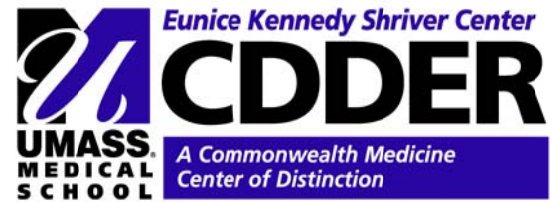


February 2012



2009 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 2009. 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 2009 for all persons 18 years of age or older who have been determined to be eligible for DDS supports. This is the eighth 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 and Regional Quality Councils 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,

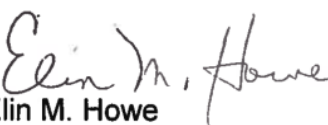

Elin M. Howe
Commissioner

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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 and December 31 of 2009.

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 2009, the Massachusetts DDS served 33,895 individuals, **24,501** of whom were **adults with intellectual disabilities over the age of 18 years**. A net increase of about 1.9%, or 449 people, was seen in the mid-year adult consumer population from June 2008 to June 2009. Population changes demonstrate a pattern of continued aging in the DDS population.

A total of **421 deaths** occurred for active DDS service recipients in 2009, resulting in a crude adult mortality rate of **17.2 individuals per thousand**. The average age at death of adults in the DDS population during 2009 was **58.7 years**. The median age at death, or the middle age if all deaths were ranked by age, of adults in the DDS population during 2008 was **58.3 years**. Mortality statistics in 2009 do not show a significant change in the rate of death for the population from 2008.

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

- **Gender:** In recent years, the adult mortality rate for females has increased while the rate for males has slightly decreased. In 2009, more deaths occurred for females than for males, which is not typical of past years. Comparison of age-adjusted rates shows that the higher mortality rate for females is due to factors other than the age distribution of the population.
- **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 significantly lower than past years at 58.7 years. This appears due in part to a lower rate of death in the oldest age groups in 2009, compared to previous years.
- **Residential Setting:** There are substantial differences in mortality between residential settings. Mortality rates are lowest in people living at home or with family. People living in this setting tend to be younger than other residential settings, and also have the lowest average age at death. Mortality rates are highest for people living in nursing homes due to advanced age and/or health conditions. The relationship between type of residence and mortality are consistent with expectations and with trends present in other state intellectual disability systems.

Causes of Death:

- Heart disease was the leading cause of death in 2009
- Alzheimer's disease was the second leading cause of death with 15.2% of deaths. In recent years, the proportion of deaths due to Alzheimer's disease has increased. In 2009, this cause was responsible for more deaths than in any previous year since 2000 (the first year of this report). The increasing impact of Alzheimer's disease on mortality is a trend that is mirrored in both the Massachusetts and U.S. adult populations.
- Cancer, the third-ranked cause of death, accounted for 13.3% of deaths, and had an adult cause-specific mortality rate of 2.3 per thousand.
- Aspiration pneumonia was the fourth leading cause of death with 7.6% of deaths and an adult mortality rate of 1.3 per thousand. This rate is lower than mortality rates seen in 2007 and 2008.
- The 2009 rate of death from Influenza and Pneumonia was similar to the 2008 rate; both years experienced rates of flu infections at an epidemic levels. Deaths from influenza infections appeared to be particularly higher than normal in young adults residing in their own home independently or with family. Prevention efforts, such as annual flu vaccination, may help reduce the instances of mortality in this subpopulation.
- The rate of death from septicemia continued to drop from previous years to 1.1 per thousand in 2009, making it the fifth leading cause of death.
- The crude adult rate of death from stroke dropped from 0.7 per thousand in 2008 to 0.2 per thousand in 2009. This is the lowest adult mortality rate due to stroke seen since 2000 (the first year of this annual report).

Other Key Findings in 2009:

- Hospice use in the population served by DDS (39% in 2009) consistently increased since 2007 (29%) and rapidly approached the rate of utilization in the general population. Consistent with previous years, a higher percentage of hospice users in the DDS population died in their own home than in the general population.
- In 2009, 25 investigations of abuse or neglect were completed. Three of the investigations were substantiated.
- Similar to previous years, the five year average for crude adult mortality rates for individuals served by the Massachusetts DDS meet many of the CDC's Healthy People 2010 targets for all-age mortality rates.
 - o The 5-year average adult crude mortality rate for female breast cancer continues to be within 25% of the HP2010 targeted mortality rate for all ages. The average mortality rate from colorectal cancer exceeds the HP2010 goal, and mortality rates from both causes are above state and national rates. In both of these types of cancer, early detection can improve survival rates; supporting ongoing efforts to advocate for mammography and colorectal cancer screening in this population.

- o The five year average crude mortality rate for unintentional injuries has risen slightly, due to more aspiration and choking deaths. However, the five year average for mortality due to falls has continued to decline
- o In 2009 the rate of death from stroke dropped substantially, bringing the 5-year average within 25% of the HP 2010 goal. Chronic Obstructive Pulmonary Disease (COPD) rates continue to be higher than goal and a substantial source of mortality.
- o The rate of deaths from unintentional injuries in 2009 was below the state and national rates. However, the 5-year average is higher than state and national rates, and exceeds the HP2010 goal.
- o While still below the HP 2010 targets, diabetes-related deaths saw an increasing trend from 2004 to 2008, but dropped in 2009 in the adults served by the MA DDS.

2009 Mortality Report

INTRODUCTION

This report presents population and mortality information about adults (18 years old and older) eligible for services from the Massachusetts Department of Developmental Services (DDS) during the period between January 1 and December 31 of 2009. The mortality information in this report includes all adults who were eligible and active service recipients (“consumers”) in the Meditech Consumer System during this period and who died during the 2009 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 individuals 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 individuals 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

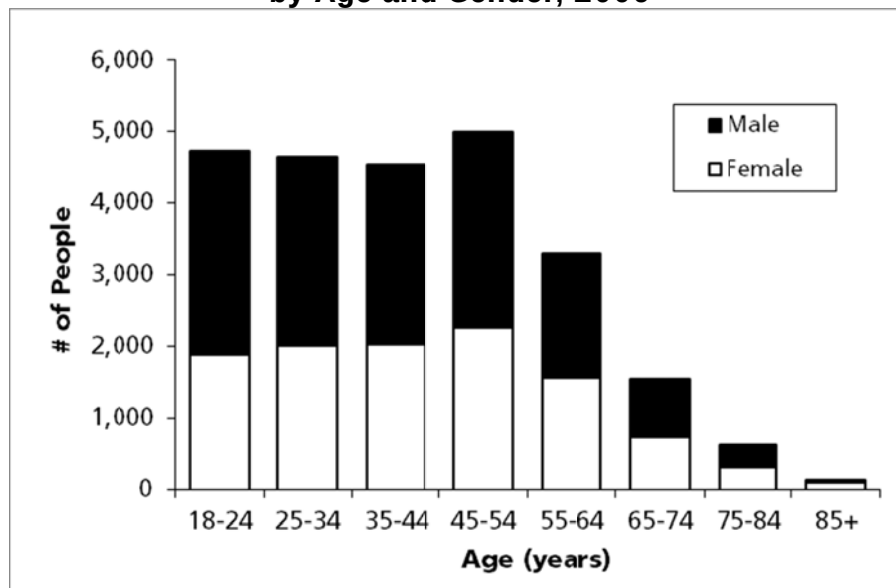
Because the population served by DDS fluctuates over the course of the calendar year, a snapshot of the population at a single point in time is used to estimate the calendar year population. Since the population served by DDS tends to increase as the year progresses, the mid-year population (June 2009) is used to model the average population across the entire year.

In the middle of calendar year 2009, the Massachusetts DDS served 33,895 individuals, 24,498 of whom were adults with intellectual disabilities over the age of 18 years. A net increase of about 1.9%, or 446 people, was seen in the mid-year adult consumer population from June 2008 to June 2009.

Age Characteristics

The age distribution for the DDS population is presented in Figure 1 by 10 year age groups. The populations in the age groups between 18 and 54 years are of similar size, each with between 4,500 – 5,000 people. Over the age of 54, the numbers of people 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.

Figure 1
Distribution of the Population Served by DDS
by Age and Gender, 2009



2009 DDS Population (Figure 1, continued)

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1,879	2,017	2,021	2,261	1,560	743	311	94	10,887
Male	2,838	2,621	2,499	2,737	1,741	803	327	46	13,614
Total	4,717	4,638	4,520	4,998	3,301	1,546	638	140	24,498

Table 1 and Figure 2 present the change in the DDS population between calendar years 2008 and 2009. The gross population change shown in Table 1 by age group reflects changes resulting from new consumers entering the DDS system, consumers aging into the next age group, consumers relocating out of the state, and consumers that have died. Small gross increases of between 1% and 9% are seen in most non-elderly age groups except for the 25-34 year old group, which had a 2% decline. The elderly age groups had gross increases of 15-26%. While the elderly age groups are the smallest and these changes represent a small change in the number of people, these changes demonstrate a pattern of continued aging in the DDS population.

Table 1
Annual DDS Population Change within Age Group
A Comparison of 2008 and 2009

Age Group	Gross Population Fluctuation ¹		
	Individuals	% Change within Age Group	Resulting % Change in DDS Consumer Population from 2008
18-24	219	4.8%	0.9%
25-34	170	3.8%	0.7%
35-44	-93	-2.0%	-0.4%
45-54	72	1.4%	0.3%
55-64	249	7.8%	1.0%
65-74	128	8.5%	0.5%
75-84	95	15.4%	0.4%
85+	36	26.3%	0.1%
Total	876	N/A	3.6%

Figure 2
DDS Population Change, 2008 - 2009



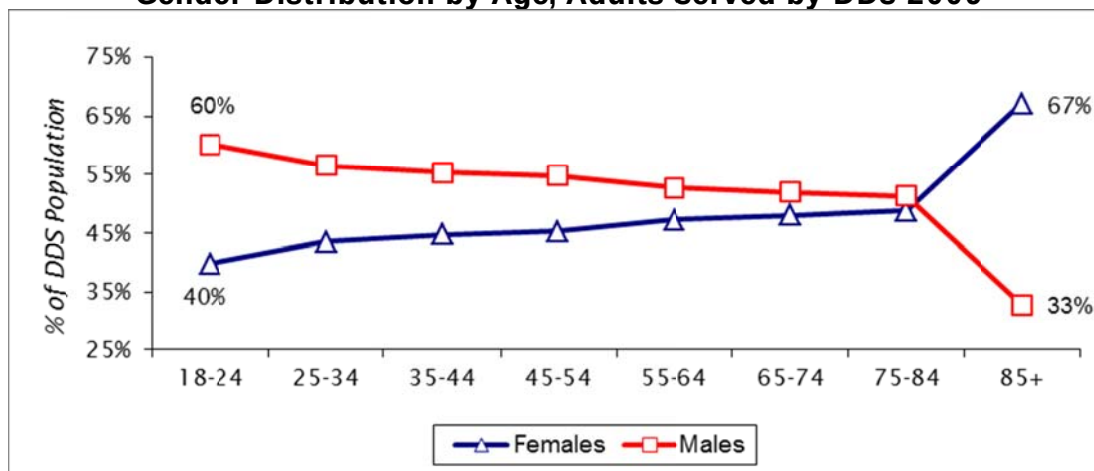
¹ Gross population change reflects the migration of living individuals between age groups. The figures take into account the individuals that must have entered the age group to compensate for death over the course of the year. The percent increase in the population will not match the net population increase presented on the previous page.

