arch Intern Med* 163: 705-711.

²⁸ Hasle H, Clemmensen IH, Mikkelsen M (2000) Risks of leukaemia and solid tumours in individuals with Down's syndrome. *Lancet* 355: 165-169.

²⁹ Al-Saleem T, Wessner LL, Scheithauer BW, et al. (1998) Malignant tumors of the kidney, brain, and soft tissues in children and young adults with the tuberous sclerosis complex. *Cancer* 83: 2208- 2216.

³⁰ Feliciano P. Epigenetic convergence in intellectual disability and cancer? *Nature Genetics*, Free Association 8/7/12. <http://blogs.nature.com/freeassociation/2012/08/epigenetic-convergence-in-intellectual-disability-and-cancer.html>

³¹ Wallace RA, Webb PM, Schluter PJ (2002) Environmental, medical, behavioural and disability factors associated with

people with intellectual 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 2010 and 2011 with 10.9-12.8% 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 past years through 2009, the proportion of deaths due to Alzheimer's been increasing. However, in 2010 and 2011, this trend has slowed since its peak in 2009. The increasing impact of Alzheimer's disease on mortality is a trend that is mirrored in both the Massachusetts and U.S. populations.

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,³³ and may develop at younger ages (as early as 35) for people with Down Syndrome.^{34,35,36} It is estimated that at least half of all people with Down Syndrome who live into their sixties will develop Alzheimer's disease.^{37,38} The higher prevalence and earlier onset of Alzheimer's disease in people with Down Syndrome, together with the

Table 8
Top Primary Sites for Cancer Deaths
in the DDS Population, 2010-2011

Primary Site	2010		2011	
	Number of Deaths	Mortality Rate (per thousand)	Number of Deaths	Mortality Rate (per thousand)
Trachea, bronchus, and lung	11	0.45	10	0.42
Colon, rectum, and anus	8	0.33	10	0.42
Female breast	6	0.55	5	0.47
Leukemia	6	0.25	2	0.08
Pancreas	3	0.12	4	0.17
Ovary	3	0.28	1	0.09
Liver and intrahepatic bile ducts	2	0.08	4	0.17

Causes ranked by Rate per 1,000

Helicobacter pylori infection in adults with intellectual disability. J Intellect Disabil Res 46: 51-60.

³²Duff M, Scheepers M, Cooper M, Hoghton M, Baddeley P (2001) Helicobacter pylori: has the killer escaped from the institution? A possible cause of increased stomach cancer in a population with intellectual disability. J Intellect Disabil Res 45: 219-225.

³³ Patel, P., Goldberg, D. & Moss, S. (1993) Psychiatric morbidity in older people with moderate and severe learning disability. II: The prevalence study. British Journal of Psychiatry, 163, 481-491.

³⁴ Mann, D. M. A. (1988) Alzheimer's disease and Down's syndrome. Histopathology, 13, 125-127.

³⁵ Wisniewski, K.E., Wisniewski, H.M., & Wen, G.Y. (1985). Occurrence of neuropathological changes and dementia of Alzheimer's disease in Down's syndrome. Annals of Neurology, 17, 278-282.

³⁶ Zigman, W.B., Schupf, N., Sersen, E., & Silverman, W. (1996). Prevalence of dementia in adults with and without Down syndrome. American Journal of Mental Retardation, 100, 403-412.

³⁷ Zigman, W., Schupf, N., Haveman, M., et al. (1997) The epidemiology of Alzheimer's disease in mental retardation: results and recommendations from an international conference. Journal of Intellectual Disability Research, 41, 76-80.

³⁸ Massachusetts Alzheimer's Disease and Related Disorders State Plan. Prepared by the Statewide Alzheimer's Disease and Related Disorder State Plan Workgroup, Massachusetts Executive Office of Elder Affairs. February 2012.

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. 72% in 2011).

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. In both 2010 and 2011, aspiration pneumonia was the fourth leading cause of death with 8.0-12.3% of deaths and an adult mortality rate of 2.0 per thousand in 2010 and 1.5 per thousand in 2011.

Aspiration Pneumonia is a significant cause of morbidity and mortality for people with intellectual and developmental disabilities. 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.³⁹ Current treatment options, such as modified food consistency, 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, 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.

Influenza and Pneumonia. The rate of death from Influenza and Pneumonia was 0.7 per thousand in 2010 and 1.3 per thousand in 2011.