Gender Characteristics

The gender distribution in the 2009 adult DDS population is similar to 2008 and previous years for most age groups. As Figure 3 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

However, this is the first time in the last decade that more men have been served than women in the 75-84 year old age group. This change may be the result of increased longevity for adult males and/or a relatively higher rate of death of females in the oldest age groups in the DDS population in recent years.

Figure 3
Gender Distribution by Age, Adults Served by DDS 2009



Residential Setting Characteristics

Adults receiving services from DDS reside in a variety of different settings. Many individuals 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 4.

Just over half of the adults served by DDS reside in their own home, which includes people living independently or with their family.³ Residential programs operated, licensed/certified or funded by DDS are shown in the sections shaded in solid grey in Figure 4. About 38% of adults served by DDS live in community residential programs, and less than 4% live in DDS facilities. The number of people living in DDS facilities continues

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

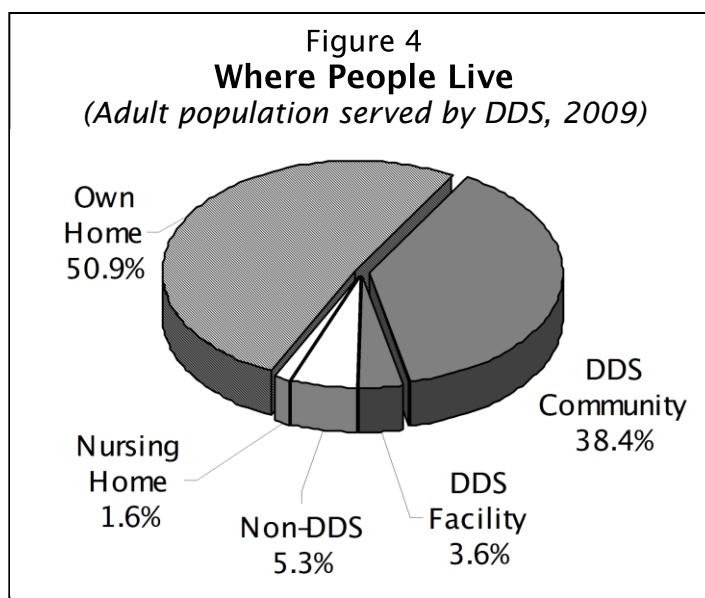
³ Due to changes in the electronic DDS tracking systems in 2008, the 'own home' category will no longer be broken out separately into people living independently and those living with their families.

to decline annually largely due to DDS's efforts to plan transitions to community settings for these residents.

About 7% 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 4, or in nursing homes. In 2009, the proportion of the population living in Non-DDS settings increased from 4.4% of the population in 2008 to 5.3% of the population in 2009.

About 0.2% of individuals live out of the state of Massachusetts (not shown in Figure 4). These people are class members in the Ricci V. Okin (1972) lawsuit living outside of the state of Massachusetts. Class members include anyone who was part of the original Class Identification List as of April 30, 1993, or who lived at a state facility for more than 30 consecutive days or for more than 60 days during any twelve-month period after this date. Class members are eligible for DDS services on a lifetime basis as described in their Individual Support Plan (ISP). Therefore, individuals in this group are active service recipients and are counted within the adult DDS population.

(See Appendix B for a more detailed description of the categories of residential settings).



MORTALITY DURING 2009

This section contains information on the deaths of individuals who were 18 years of age or older at the time of death and who were eligible for DDS services and supports during calendar year 2009. Appendix A describes the methodology used to collect and analyze the information and data contained in this section.

A total of **421 deaths** occurred for active DDS service recipients in 2009, resulting in a crude adult mortality rate⁴ of **17.2 individuals per thousand**.⁵ DDS received death reports for 415 decedents for calendar year 2009. A validation exercise was conducted between the electronic DDS mortality reports filed for 2009, consumers listed in the agency's Meditech Consumer System, and the Social Security Death Index. Six additional decedents were confirmed to be DDS consumers for whom a DDS death report had not

⁴ 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 individuals who died during the year times one thousand and dividing this by the total number of individuals served by DDS during the same year. The crude death rate can be useful when comparing deaths across populations of varying sizes.

⁵ 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.

yet been filed, bringing the total number of deaths to 421. To date, two of the DDS death reports have now been completed for these consumers.

The average age at death of adults in the DDS population during 2009 was **58.7 years**. The median age at death, or the middle age if all deaths were ranked by age, of adults in the DDS population during 2009 was **58.3 years**. Mortality statistics in 2009 do not show a significant change in the rate of death for the population from 2008⁶.

Age

Mortality statistics for the adult population by age group are presented in Table 2. The table includes the number of individuals who died, the relative percentage of 2009 deaths, and the crude mortality rate. The use of a mortality rate (deaths per thousand individuals) 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 2
Distribution of Deaths by Age Group, 2009

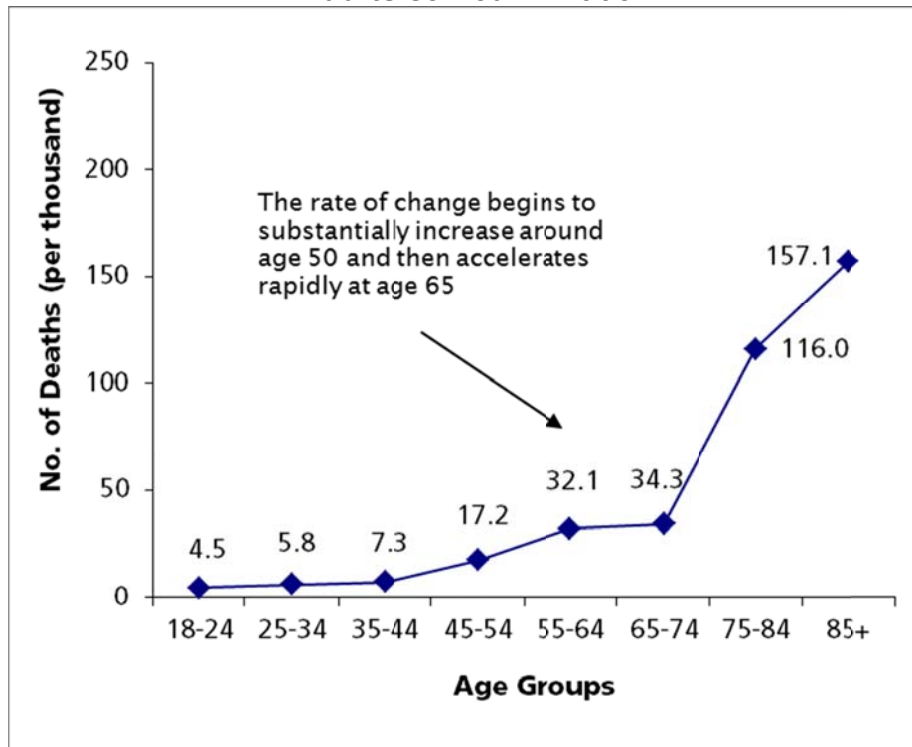
Age Range	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)
18 - 24 yrs	21	5.0%	4.5
25 - 34 yrs	27	6.4%	5.8
35 - 44 yrs	33	7.8%	7.3
45 - 54 yrs	86	20.4%	17.2
55 - 64 yrs	106	25.1%	32.1
65 - 74 yrs	53	12.6%	34.3
75 - 84 yrs	73	17.3%	114.0
85 yrs & older	22	5.2%	157.1
Total	421	100%	17.2

Mortality rates are lowest in the youngest age groups, and increase with each age group. The age group around the average at death, 55-64 years, accounts for the largest number of deaths. This proportional relationship between age and mortality is seen in most other populations and is reflective of the increasing risk of mortality with advancing age.

The relationship between age and rate of death for adults served by DDS is displayed in Figure 5. The line in Figure 5 is used to illustrate 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.

⁶ χ^2 Test of Independence. $\chi^2 = 0.22$, d.f.=1

Figure 5
Mortality Rate by Age Group
Adults Served in 2009



Gender

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

Table 3
No. Deaths, Average Age at Death and Death Rate by Gender, 2009

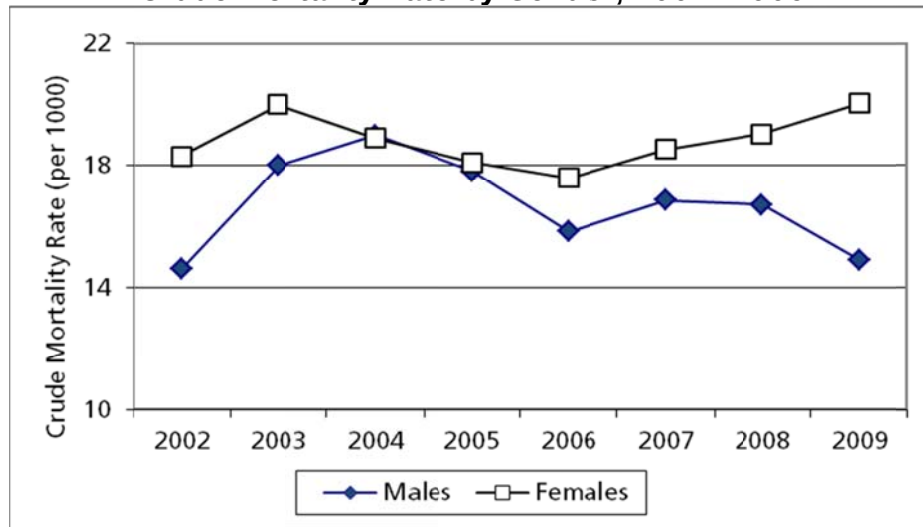
Gender	Adult Population	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	10,887	218	52%	60.3	20.0
Male	13,614	203	48%	56.9	14.9

Table 3 displays the adult population, number of deaths, percent of overall deaths, average age at death and rate of death for each gender. The crude adult mortality rate of females is 20.0 per thousand and 14.9 per thousand for men in 2009.

Figure 6 shows the crude adult mortality rate for each gender over the past 9 years. In recent years, the adult mortality rate for females has increased, while the rate for males has slightly decreased. In 2009, more deaths occurred for females than for males, which is not typical of past years. Because there are substantially more males served by DDS, initial expectations may be to have more deaths in males than females.

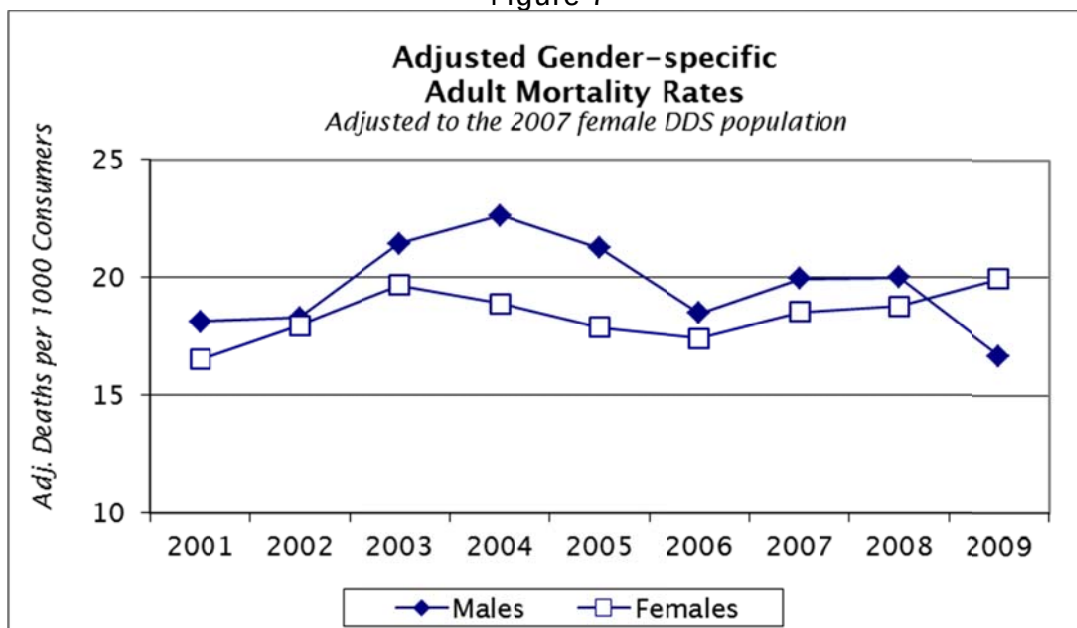
However, females served by DDS may experience certain factors that put them at a higher risk for mortality than males such as more people in older age groups, or more people with serious health conditions.

Figure 6
Crude Mortality Rate by Gender, 2002 - 2009



Because the age distribution within each gender differs, age-adjusted adult mortality rates are presented in Figure 7. These adjusted rates allow for comparison of the mortality rates across genders as if both genders had the same age distribution. Because age is such a strong risk factor for mortality, this allows us to examine differences due to factors other than age. From 2002 – 2009, the adjusted mortality rate for females has generally been lower than that of males. In 2009, the adjusted mortality rate for females is greater at 19.9 per thousand than for males at 16.7 per thousand. This comparison of adjusted rates shows that the higher mortality rate for females due to factors other than the age distribution of the population.

Figure 7
Adjusted Gender-specific Adult Mortality Rates
Adjusted to the 2007 female DDS population



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. In addition, a small proportion of the population (0.2%) is made up of Ricci class members residing outside of the Commonwealth of Massachusetts. (For more information on the residential distribution in this population, see 'Residential Setting Characteristics', above.) Specific definitions, including residential codes, are contained in Appendix B. Mortality statistics for these residential categories are displayed in Table 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 2009 continued to follow this pattern with the exception of the 'non-DDS' supported setting which is small and subject to annual fluctuation.

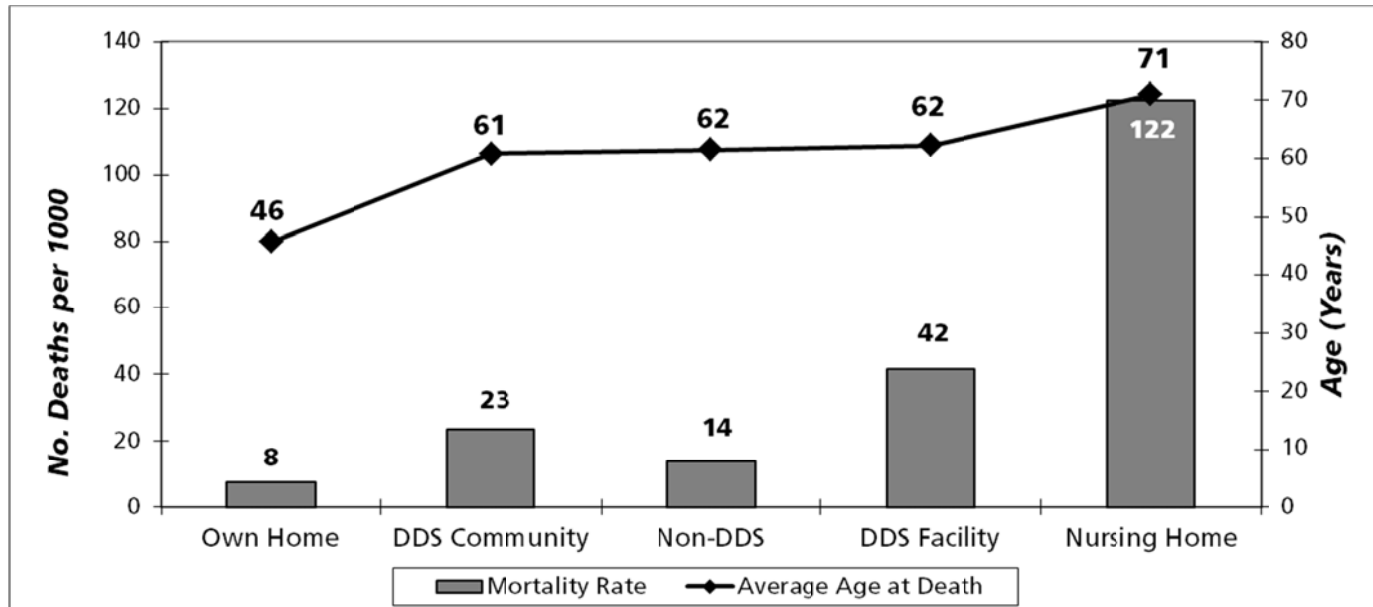
Table 4
Age and Mortality by Type of Residential Setting,
Adults Served by DDS, 2009

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	12,480	51%	5%	95	23%	45.7	7.6
DDS Community	9,389	38%	12%	220	52%	60.8	23.4
Non-DDS	1,307	5%	12%	18	4%	61.5	13.8
DDS Facility	890	4%	29%	37	9%	62.2	41.6
Nursing Home	392	2%	38%	48	11%	71.0	122.4
Out of State	47	<1%	15%	2	<1%	59.5	N/A
Total (Statewide) ⁷	24,498	100%	9%	421	100%		
Average						58.7	17.2

Average age at death was lowest for individuals living in their own home (45.7 years). The average age at death is highest for those living in nursing homes (71.0 years). The average ages of death for decedents were similar for those living in the DDS community (60.8 years), DDS facilities (62.2 years), and non-DDS settings (61.5 years).

⁷ 7 consumers had duplicate residential enrollments in 2009. Therefore, the total reflected here will be 7 less than the sum of each residential setting. 1 decedent in 2009 had an unknown residential setting at the time of this report; this person refused services from DDS.

Figure 8
Relationship between Mortality Rate, Average Age at Death,
and Type of Residence, 2009



The relationship between type of residence and mortality are consistent with expectations and with trends present in other state intellectual disability systems.⁸ This is because the average population age and health tends to vary by type of residential setting.⁹

Own Home

Individuals served by DDS living independently in their own home or with family had the lowest mortality rates in 2009, similar to previous years. The crude adult rate of death for those living in their own home was 7.6 per thousand in 2009, which is not significantly different from the 2008 crude death rate for this group.¹⁰ The crude adult mortality rates for people living in their own home is lower than both the crude mortality rate of 8.2 per thousand and the age-adjusted rate of 7.0 per thousand for all ages of the general population of Massachusetts.¹¹ (See the 'Age-adjusted Mortality Rates' section of this report for the age-adjusted mortality rate for the MA DDS.) The residential subgroup of people living in their own homes is the youngest on average of all residential subgroups and has the smallest percentage of individuals over the age of 65; this is reflected in the relatively low average age at death of 45.7 years.

DDS Community

The DDS Community is a diverse residential subgroup both in terms of age and level of service need, and supports the second-largest residential subpopulation of DDS

⁸ State of Connecticut. *Mortality Annual Report FY09*, March 2010.

⁹ 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 and facilities falls in the middle in terms of average age.

¹⁰ Z-test between proportions of residential-specific deaths and populations, $z = 0.75$

¹¹ *Massachusetts Deaths 2008*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, April 2010. Table 1: Trends in Mortality Characteristics, Massachusetts: 1998 – 2008.

consumers in Massachusetts. The crude adult mortality rate for individuals served by DDS living in the DDS Community in 2009 was 23.4 per thousand. This rate has not changed significantly from 2008.¹² The average age at death (60.8 years) is similar to the average age at death 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 Service Agencies as well as some special programs. Because of this, demographics among this group tend to vary greatly. Eighteen (18) individuals served by DDS living in Non-DDS residences died in 2009, resulting in a crude adult mortality rate of 13.8 per thousand. No significant change in the mortality rate was seen from 2008.¹³

DDS Facilities. In 2009, 37 people who were residing in DDS facilities died; the crude adult mortality rate for this setting was 41.6 per thousand in 2009.

DDS continued efforts in 2009 to move people out of DDS facilities into community settings. Because of these efforts, the population of people living in facilities changes each year, and these changes may affect mortality statistics for this population. Because of the changes to the underlying population in this setting, comparisons between years should be made with caution.

Nursing Homes. In 2009, 48 people who were residing in nursing homes (for more than 30 days) died. This setting had a crude adult mortality rate of 125.0 per thousand and represented 11.0% of all deaths for people served by DDS. People residing in nursing homes tend to experience the highest rates of death of all residential settings, despite accounting for only about 2% of the total DDS population in 2009. The people residing in nursing homes are much older than those living in other settings, with 38% of residents over the age of 65, and tend to have substantial health care needs.

The 2009 crude mortality rate in nursing homes decreased significantly¹⁴ from the 2008 rate, resulting in proportion of deaths that was more similar to calendar year 2007. The number of people living in nursing homes is small, and has decreased over the

Table 5
**Mortality Rate in Nursing Homes
A Comparison of US and MA DDS
Populations**

Age Group	Rate of Death (per thousand)	
	US 2005 (estimated)	DDS 2009
65+	420.7	223.0
85+	414.3	259.3
All Ages	373.4	125.0

¹² Z-test between proportions of residential-specific deaths and populations, $z = 1.04$

¹³ Z-test between proportions of residential-specific deaths and populations, $z = -0.09$

¹⁴ Z-test between proportions of residential-specific deaths and populations, $z = -2.72$

last few years. As such, this fluctuation is not unusual, as a difference of a small number of deaths may result in large changes in proportions or rates.

The crude mortality rate continues to be lower than the general population approximate rate of death in Massachusetts nursing homes (356.4 per thousand) in 2008¹⁵ and U.S. nursing homes in 2005 (373.4 per thousand).¹⁶ Rate of death by age for both the MA DDS and the US population are shown in Table 5.