Septicemia. The rate of death from septicemia was 1.4 per thousand in both 2010 and 2011, making it the fifth leading cause of death in both years.

Other Causes. In 2011, the seventh ranked cause of death was unintentional injuries with 0.9 deaths per thousand. However, in 2010, the rate of death from this cause was much lower at 0.4 per thousand.

Cardiopulmonary Arrest/Seizure was the eighth leading cause of death in 2011 with 0.7 per thousand deaths. The mortality rate for this cause was much lower in 2010 with a rate of 0.2 per thousand. This category contains certain 'sudden' deaths. Within this category, cardiopulmonary arrest may be listed as the cause of death when the primary or underlying cause of death is not fully known. Cardiopulmonary arrest is a terminal event or mechanism of death and instructions for the completion of death certificates for many

³⁹ Rogers, B., Stratton, P., et al, Long-Term Morbidity and Management Strategies of Tracheal Aspiration in Adults with Severe Developmental Disabilities, American Journal of Mental Retardation, Vol. 98, No. 4, 1994, 490-498.

US states do not consider cardiac arrest a valid primary or underlying cause of death. As the quality of information related to cause of death improves, the number of deaths contributed to this cause tends to decrease.

For the first time, gastrointestinal issues have made the top 10 ranked causes in 2011 with 0.7 deaths per thousand. This category includes causes such as gastrointestinal bleeds and obstructions.

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 9.

Table 9
Top Causes of Death for DDS Community⁴⁰

2011		2010		2011	
Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)	Number of Deaths	Rate of Death (per thousand)
1	Heart Disease	42	4.5	49	5.0
2	Alzheimer's Disease	32	3.4	33	3.4
3	Cancer	30	3.2	31	3.2
4	Septicemia	19	2.0	21	2.2
5	Aspiration Pneumonia	26	2.8	17	1.8

The top three causes of death in people residing within the DDS community are chronic conditions: heart disease, Alzheimer's disease and cancer. The next two causes are not chronic and may be more amenable to medical treatment to prevent mortality, or in the case of aspiration pneumonia, may be preventable in some cases.

The top causes of death for people residing in their own home or with family 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.⁴¹ As shown in Table 10, the top causes of death include cancer and heart disease, similar to the DDS community. However, the rate of death from influenza and pneumonia (0.3-0.6 per thousand) is higher than seen in the general population (0.159 per thousand).

⁴⁰ The person may have passed away in a setting other than the DDS Community, however, people are listed by their primary residential setting.

⁴¹ 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.

Table 10
**Top Causes of Death for Adults
 Served by DDS and Residing in Their Own Home⁴²**

2011 Rank	Cause of Death	2010		2011	
		Number of Deaths	Rate of Death (per thousand)	Number of Deaths	Rate of Death (per thousand)
1	Cancer	17	1.3	22	1.7
2	Heart Disease	12	0.9	19	1.5
3	Influenza and Pneumonia	4	0.3	8	0.6
4	Alzheimer's Disease	7	0.5	6	0.5
5	Aspiration Pneumonia	9	0.7	6	0.5

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

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 2010 and 99% of reviews were completed in 2011. A total of 251 mortality reviews were completed for 2010 deaths and 270 were completed for 2011 deaths. Over the two years 513 of these reviews were required by DDS policy and 8 were requested.

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

⁴² The person may have passed away in a setting other than their own home, however, people are categorized by their primary residential setting.

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.⁴³

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 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 of the person received while in an acute care hospital.

Table 11 displays investigation information for 2003 – 2011. During 2010 there were 26 deaths investigated by one or more of the agencies identified above; in 2011 24 deaths were investigated. DDS conducted 5 investigations on deaths that occurred in 2010 and 3 on deaths that occurred in 2011; a total of 4 investigations were conducted by DPPC across the two years. Law enforcement reviewed 10 cases in 2010 and 12 cases in 2011.

⁴³ "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."