AGE - ADJUSTED MORTALITY RATES

A variety of factors can influence the risk of mortality - and the resultant mortality rates - within different populations. When comparing the DDS population to the overall U.S. population, differences in characteristics such as age, presence of physical disability and the incidence of medical and health related disorders are important variables that should be taken into consideration. Unfortunately, there is a relative dearth of comparable incidence data readily available for many of these variables. Age, however, is one factor that can be easily controlled when comparing the DDS population to the U.S. population. Therefore, an *age-adjusted adult rate of death* is presented in this section to allow for more direct comparisons of the DDS consumer population to the U.S. 2000 population. This adjusted mortality rate represents the *relative* rate of death for the DDS population *if* it had the same age distribution as the general estimated U.S. adult population (2000). Methods used to calculate adjusted rates differ from previous reports, and therefore are not comparable.

See Appendix D for a detailed description of the methods used in this section and additional details about the age adjustments.

Age-adjustment within the DDS Population

Age-adjusted death rates are used to compare relative mortality rates between groups and should be viewed as *relative indexes* rather than as actual measures of mortality.

The overall **adjusted adult death rate** for the DDS population is approximately **23.4 per thousand**. The age-adjusted rate is higher than the crude adult mortality rate of 17.2 per thousand. This difference is due to the larger proportions of the population in younger age groups, which have low death rates.

¹⁵ Approximate 2007 Crude Rate of Death in Massachusetts Nursing Homes calculated from a population in 2007 of 45,172 living in MA Nursing Homes (from *Across the States: Profiles of Long Term Care: Massachusetts, 2009*, Public Policy Institute, AARP) and a total number of 16,098 deaths in MA Nursing Homes from (*Massachusetts Deaths 2008*, Bureau of Health Statistics, Research and Evaluation Massachusetts Department of Public Health).

¹⁶ US Nursing Home Mortality Rate estimates are based upon 2005 death counts from: Worktable 309. Deaths by place of death, age, race, and sex: United States, 2005, April 10, 2008, National Center for Health Statistics. 2005 data is most recent US mortality data available by location of death. Estimated using the 2005 US Nursing facility residential population is taken from: *Across the States: Profiles of Long Term Care, Seventh Edition, 2006*, Public Policy Institute, AARP. Age-specific nursing facility populations estimated using % occupancy figures from 2007 reported in *Across the States: Profiles of Long Term Care, Eighth Edition, 2009*, Public Policy Institute, AARP.

This age-adjusted mortality rate for the DDS population is higher than the 2008 age-adjusted U.S. overall mortality rate of 8.1 per thousand¹⁷ and the age-adjusted adult 2008 mortality rate for Massachusetts of 8.0 per thousand¹⁸. The findings in the DDS client population are relatively consistent with the nationwide consensus for populations with similar disabilities; the average age at death and the lifespan both tend to be lower in individuals with intellectual disabilities.¹⁹

TRENDS OVER TIME

Mortality Statistics

The number of deaths and mortality rate for people served by DDS was about the same in 2009 as findings in 2007 and 2008. The mortality rate is well within the normal range for this population, as evidenced by the historic data on the number of deaths and mortality rate presented in Table 6 and illustrated in Figure 9.

Table 6
Mortality Trends in DDS²⁰, 2002 - 2009

Year	No. Deaths	Mortality Rate (No. Deaths/1000)	Ave. Age at Death (in years)
2002	405	17.9	61.5
2003	431	18.9	61.7
2004	439	19.0	62.1
2005	409	17.9	60.8
2006	383	16.6	61.6
2007	416	17.6	62.0
2008	427	17.8	61.5
2009	421	17.2	58.7

The average age of death, as presented in Figure 10, was significantly lower than past years at 58.7 years.²¹ This appears due in part to a lower rate of death in the oldest age groups in 2009, compared to previous years.

¹⁷ Deaths: Final Data for 2008. National Vital Statistics Reports Volume 59, Number 10, December 2011

¹⁸ Estimate of adult age-adjusted rate from populations and number of deaths per age group presented in the 2007 Massachusetts Mortality Report. Also, "adult" defined as 15 years +, as a 15-24 year old age group is presented in the report.

¹⁹ Eyman RK, Grossman HJ, Chaney RH, Call TL. The life expectancy of profoundly handicapped people with mental retardation. N Engl J Med. 1990 Aug 30;323(9):584-9.

²⁰ Rates for 2002 have been adjusted by using the current methodology (adopted in the 2003 mortality report) to calculate the overall client population (denominator for calculating rates). The number of deaths was unchanged (numerator). These adjusted rates are provided to increase the validity of analyses that compare mortality rates from prior years with the data presented for 2003-2004. It is important to note that the methodology used to calculate the actual number of annual deaths did not change.

²¹ Two-tailed Student's T-test assuming unequal variance, $t=-2.35$, $p=0.019$, $d.f. = 844$)

Figure 9
Statewide Mortality Rates, 2005 - 2009
(Deaths per 1000)

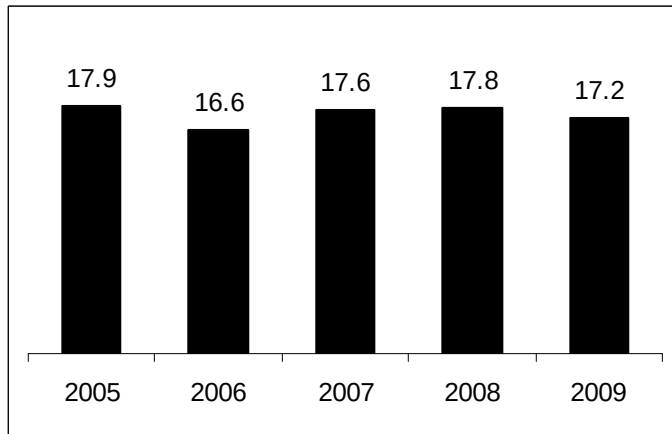


Figure 10
Average Age at Death per Year
2005 - 2009

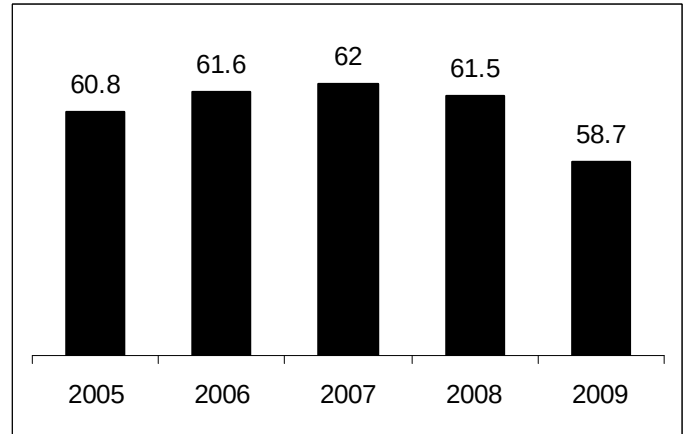


Figure 11
Comparison of Mortality Rate by Age Group Over Time, 2005 - 2009

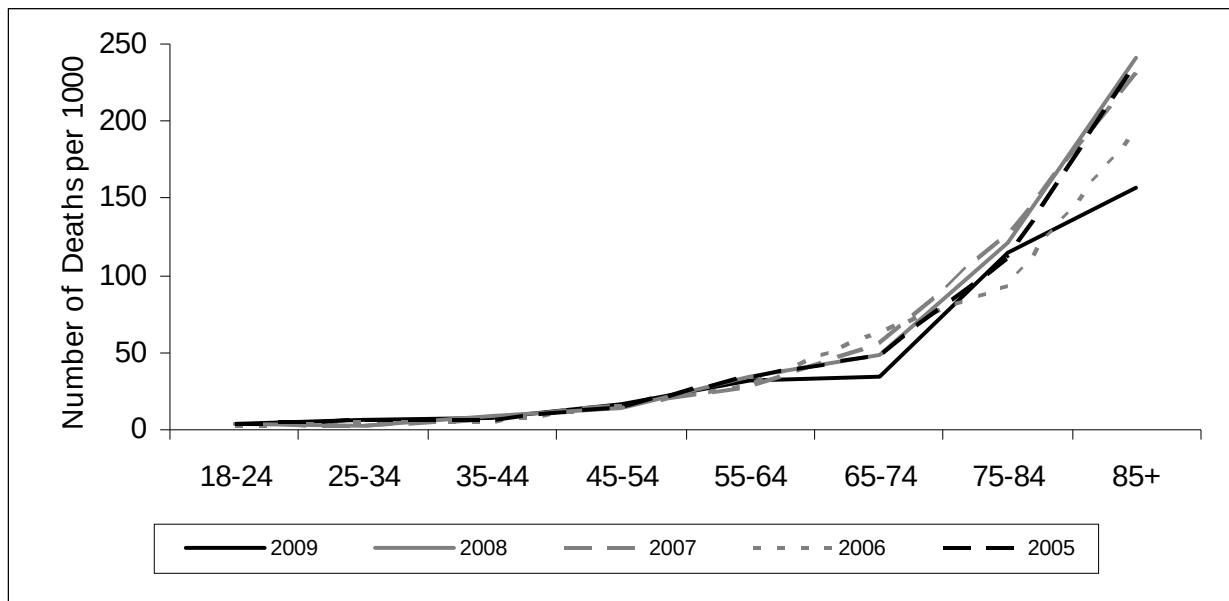


Figure 11 shows mortality rates by age group for 2009 and the past four calendar years. As expected, the mortality rate for each age group increases with age. It is important to note that the older age groups have relatively small populations and are typically at a higher risk of mortality. Because of this, small changes in the number of deaths, or the population size, can have a large impact on mortality rates. The age-specific mortality rates are essentially the same for the age groups under 65 years. Some variability is seen in the age groups of 65 years and above; however, the variation is not unexpected due to the high mortality risk and small age-specific populations.

CAUSES OF DEATH

The following section presents information about the causes of death for adults served by the Massachusetts DDS during 2009. 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 individual was obtained from the DDS Death Report (an electronic system) and in some cases, the Death Certificate. In the case of individuals subject to clinical mortality review, the cause may have been confirmed by the DDS Mortality Review Committee.²² [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.

*"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."*²³

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 E).

The top ten causes of death in the DDS client population for 2009 are compared with data from four previous years and with state and national data in Table 7. Table 8 displays cause-specific mortality rates for the major causes of death in the DDS population for the five year time period between 2005-2009.²⁴

The cause of death for three 2009 decedents was unknown. Two of these people died outside of the state of MA, and the information on the cause of their death was not made available to DDS. For the third, the cause of death was listed as unknown on the person's final death certificate.

Heart Disease. Heart disease is the leading cause of death in 2009 for people served by DDS, consistent with data from previous years and with data from the Massachusetts and

²² In some cases, additional reports were available to confirm the cause of death, such as toxicology, autopsy or medical examiner reports.

²³ 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.

²⁴ This analysis is based on relatively small numbers of individuals and is therefore subject to rate fluctuations based on minor changes in the number of deaths from year to year for any given cause.

U.S. general populations. The adult rate of death from Heart disease was 2.9 per thousand in 2009 and this was the underlying cause for 16.6% of deaths. While still the top ranked cause of death, heart disease accounted for a slightly smaller proportion of deaths than in previous years.

Table 7
Top 10 Leading Causes of Death

Rank	U.S. 2007 ²⁵	MA 2008 ²⁶	DDS				
			2005	2006	2007	2008	2009
Age inclusion	All ages	15+	18+				
1	Heart Disease 25.4%	Cancer 24.5%	Heart Disease 16.4%	Heart Disease 21.9%	Heart Disease 16.8%	Heart Disease 18.7%	Heart Disease 16.6%
2	Cancer 23.2%	Heart Disease 24.3%	Cancer 12.0%	Alzheimer's Disease 14.4%	Cancer 13.7%	Alzheimer's Disease 14.1%	Alzheimer's Disease 15.2%
3	Stroke 5.6%	Stroke 5.0%	Influenza & Pneumonia 10.8%	Cancer 9.9%	Septicemia 13.0%	Aspiration Pneumonia 11.2%	Cancer 13.3%
4	CLRD 5.3%	CLRD 4.9%	C-P Arrest/ Seizure ²⁷ 10.8%	Aspiration Pneumonia 8.4%	Alzheimer's Disease 11.3%	Cancer 8.7%	Aspiration Pneumonia 7.6%
5	Unintentional Injuries 5.1%	Unintentional Injuries 3.8%	Aspiration Pneumonia 9.3%	CLRD 5.7%	Aspiration Pneumonia 10.6%	Septicemia 8.7%	Influenza & Pneumonia 6.9%
6	Alzheimer's Disease 3.1%	Alzheimer's Disease 3.5%	Alzheimer's Disease 8.6%	C-P Arrest/ Seizure ²⁷ 5.5%	Unintentional Injuries 6.5%	Influenza & Pneumonia 6.3%	Septicemia 6.4%
7	Diabetes 2.9%	Influenza & Pneumonia 3.0%	Septicemia 5.9%	Stroke 5.2%	C-P Arrest/ Seizure ²⁷ 3.6%	CLRD 4.9%	CLRD 6.2%
8	Influenza & Pneumonia 2.2%	Nephritis & Other Renal Diseases 2.6%	CLRD 4.6%	Septicemia 5.2%	Influenza & Pneumonia 3.4%	Stroke 4.0%	C-P Arrest/ Seizure ²⁷ 5.2%
9	Nephritis & Other Renal Diseases 1.9%	Diabetes 2.1%	Stroke 4.2%	Influenza & Pneumonia 3.9%	Stroke 2.9%	Unintentional Injuries 3.7%	Unintentional Injuries 4.3%
10	Septicemia 1.4%	Septicemia 1.5%	Unintentional Injuries 3.4%	Unintentional Injuries 3.7%	CLRD 2.6% Congenital anomalies 2.6%	C-P Arrest/ Seizure ²⁷ 3.3%	Nephritis & Other Renal Diseases 2.9%

**CLRD = Chronic Lower Respiratory Disease

²⁵ Table 10. Number of deaths from 113 selected causes and Enterocolitis due to *Clostridium difficile*, by age: United States, 2007. Deaths: Final Data for 2007. National Vital Statistics Reports, Vol. 58, No. 19, May, 2010

²⁶ Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2008, *Massachusetts Deaths 2008*. Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, August 2010. (Most recent data available)

²⁷ Includes sudden deaths reported as cardio-pulmonary arrest whether or not seizure was present.

Table 8
Cause-specific DDS Mortality Rates, 2005 - 2009

2009 Rank	Previous Ranking	Cause of Death	DDS Rates of Death (per thousand)				
			2005	2006	2007	2008	2009
1	1	Heart Disease	2.9	3.6	3.0	3.3	2.9
2	2	Alzheimer's Disease	1.5	2.4	2.0	2.5	2.6
3	4	Cancer	2.1	1.6	2.4	1.5	2.3
4	3	Aspiration Pneumonia	1.7	1.4	1.9	2.0	1.3
5	6	Influenza and Pneumonia	1.9	0.7	0.6	1.1	1.2
6	4	Septicemia	1.1	0.9	2.3	1.5	1.1
7	7	Chronic Lower Respiratory Disease	0.8	1.0	0.5	0.9	1.1
8	10	CP Arrest/Seizure	1.9	0.9	0.6	0.6	0.9
9	9	Unintentional Injury ²⁸	0.6	0.6	1.1	0.7	0.7
10	11	Nephritis and Other Renal Diseases	0.4	0.5	0.4	0.5	0.5

Alzheimer's Disease. Alzheimer's disease was the second leading cause of death with 15.2% of deaths. In recent years, the proportion of deaths due to Alzheimer's increased. In 2009, this cause was responsible for more deaths than in any previous year since 2000 (the first year of this report). 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,²⁹ and may develop at younger ages (as early as 35) for individuals with Down Syndrome.^{30,31,32} It is estimated that at least half of people with Down Syndrome those who live into their sixties will develop Alzheimer's disease.^{33,34} 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.

²⁸ Category codes include ICD 10 codes V01-X59, Y85-Y86 in an effort to report categories in a similar to state and national report. In 2001-2003, "accidental injuries" and "aspirations" were counted in separate categories. Therefore the rates listed here may appear higher than in past mortality reports from these years because they reflect both the 'accidental injury' group as defined at that time and the 'aspiration' group.

²⁹ 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.

³⁰ Mann, D. M. A. (1988) Alzheimer's disease and Down's syndrome. *Histopathology*, 13, 125-127.

³¹ 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.

³² 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.

³³ 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.

³⁴ 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.

Cancer. Cancer accounted for 13.3% of deaths, and had an adult cause-specific mortality rate of 2.3 per thousand. The rate of death from cancer in this population has fluctuated since 2005 in the DDS population. In 2009, the rate of death is higher than the 2008 rate of 1.5 per thousand, and similar to the rate of 2.5 per thousand in 2007. The primary sites of cancers causing death in 2008 are ranked in Table 9.

The age distribution of deaths from cancer generally differs between the Massachusetts DDS and the Massachusetts general population: typically about two-thirds of deaths from cancer in the Massachusetts population occur in people aged 65, whereas the population served by the Massachusetts DDS has a higher proportion of deaths from cancer at younger ages than in the general population (see previous DDS mortality reports). This finding is consistent with medical literature, which finds both a predisposition for certain types of cancers^{35,36,37,38} and the appearance of cancers at significantly younger ages (e.g. colorectal cancer around age 35³⁵) in individuals with intellectual disabilities of certain etiologies.

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 2009, aspiration pneumonia was the fourth leading cause of death with 7.6% of deaths and an adult mortality rate of 1.3 per thousand. This rate is lower than mortality rates seen in 2007 and 2008.

Aspiration Pneumonia is a significant cause of morbidity and mortality for individuals 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

Table 9
**Top Primary Sites for Cancer Deaths
in the DDS Population, 2009**

Primary Site	Number of Deaths	Rate (per thousand)
Female breast	8	0.7
Lymphoid, hematopoietic and related tissue	9	0.4
Colon, rectum, and anus	8	0.3
Ovary	2	0.2
Esophagus	4	0.2
Liver and Intrahepatic bile	4	0.2
Stomach	4	0.2
Trachea, bronchus, and lung	4	0.2
Other sites	13	0.5

Causes ranked by Rate per 1,000

³⁵ 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.

³⁶ 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.

³⁷ 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.

³⁸ Patja K, Eero P & Livanainen M. Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research*. 2001 Aug 45(4):300-307.

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 or surgical interventions, are available to help individuals 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. 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 1.2 per thousand in 2009. This rate was similar to the 2008 rate of 1.1 per thousand. In 2008, the US (including Massachusetts) experienced a flu epidemic and the mortality rate due to this cause could be expected to be higher than normal. In 2009, the world experienced a pandemic of H1N1 influenza (announced in June 2009, ending in June 2010)⁴⁰ and flu infections in the US grew above epidemic levels for the last 2 months of 2009.⁴¹ Deaths from influenza infections appeared to be particularly higher than normal in young adults residing in their own home independently or with family. Prevention efforts, such as annual flu vaccination, may help reduce the instances of mortality in this subpopulation.

Other Causes. The rate of death from septicemia continued to drop from previous years to 1.1 per thousand in 2009, making it the fifth leading cause of death. Chronic Lower Respiratory Disease (CLRD) was the seventh leading cause of death in 2008 with 6.2% of deaths and a crude adult mortality rate of 1.1 per thousand.

Cardiopulmonary Arrest/Seizure was the eighth leading cause of death in 2008 with 5.2% of deaths and a crude adult mortality rate of 0.9 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 US states do not consider cardiac arrest a valid primary or underlying cause of death. Therefore additional information such as the results of an autopsy may have suggested other causes of death for some people within this group, if it was available.

The rate of death due to unintentional injuries was 0.7 per thousand in 2009, and similar to the rate in 2008. It was the ninth leading cause of death in 2009.

Nephritis and other diseases of the kidney were ranked as the tenth leading cause of death. The crude adult rate of death from nephritis was 0.5 per thousand in 2009, and was similar to the rate for previous years.

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.

⁴⁰ The 2009 H1N1 Pandemic: Summary Highlights, April 2009-April 2010, Updated: June 16, 2010, Center for Disease Control and Prevention

⁴¹ 2009-2010 Influenza Season Week 20 ending May 22, 2010. Center for Disease Control and Prevention

The crude adult rate of death from stroke dropped from 0.7 per thousand in 2008 to 0.2 per thousand in 2009. This is the lowest adult mortality rate due to stroke seen since 2000 (the first year of this annual report).

Cause of Death by Age Group

Age-specific causes of death for the 2009 population served by DDS and the 2008 Massachusetts population are presented in Tables 10 and 11.⁴² For the youngest age group (15-24 years), the most common cause of death for the DDS population was influenza and pneumonia. This is not typical for this age group in either the DDS population, or the general population. Instead, the most common cause of death in this age group for the DDS population is congenital anomalies. This difference may be related to the H1N1 pandemic in 2009. In the Massachusetts general population, the most frequent causes of death for the youngest age groups of adults (15-24) are all non-natural causes of death (unintentional injuries, homicide and suicide).

Table 10
Cause of Death by Age Group for DDS, 2009
(Multiple causes appearing in the same box are tied in rank)

Rank	Age range (years)								
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	All
1	Influenza and Pneumonia	C-P Arrest/ Seizure	Cancer	Heart Disease	Alzheimer's Disease	Cancer	Heart Disease	Heart Disease	Heart Disease
2	Multiple Causes	Heart Disease	C-P Arrest/ Seizure; Aspiration Pneumonia	Alzheimer's Disease	Cancer	Alzheimer's Disease; Heart Disease	Septicemia	Septicemia; Influenza and Pneumonia; Cancer	Alzheimer's Disease
3		Aspiration Pneumonia		Cancer	Heart Disease		Alzheimer's Disease; CLRD		Cancer

Table 11
Cause of Death by Age Group for Massachusetts Population, 2008⁴³

Rank	Age range (years)						
	15-24	25-44	45-64	65-74	75-84	85+	All
1	Unintentional Injuries	Unintentional Injuries	Cancer	Cancer	Cancer	Heart Disease	Cancer
2	Homicide	Cancer	Heart Disease	Heart Disease	Heart Disease	Cancer	Heart Disease
3	Suicide	Heart Disease	Unintentional Injuries	CLRD*	CLRD*	Stroke	Stroke

* CLRD = Chronic Lower Respiratory Disease

⁴² The most current data available for the Massachusetts general population was for the year 2008.