Table 11
Summary of Investigations, 2003 to 2011

Type of Activity	2003	2004	2005	2006	2007	2008	2009	2010	2011
DDS Investigation	9	5	10	2	9	8	13	5	3
DPPC Investigation	4	6	5	3	10	5	3	3	1
Refer to Other Agency	10	9	4	2	7	0	3	4	4
District Attorney/Law Enforcement Investigation	2	4	4	2	9	10	3	10	12
Other/dismitted ⁴⁴	2	1	2	3	5	4	2	3	2
Resolved Fairly and Efficiently					1	0	1	1	0
Total Number of Deaths Investigated	27	20	19	9	34	18	25	26	24

Table 12 presents the findings of investigations by either DDS or DPPC. Investigations regarding 5 of the deaths that occurred in 2010 and 4 of the deaths that occurred in 2011 found the allegations were substantiated. Three investigations from 2010-2011 are still pending. Twenty investigations in 2010 and eighteen in 2011 were found to be unsubstantiated allegations.

Table 12
Findings in Cases Investigated by DDS or DPPC, 2003 to 2011
(Includes cases deferred to law enforcement)

Findings	2003	2004	2005	2006	2007	2008	2009	2010	2011
No. Substantiations	2	1	4	2	3	1	3	5	4
Pending				3	3	2	1	1	2

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

⁴⁴ Complaint was Dismissed, Resolved w/o Investigation or Referred to the Regional Office for administrative review.

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. And, 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 2010 and 2011 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 Connecticut⁴⁵ and Louisiana.⁴⁶ 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 13.

While rank order only a relative comparison, the most common causes of death for the populations served by these state agencies have many similarities. For example, heart disease is the most frequent cause, representing a similar percent of deaths (17.5% - 27.49%) in all service systems. Compared to previous years, this cause is responsible for a larger proportion of deaths across these service systems. Cancer was the second leading cause of death across most systems, representing between 11.3% and 13.5% of deaths.

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 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. Even with these differences, CT DDS found for the first time that Alzheimer's Disease ranked within their top 10 causes of death across the lifespan (rank of 7).

⁴⁵ State of Connecticut DDS Mortality Annual Report, FY 2011. An error in the original report in the rate for the 30-39 age group has been corrected in the information presented in the current report.

⁴⁶ Annual Mortality Report 2011, Home & Community-Based Services (Waiver Program), Louisiana Department of Health & Hospitals, Office for Citizens with Developmental Disabilities. Issued October 2012.

Table 13
**Comparison of the Top 5 Leading Causes of Death
 As Reported by Four State I/DD Agencies**

Rank	MA DDS CY2010 (adults)	MA DDS CY2011 (adults)	CT DDS ⁴⁵ FY2011 (all ages)	OH DDD ⁴⁷ 2010 (Adults)	LA OCDD FY2011 (all ages)
Method	Underlying		Primary	Unknown	Unknown
1	Heart Disease 18.0%	Heart Disease 17.5%	Heart Disease 27.4%	Heart Disease 18.9%	Heart Disease 18.4%
2	Cancer 13.8%	Cancer 12.7%	Cancer 13.5%	Cancer 11.3%	Septicemia 17.3%
3	Alzheimer's Disease 12.8%	Alzheimer's Disease 10.9%	Aspiration Pneumonia 12%	Influenza & Pneumonia 9.0%	Congenital Condition 16.3%
4	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 8.0%	Respiratory Disease ⁴⁸ 11.1%	Congenital Diseases 8.3%	Pneumonia 10.2%
5	Septicemia 8.6%	Septicemia 7.7%	Pneumonia 8.2%	Aspiration Pneumonia 7.1%	Malignant Neoplasm (Cancer) 7.1%

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 different causes of pneumonia, Table 14 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 7.1% and 12.2% 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'.

Table 14
Relative Percent of Annual Deaths by Pneumonia Type

% of annual deaths	MA DDS CY2010 (adults)	MA DDS CY2011 (adults)	CT DDS ⁴⁵ FY2011 (all ages)	OH OMRDD 2010 ⁴⁷ (all ages)	LA OCDD FY2011 (all ages)
Aspiration Pneumonia	12.3%	8.0%	12.0%	7.1%	Unknown
Influenza and Pneumonia	4.4%	7.0%	8.2%	9.0%	Unknown
Total	16.7%	15.0%	20.2%	16.1%	10.2%

⁴⁷ Ohio, Cause of Death Annual 2010, Adults only

⁴⁸ Includes Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma. In other state, national, and in this report, pulmonary embolisms are included within the category of Heart Disease

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 Health 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 15 below displays data associated with 19 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. Because only adults are included in this report, mortality objectives relating exclusively to children and child-birth are not incorporated into this analysis.

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 (2007-2011). 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.