⁴³ Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2008, *Massachusetts Deaths 2008*. Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, August 2010. (Most recent data available)

In older age groups, some similarities do exist between the population served by DDS and the general Massachusetts population, such as the large impact of heart disease on mortality in older age groups. Alzheimer's disease appears at younger ages (see discussion of Alzheimer's disease above) in the population served by DDS. Aspiration pneumonia (see discussion above) appears as a leading cause of death in multiple age groups, and is not a leading cause of death in the general population.

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 12.

Table 12
Top Causes of Death for DDS Community⁴⁴

Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)
1	Alzheimer's Disease	44	4.7
2	Heart Disease	37	3.9
3	Cancer	30	3.2
4	Aspiration pneumonia	23	2.4
5	Septicemia	14	1.5

The top causes of death for individuals 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.⁴⁵ As shown in Table 13, the top causes of death include heart disease and cancer. However, the rate of death from influenza and pneumonia is higher than seen in the general population. This higher rate may be due to partial misclassification of aspiration pneumonia deaths, as in some cases health care providers do not specify the type of pneumonia, or the pneumonia may be due to undetected aspiration.

⁴⁴ The individual may have passed away in a setting other than the DDS Community, however, individuals are listed by their primary residential setting.

⁴⁵ 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 13
**Top Causes of Death for Individuals
 Served by DDS and Residing in Their Own Home⁴⁶**

Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)
1	Heart Disease	14	1.1
2	Influenza and pneumonia	11	0.9
	Cancer	11	0.9
4	Cardiopulmonary arrest/Seizure	10	0.8
5	Unintentional injury	9	0.7

Table 14 presents the most frequent causes of death for residential settings with smaller populations. Heart disease, Alzheimer's disease and aspiration pneumonia all prominently affect mortality in these settings.

Table 14*
**Top Causes of Death for Individuals
 Served by DDS in Other Residential Settings**

Rank	Nursing Home (Total 49 deaths)	Non - DDS (Total 18 deaths)	DDS Facility (Total 37 deaths)
1	Heart Disease	Alzheimer's Disease, Cancer, CLRD, Heart Disease	Aspiration Pneumonia
2	Cancer		Septicemia, Heart Disease, CLRD
3	CLRD		

**Populations are small for each residence (about 1,000), therefore rates of death will not be split within these residential settings*

MORTALITY REVIEW PROCESS AND COMMITTEE

Clinical mortality reviews are completed by DDS for all deaths involving individuals 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

⁴⁶ The individual may have passed away in a setting other than their own home, however, individuals are categorized by their primary residential setting.

reviews required by DDS policy were completed, resulting in 100% compliance. A total of 255 mortality reviews were completed for 2009 deaths: 251 of these reviews were required by DDS policy and 4 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 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 an individual 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.⁴⁷

⁴⁷ "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 15
Summary of Investigations, 2002 to 2009

Type of Activity	2002	2003	2004	2005	2006	2007	2008	2009
DDS Investigation	14	9	5	10	2	9	8	13
DPPC Investigation	2	4	6	5	3	10	5	3
Refer to Other Agency	10	10	9	4	2	7	0	3
District Attorney/Law Enforcement Investigation	3	2	4	4	2	9	10	3
Other/dismissed ⁴⁸	4	2	1	2	3	5	4	2
Resolved Fairly and Efficiently						1	0	1
Total Number of Deaths Investigated	33	27	20	19	9	34	18	25

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 individual received while in an acute care hospital.

Table 15 displays investigation information for 2002 – 2009. During 2009 there were 25 deaths investigated by one or more of the agencies identified above. DDS conducted 13 investigations on deaths that occurred in 2009; a total of 3 investigations were conducted by DPPC. For three of the cases investigated by DDS and DPPC, 3 were referred to law enforcement for investigation. The cases listed as “other/dismissed” had an administrative review by DDS (two cases).

Table 16
Findings in Cases Investigated by DDS or DPPC, 2002 to 2009
(Includes cases deferred to law enforcement)

Findings	2002	2003	2004	2005	2006	2007	2008	2009
No. Substantiations	2	2	1	4	2	3	1	3
Pending					3	3	2	1

Table 16 presents the findings of investigations by either DDS or DPPC. Investigations regarding 3 of the deaths occurring in 2009, out of the 16 deaths reviewed, were found to be substantiated. One investigation that was deferred to law enforcement is still pending due to the timeline of the law enforcement investigation. Twelve investigations were found to be unsubstantiated allegations.

⁴⁸ Complaint was Dismissed, Resolved w/o Investigation or Referred to the Regional Office for administrative review.

BENCHMARKS

Each of the annual DDS Mortality Reports devotes a section to the discussion of comparative benchmarks in an effort to enhance the understanding of analytical mortality findings for Massachusetts. Such benchmarks provide a context for reviewing the descriptive mortality statistics and can assist in illustrating whether findings are substantially different from or similar to expectations for a population of persons with intellectual disabilities and/or developmental disability.

Individuals 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. While age-adjustment is used to correct for varying mortality risk as a result of differences in age distribution, this method of adjustment corrects for only the factor of age. It does not correct for other 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 individuals 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 2009 Massachusetts findings. Direct comparisons of specific data should NOT be made, especially where important differences are noted.

NOTE: There is an important difference between the MA DDS and other state I/DD systems: children are included in mortality statistics for other states, and the MA DDS includes only adults. Therefore the mortality rate and average age at death for the other state I/DD systems are expected to be lower than the adult-only statistics presented from the MA DDS.

Mortality Rate Benchmarks

A review of selected state I/DD reports and data regarding mortality identified seven state systems that included information on crude mortality rates. Findings from these reports are presented below in Table 17.

Differences in population characteristics (e.g., persons with only intellectual disabilities vs. persons within the broader category of developmental disabilities), the age range included in the analysis and age distribution of persons served, service definitions reporting time periods and requirements and the general absence of national conventions for organizing and reporting mortality data make direct comparisons between state I/DD

systems difficult. The reported crude death rate for the MA DDS appears to be higher than that reported by the other five states for their entire populations. However, it is similar to the CT adult-only crude mortality rate. **Given that age is the single most important risk factor for mortality, it is to be expected that adult-only mortality rates (such as the rate reported for MA) will be higher than mortality rates that include populations of both children and adults.** The exact nature of the differences due to age and disability composition cannot be determined without formal risk adjustment of all the data from all of the state systems.

Table 17
Comparison of Crude Mortality Rates for Selected State I/DD Systems

Comparative Mortality Rates	MA DDS 2009	CT DDS ⁴⁹ FY2009		VT DDS ⁵⁰ FY2009	OH ⁵¹ 2009	LA OCDD ⁵² FY2009	CA ⁵³ FY2009
Population Served	ID only	ID only		DD	DD	DD	DD
Age Range (for computing rate)	adults only (18+ yrs)	adults only (18+ yrs)	children and adults	children and adults	children and adults	children and adults	children and adults
No. Deaths	421	179	188	32	755	114	1504
Mortality Rate (no./1000)	17.2	15.0	12.1	8.6	9.3	12.2	7.7

Mortality and Age Benchmarks

Crude mortality rates by age range are presented in mortality reports for Massachusetts, Connecticut and Louisiana; however, the age groupings each state uses are different. Therefore, a direct comparison is not possible. Table 18 and Figure 12 illustrate that the general pattern of mortality by age is similar between the three states, with death rates showing a sharp increase after age 60-65 years. Differences in the age ranges utilized for the analyses conducted by these state systems makes it difficult to draw direct comparisons, particularly in the more elderly age groups where each year of age begins to substantially increase risk of mortality (i.e., Massachusetts ranges are about 5 years older than Connecticut's resulting in an older age cohort, a factor that can be significant in the 60-yr plus groupings).

⁴⁹ State of Connecticut DDS Mortality Annual Report, FY 2009

⁵⁰ Data obtained from the Division of Disability and Aging Services, Department of Disabilities, Aging and Independent Living, 103 South Main Street, Weeks Building, Waterbury, Vermont 05671-1601.

⁵¹ Number of deaths taken from: Cause of Death Summary 2009. Rate of death calculated with population served in 2008 as listed in: Reporting Rates per MUIS per 1000 individuals 2009, available at <http://test.mr.state.oh.us/health/MUIReport/2008/report08.htm>

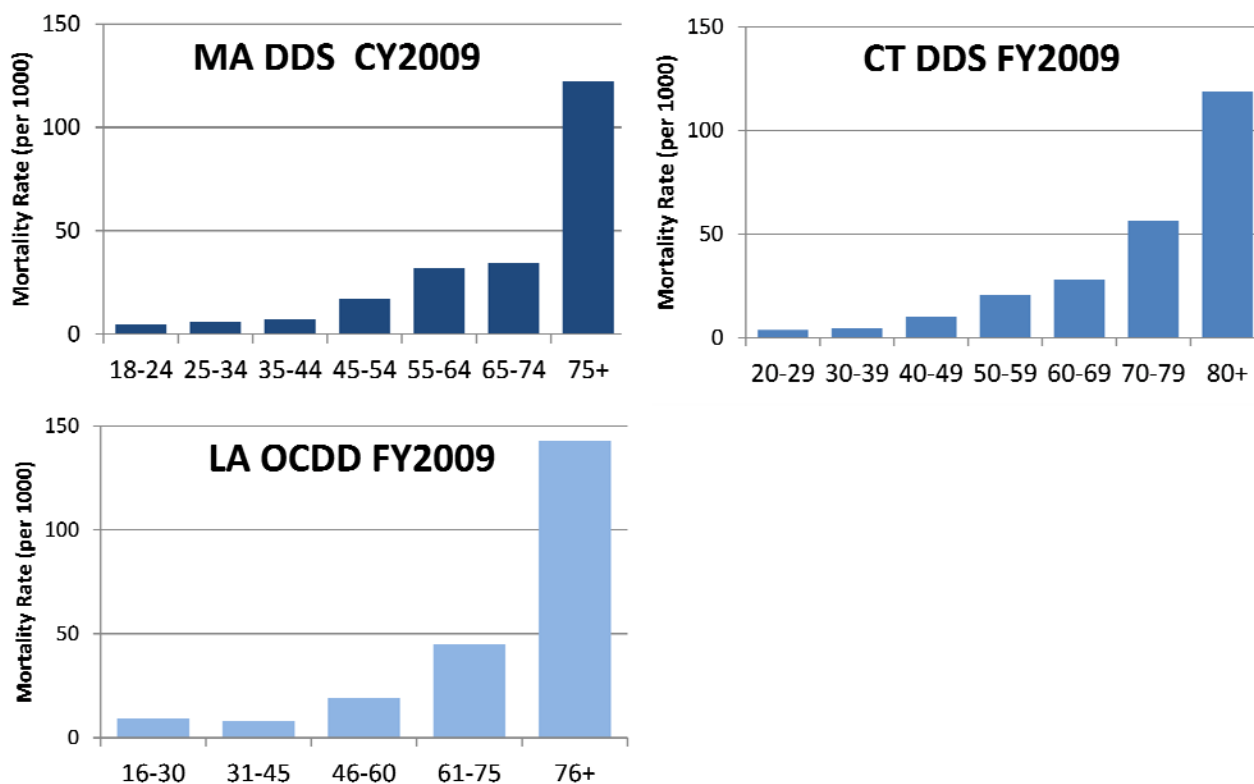
⁵² Louisiana OCDD Waiver Services 2009 Mortality Review Report – Issued 04/01/2010.

⁵³ Semi-Annual Report on Mortality, January-June 2009. Population from Jan-Jun 2009 used to calculate mortality rate.

Table 18
**Mortality Rates by Age
 for Three State I/DD Agencies**

Crude Mortality Rate by Age					
MA DDS (CY2009)		CT DDS⁴⁹ (FY2009)		LA OCDD⁵² (FY2009)	
Age Range	Mortality Rate	Age Range	Mortality Rate	Age Range	Mortality Rate
18-24	4.5	0-19	2.5	0-15	8.7
25-34	5.8	20-29	3.7	16-30	9.2
35-44	7.3	30-39	4.8	31-45	8.0
45-54	17.2	40-49	10.0	46-60	19.1
55-64	32.1	50-59	20.5		
65-74	34.3	60-69	28.3	61-75	44.8
75+	122.1	70-79	56.2	76+	142.9
		80+	118.5		

Figure 12
Mortality Rates by Age for Three State ID/DD Agencies



Mortality and Gender Benchmarks

In addition to the Massachusetts DDS, the Connecticut DDS and now the Louisiana OCDD are three of the few state agencies that serve adults with intellectual disabilities to publish mortality statistics by gender. Massachusetts, Connecticut and Louisiana are compared by gender in Table 19.

All state systems presented here have a higher proportion of deaths in females than the proportion they represent in the population. It may be that the age distribution for females is older than for males, which affects the average risk of mortality. It should be noted that the relative mortality rates by gender for Connecticut and Louisiana include children whereas the Massachusetts rates are computed for an adult population only. This difference in population characteristics may contribute to more extreme differences in mortality rates by gender in MA DDS, as gender age distributions vary most in the oldest age groups.

Table 19
**Comparison of the Percentage of Deaths by Gender
for Three State I/DD Systems**

Gender	Measure	MA DDS 2009 (Adults)	CT DDS⁴⁹ FY2009 (All ages)	LA OCDD⁵² FY2009 (All ages)
Male	Population Percentage	56%	57%	56%
	Percentage of Deaths	48%	54.8%	53%
	Death Rate	14.9	11.5	11.4
	Ave. Age of Death	56.9	58.0	--
Female	Population Percentage	44%	43%	44%
	Percentage of Deaths	52%	45.2%	47%
	Death Rate	20.0	12.8	13.2
	Ave. Age of Death	60.3	56.2	--

Mortality and Residence Benchmarks

Important differences exist in the populations served and residential groupings utilized by different state I/DD agencies that make direct comparisons of mortality by residential setting difficult.⁵⁴ Of special concern are the differences in population characteristics, e.g., the Connecticut DDS provides some residential services to children with intellectual disabilities who are included in the base for computing mortality rates. The influence of this age difference on resultant mortality rates is not known, but should be taken into consideration when comparing the mortality rates by residence for these benchmark state systems.

⁵⁴ For example, in addition to Massachusetts, only a small number of other states have a specific ID/DD agency dedicated to serving only persons with intellectual disabilities. Most state systems serve a broader DD population. In addition, available data on mortality is very limited, especially with regard to cause of death by residential setting.

Table 20
**Comparison of Mortality Rates by Residential Setting
 for the Massachusetts DDS and Connecticut DDS**

Type of Residential Setting	Mortality Rate (per thousand)	
	MA DDS CY 2009 (adults)	CT DDS ⁴⁹ FY 2009 (all ages)
At Home/Family, Independent & Supported Living	7.7	7.1
Community Group Home, Community Training Home	23.4	14.3
Facility-ICF/ID	41.6	32.2
Nursing Facility	125.0	142.5

Table 20 provides crude mortality rates (no. of deaths per 1000 people served) by type of residential setting for the Connecticut DDS and Massachusetts DDS state systems. The adult crude mortality rate for home and independent support living settings in Massachusetts is similar to the crude mortality rate for all ages in same setting in Connecticut. The crude mortality rate for adults served by MA DDS in facilities is the same as for the population served by the Connecticut DDS. The adult crude mortality rate is higher in Massachusetts for community settings than for adults in Connecticut for the same setting. However, it is difficult to know how much of this difference is due to the age differences in the population counted. The crude mortality rate for nursing homes is higher in state I/DD system for Connecticut than in Massachusetts. This setting has a higher degree of variability in mortality rate than other settings, and therefore annual comparisons fluctuate between the two state systems. While the majority of people living in nursing homes in the Connecticut I/DD system are older, it is not known how many children were living in this setting in FY08.

Place of Death

Examining patterns in the place of death for recent decedents can provide useful information about the settings and types of care received toward the end of life. The home environment is often the desired place to pass away, rather than a nursing home or hospital setting. However, a substantial amount of people experience a change in their place of residence or care in the last year of their life. In the past decade, there has been a national movement to provide services in more home and community-based settings rather than nursing homes, hospitals and other congregate settings. Increased options for end-of-life care can help avoid unnecessary transfers to higher intensity care settings. Population statistics for place of death can provide an important baseline for the population served by DDS and allow for comparisons with other relevant populations.

Figure 13 compares place of death for the MA DDS to the MA state data from 2008. The relative distribution of place of death is similar between the MA state population and the MA DDS, but some differences exist. For decedents served by DDS, a slightly higher percentage (27%) passed away in their homes than the state population (23%). Of those served by DDS that die in their own home, about 60% live in DDS-funded community

residences, about one quarter live in their own home independently or with their family, and just over 10% live in a DDS facility.

Consistent with 2007 and 2008 data, a smaller percentage (21%) of people served by DDS died in nursing homes than the general population of Massachusetts (30%). It is important to note that the information presented in Figure 10 regarding deaths in nursing homes is not the same as what is presented in Table 4 and Figures 8 and 9 in the previous section. In the previous section, nursing home residents are defined as those that have been in a nursing home for over 30 days. The information presented in Figure 10 counts any death that occurred in a nursing home, including those people who may have been in the nursing home for less than 30 days.

A higher percentage of people (50%) served by DDS die in hospital settings, either inpatient or outpatient, than in the Massachusetts population (42%).

Figure 13
Comparison of Place of Death in
MA State and MA DDS Populations

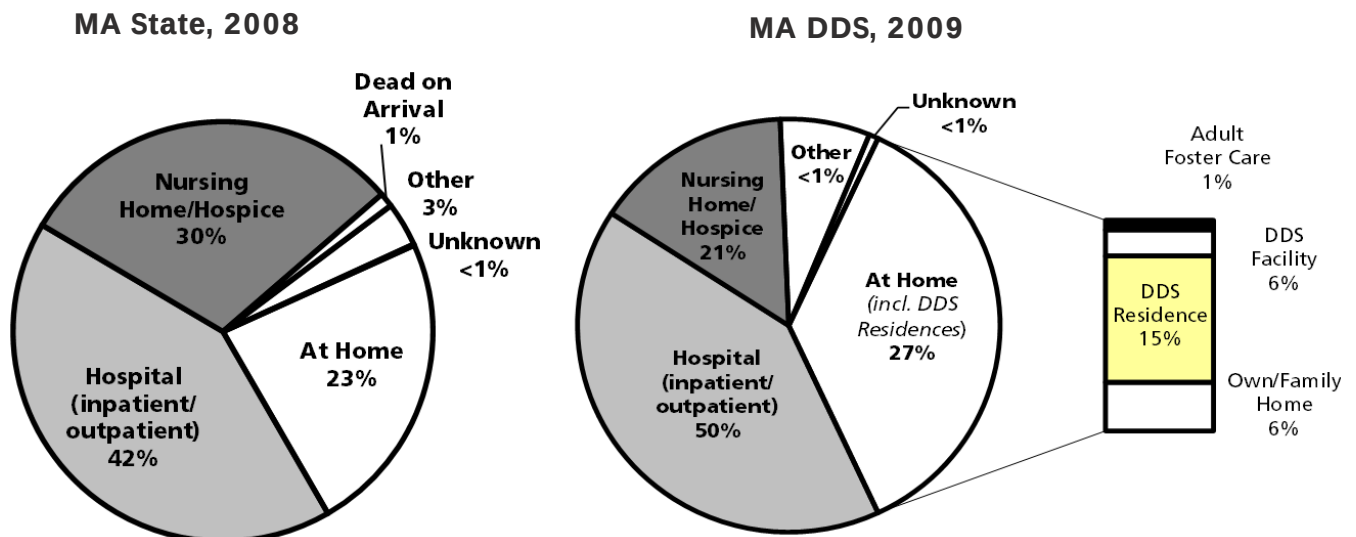


Table 21 compares place of death for MA DDS 2009 adult decedents with decedents from CT DDS of all ages. A slightly larger proportion of MA DDS decedents (36%) die at home compared with 23% of CT DDS decedents. Similar proportions die in nursing homes in the two state systems. In CT DDS more decedents die in hospital settings than in MA DDS. It is not known how the inclusion of children in the CT DDS data changes the proportions across these categories.

Table 21
Place of Death in MA DDS and CT DDS

Place of Death	MA DDS CY2009 (adults)	CT DDS FY09 (all ages)
Hospital (inpatient/outpatient)	41%	63%
Home	36%	23%
<i>Adult foster care</i>	2%	0%
<i>DDS Facility</i>	5%	8%
<i>DDS Residence</i>	22%	9%
<i>Own/Family Home</i>	8%	6%
Nursing Home/Hospice	15%	14%
Other	7%	0%
Dead on Arrival	0%	0%
Unknown	<1%	0%
Total	100%	100%

Hospice

Background

Hospice services are an important option for patients with terminal conditions that can prolong and improve the quality of their lives. Hospice services draw upon an interdisciplinary team to build individualized palliative care plans to address the comfort and support needs of terminally ill patients. Services are provided primarily in the person's home setting and include medical, emotional, and spiritual care for terminally ill patients and their families.

Most people served by DDS are dually eligible for Medicaid and Medicare benefits and receive most or all of their health insurance coverage from these programs. It is therefore important to note that the Medicare eligibility requirement for hospice care is that a person be certified as terminally ill with a prognosis of 6 months or less to live, should the illness run its normal course, by their physician and the hospice physician.