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 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.**

Similar to previous years, crude mortality rates for adults served by the Massachusetts DDS meet many of the HP2020 targets. Because many of the causes of death targeted by the HP2020 benchmarks are chronic conditions or conditions with an older age at onset, it is likely that mortality rates that included children for the population served by DDS would be even lower for many of the objectives. Despite this, many DDS mortality rates for HP2020 targets are lower than age-adjusted mortality rates for the general Massachusetts population or the national population.

While the overall cancer mortality rate does not meet the HP2020 goal, the population meets many of the goals for specific types of cancer, including lung, and uterine cancers and melanoma. Mortality rates for some types of cancer including lung, female breast and colorectal have increased since the last time the 4-year average rates were examined. The mortality rate for colorectal cancer continues to exceed the HP2010 goal, and mortality

rates from these causes are above 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 2007 to 2011 from unintentional injuries continues to be above state and national rates on average, particularly for deaths from falls. The HP2020 goal for deaths from falls is 7.0 per 100,000 people. The MA state mortality rate was 6.9 per 100,000 from this cause in 2010; the average mortality rate for MA DDS service recipients across 2007-2011 was 10 per 100,000 people. The majority of deaths from unintentional injury in the population served by the MA DDS are due to choking or aspiration.

Table 15
Target Status for Selected Healthy People 2020 Mortality Objectives
Rates per 100,000 population

Objective Number	HEALTHY PEOPLE 2010 OBJECTIVE	TARGET 2020 ⁴⁹	DDS 2007-2011		MA 2010 ⁵⁰	US 2010 ⁴⁹
			Avg. Crude Rate	Target Status		
C-1	Overall Cancer death rate	160.6	219.3	●	171.0	186.2
C-2	Lung Cancer	45.5	25.1	✓	47.3	51.3
C-3	Female Breast Cancer (per 100,000 females)	20.6	30.3	●	19.1	26.1
C-4	Uterine cervix (per 100,000 females)	2.2	0.0	✓	1.3	N/A
C-5	Colorectal Cancer	14.5	30.1	●	14.9	N/A
C-6	Oropharyngeal Cancer	2.3	1.7	✓	3.0	N/A
C-7	Prostate Cancer (per 100,000 males)	21.2	13.6	✓	21.2	N/A
C-8	Malignant Melanoma	2.4	0.8	✓	3.1	N/A
HDS-3	Stroke deaths	33.8	51.1	●	31.2	41.9
HIV-12	HIV-infection deaths	3.3	0.8	✓	1.6	2.7
	<u>Injuries</u>					
IVP-11	Unintentional injuries (Accidents)	36.0	77.3	●	28.3	39.1
IVP-23.1	Falls	7.0	10.0	●	6.9	8.4
IVP-30	Firearm-related	9.2	0.0	✓	4.0	10.3
IVP-9	Poisonings	13.1	**	✓*	12.2	13.7
IVP-24.1	Hanging, strangulation or suffocation	1.7	1.7	✓	5.8	N/A
IVP-28	Residential fire deaths	0.86	4.2	●	0.2	N/A
IVP-25	Drowning	1.1	4.2	●	1.2	1.3
IVP-29	Homicide	5.5	**	✓*	3.2	5.3
MHMD-1	Suicide	10.2	**	✓*	8.7	12.4
✓ = YES, met target ○ = NO, but within 25% of target ● = NO, > 25% from target * = Too few deaths from this cause to provide rate						

⁴⁹ Data2020. <http://healthypeople.gov> CDC Accessed October 2013.

⁵⁰ Massachusetts 2010, *Massachusetts Deaths 2010*. Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, January 2013. (Most recent data available)

Appendix A

Methodology for Mortality Review and Analysis

This mortality report analyzes information on all deaths occurring in calendar year 2010 and 2011 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 a person's death according to DDS policy. This report includes statistics on all deaths of people who died in calendar year 2010 and 2011 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, 2010 and July 1, 2011.⁵¹ 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:

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

⁵¹ 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
Residential Codes and Definitions
(new Meditech codes added)

DDS Community: *DDS-funded residential programs or state-operated group residences*

3150	Placement Services / Shared living
3153	Residential Supports
3161	M.S.A. Residential Supports
3182	DDS Respite facility
3286	Ind. Support & Community Habilitation
3288	Placement Services Tier 1
3712	Emergency Stabilization
3749	INDIVIDUAL SUPPORT AND COMMUNITY HABILITATION
3759	Respite – Adult – Site-based
3775	Planned facility respite
3798	INDIVIDUAL SUPPORT AND COMMUNITY HABILITATION
3975 / zTEMPRES	Temporary Residence
4157	DDS State Operated Residential
5150	Self-Directed Supports – Shared Living/Home Share
5153	Self-Directed Supports – Residential Supports
5154	Self-Directed Supports – Residential Supports (24 hr)
5286	Self-Directed Supports – Ind. Support & Community Habilitation
5288	ISO-Placement Services Tier 1
zTEMPRES	Temporary Residence

DDS Facility: *State-operated institutions funded by DDS that provide services as an intermediate care facility*

3200 / ICFID	ICF-ID
4000	DDS Nursing Facility

Nursing Home: *Long-term care facilities and rest homes providing nursing care*

3000 / zNURFACAD	Nursing Facility
3000 / zNURFACPED	Nursing Facility
/ zRESTHOME	Rest Home

Own Home: *Residents live at home with family members or independently in the community.*

0000 / LIVFAM	Living at Home with Family
9999 / LIVIND	Living at Home-Independently
3177	Individual Supports
5177	Ind Support and Comm Hab
5703	Individual Home Supports - SD

Non-DDS: *A small segment of the DDS population lives in residences and facilities not covered by the above definitions and not funded by DDS.*

3001 / zDMHINPT	DMH Inpatient
3174	MSA Support Services
3287	AFC Individual Supports
3950 / zADFOS CARE	Adult Foster Care

3951 / zHOMELESS	Homeless/Homeless Shelter
3952 / zINCAR	Incarceration
3953 / zDMHCOMRES	Community Residential Program
3977 / zDOERES	766 Residential Program
3978 / zREHABHOSP	Rehab Hospital (non-DMH)
9153	MCB Residential Supports
/ zDPHFAC	DPH Facility
/ zDSSRES	DSS Residential Program
/ zGRPASSTLV	Group Assisted Living
/ zNONDMHPSY	Non-DDS Psychiatric Facility
/ zPPASSTLIV	Private Pay Assisted Living
/ zPPRES	Private Pay Residential Program
/ zDSSRES	DSS Residence

Appendix C

Demographic Data

Table 16
2010 DDS Population

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	2,040	2,092	1,908	2,203	1,517	718	299	79	10,856
Male	3,049	2,739	2,349	2,680	1,614	767	296	43	13,537
Total	5,089	4,831	4,257	4,883	3,131	1,485	595	122	24,393

Table 17
2011 DDS Population

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1,947	2,131	1,805	2,158	1,475	739	264	71	10,590
Male	2,963	2,811	2,232	2,653	1,619	745	268	46	13,337
Total	4,910	4,942	4,037	4,811	3,094	1,484	532	117	23,927

Table 18
Annual DDS Population Change within Age Group
A Comparison of 2010 and 2011

Age Group	Gross Population Fluctuation ⁵²		
	People	% Change within Age Group	Resulting % Change in DDS Consumer Population from 2010
18-24	-159	-8.1%	-0.7%
25-34	127	2.6%	0.5%
35-44	-189	-4.4%	-0.8%
45-54	-11	-0.2%	0.0%
55-64	61	1.9%	0.3%
65-74	82	5.5%	0.3%
75-84	0	0.0%	0.0%
85+	29	24.6%	0.1%
Total	-60	-0.2%	-0.2%

⁵² 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 presented on the previous page.

Appendix D

ICD-10 Codes Used in this Publication

(Sorted by ICD-10 Codes)

<u>Cause of Death</u>	<u>ICD-10 CODE</u>
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 Diseases¹	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 E

ICD-10 Codes Used in this Publication

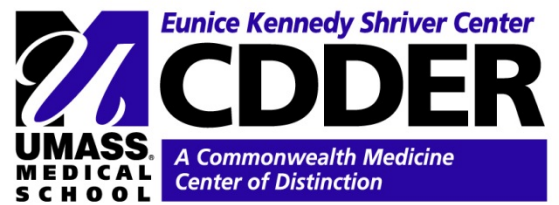
(Sorted by Category)

<u>Cause of Death</u>	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 ¹	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 F
**ICD-10 Codes for Selected Healthy People 2010
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 2010 objectives use data on underlying causes of death.



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