Little information exists on the use of hospice services by populations of people with intellectual disabilities. The purpose of this section is to provide more information about the utilization of this important care option in the population served by DDS and increase awareness about hospice options. Understanding and benchmarking the utilization rates across demographic factors can serve as an important baseline against which future educational efforts can be compared. Benchmarking can also assist with targeting of educational efforts, and can serve as a means of comparison for other state agencies that may be interested in comparing their utilization rates for similar populations.

Findings

In 2009, 164 people, or 39% of DDS decedents, utilized hospice services before their death as shown in Figure 14. For 5% of decedents (20 people) served by DDS, it is not known whether hospice services were utilized. The National Hospice and Palliative Care Organization estimates that approximately 41.6% of all deaths in 2009 in the United

States were under the care of a hospice program.⁵⁵ Hospice use in the population served by DDS has rapidly approached the rate of utilization in the general population, and has consistently increased since 2007 (29%).

Figure 15 shows the percentage by gender of people served by DDS who died in 2009 and used hospice services before their death. The relative portion of consumers who used hospice services is not significantly different between genders.

Figure 14
Percentage of Decedents
Who Utilized Hospice Services

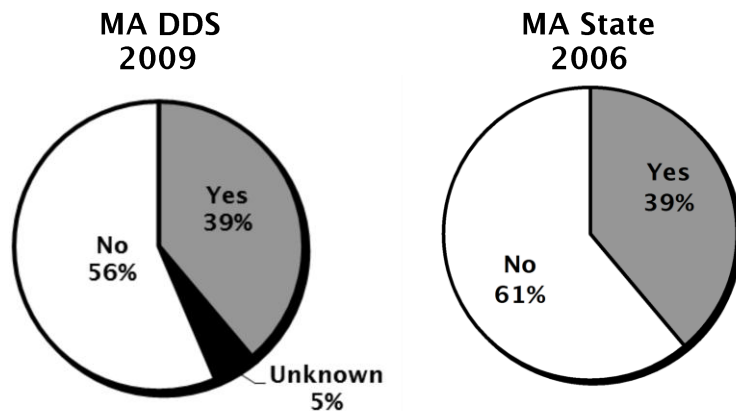


Figure 15
Utilization of Hospice Services by Gender
for 2009 Decedents Served by DDS

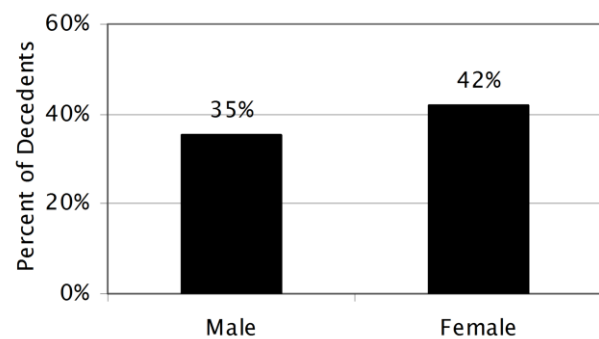


Table 22 compares the place of death for 2009 decedents using hospice between those served by the DDS population and the general population of the United States. The place of death is important to examine in hospice services, as care plans often include a desire to die at home. Consistent with previous years, a higher percentage of decedents in the DDS population using hospice died in their place of residence (76%) than in the general population (69%).

Table 22
Location of Death for Hospice Patients

United States 2009 ⁵⁶		MA DDS 2009	
Patient's Place of Residence	69%	Patient's Place of Residence	76%
Private Residence	41%	Own Home or DDS Residence	45%
Nursing Facility	19%	Nursing Home	22%
Residential Facility	10%	DDS Facility	7%
Acute Care Hospital	10%	Acute Care Hospital	12%
Other	21%	Other	3%
Total	100%	Total	100%

⁵⁵ NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, 2010. Percent derived from (1,020,000 / 2,450,000 deaths)

⁵⁶ NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, 2010. Table 1: Location of Death

Within this category for DDS are decedents who were living in their own home or a DDS-funded community residence (45%), who were living in a nursing home (22%), or a DDS facility (7%). In 2009, a smaller proportion of DDS decedents that used hospice died in nursing homes, and a larger proportion died in their own home. A similar percentage of decedents utilizing hospice served by DDS died in acute care hospitals as in the U.S.

When the option of hospice was created nationally, the vast majority of initial users were cancer patients. The Medicare Payment Advisory Commission (MedPAC) found the patterns of service use differ between cancer and non-cancer decedents. In particular, MedPAC found that “hospice decedents without cancer tend to use more intense hospital inpatient services before they enter hospice...”⁵⁷ Currently, fewer than half of hospice users in the US have a diagnosis of cancer and use is growing among those with non-cancer diagnoses.⁵⁷

Table 23 shows the terminal diagnoses for hospice admissions nationally in 2009, and the primary cause of death for hospice users served by DDS that died in 2009.

Table 23
Diagnoses for Hospice Users

	National 2009 ⁵⁸ Admissions (Primary Diagnosis)	DDS 2009 (Underlying Cause of Death)
Cancer (malignancies)	40%	29%
Non - Cancer Diagnoses	60%	71%
<i>Heart Disease</i>	<i>12%</i>	<i>7%</i>
<i>Debility Unspecified</i>	<i>13%</i>	<i>7%</i>
<i>Dementia, including Alzheimer's Disease</i>	<i>11%</i>	<i>27%</i>
<i>Lung Disease, including COPD/CLRD</i>	<i>8%</i>	<i>5%</i>
<i>Stroke or Coma</i>	<i>4%</i>	<i>1%</i>
<i>Kidney Disease, including End Stage Renal Disease</i>	<i>4%</i>	<i>4%</i>
<i>Liver Disease</i>	<i>2%</i>	<i>1%</i>
<i>HIV / AIDS</i>	<i><1%</i>	<i>0%</i>
<i>Other Diagnoses</i>	<i>8%</i>	<i>16%</i>
Total	100%	100%

It is important to note that the information presented is slightly different for the two groups. The cause of death for DDS consumers may differ from the primary diagnosis for which they entered into hospice. However, because the condition that led them to utilize hospice services is terminal (by definition of the eligibility for the service), it is expected that the underlying cause of death is not typically different from the primary diagnosis for hospice admission. Any differences between these two groups are expected to be small, and the comparison in Table 8 is still useful to understand diagnostic differences between the two groups; however the data must be viewed with caution.

⁵⁷ Medicare payment Advisory Commission (MedPAC). Report to the Congress: New Approaches in Medicare, June 2004. Chapter 6: Hospice care in Medicare: Recent trends and a review of the issues.

⁵⁸ NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, October 2009. Table 6: Percentage of Hospice Admissions by Primary Diagnosis

Seventy-one percent (71%) of decedents using hospice served by DDS had non-cancer diagnoses. This is a slightly larger proportion of non-cancer conditions than seen 2009 admissions nationally (60%). Of these non-cancer diagnoses, the incidence of a primary terminal condition of dementia or Alzheimer's Disease continued to be the most common reason for hospice admission in the DDS population, and more frequent in DDS hospice users than in the national admissions data. This may be related to the higher incidence, earlier onset, and more rapid progression of Alzheimer's Disease in people with Down Syndrome. The representation of other non-cancer diagnoses in hospice decedents served by DDS is slightly lower than national admissions.

Cause of Death Benchmarks

A comparison of the top five leading causes of death as reported by the I/DD state agencies in Connecticut, Ohio, Vermont and Louisiana are presented in Table 24.

It is important to note that the Connecticut DDS does not and other states may not use underlying causes of death in their reporting. For example, the cause of death for a person with late-stage Alzheimer's disease who died from a complication of this disease (e.g. cardiac arrest) would be categorized as "Alzheimer's Disease" in Massachusetts DDS report, but would be categorized as "cardiac arrest" in the Connecticut DDS report. The underlying cause of death is used in the mortality reports for both the general population in Massachusetts and the U.S. Without additional information, it is not possible to determine which methodology was employed from the data released by Ohio MRDD. The Vermont DDS categorizes cause of death by underlying cause, and is therefore more directly comparable with Massachusetts.

Rank order is a general and relative comparison that can be very sensitive to small changes in the number of deaths within each category due to the small population size and the relatively small number of deaths within any given state. Despite this, 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 (14.9% - 16.9%) in Massachusetts, Ohio and Louisiana. Heart disease represents a much higher proportion of deaths in Connecticut (30%). Cancer represents a similar proportion of deaths in populations served by the state I/DD systems in Massachusetts and Ohio (8.9%-13.3%), but represents a much smaller proportion of deaths in the population served by Louisiana OCDD and CT DDS.

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. However, the Connecticut DDS found, for example, in a review by their mortality review committee that in 17% of deaths the person had a diagnosis of Alzheimer's Disease at the time of death. While not all of these deaths may be due to Alzheimer's Disease, it presents evidence that this condition plays a significant role in the underlying cause of death in Connecticut as it does in Massachusetts. In Louisiana, 1.8% deaths are reportedly due to Alzheimer's Disease. It is not known if the counting method

for Louisiana relies solely on death certificate data, or whether other information sources are used. Information on this cause of death was not available from the Ohio MRDD.

Table 24
Comparison of the Top 5 Leading Causes of Death
As Reported by Four State I/DD Agencies

Rank	MA DDS CY2009 (adults)	CT DDS ⁴⁹ CY2009 (all ages)	OH OMRDD ⁵⁹ 2009 (all ages)	LA OCDD FY2009 (all ages)
Method	Underlying	Primary	Unknown	Unknown
1	Heart Disease 16.6%	Heart Disease 29.9%	Heart Disease 16.9%	Diseases of the Heart 14.9%
2	Alzheimer's Disease 15.2%	Respiratory Disease ⁶⁰ 13.7%	Influenza & Pneumonia 9.4%	Influenza and Pneumonia 14.9%
3	Cancer 13.3%	Influenza & Pneumonia 12.8%	Cancer 8.9%	Septicemia 10.5%
4	Aspiration Pneumonia 7.6%	Aspiration Pneumonia 10.3%	Congenital Diseases 8.7%	Cerebrovascular Diseases (Stroke) 6.1%
5	Influenza and Pneumonia 6.9%	Septicemia 9.8%	Aspiration Pneumonia 8.3%	Chronic Lower Respiratory Diseases 5.3%

Table 25
Relative Percent of Annual Deaths by Pneumonia Type

% of annual deaths	MA DDS CY2009 (adults)	CT DDS ⁴⁹ CY2009 (all ages)	OH OMRDD 2009 ⁵¹ (all ages)	LA OCDD FY2009 (all ages)
Aspiration Pneumonia	7.6%	10.3%	8.3%	Unknown
Influenza and Pneumonia	6.9%	12.8%	9.4%	Unknown
Total	14.5%	23.1%	17.7%	14.9%

Aspiration Pneumonia is a significant cause of mortality in Massachusetts, Connecticut and Ohio, representing between 7.6% and 12.8% 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 'influenza and pneumonia'. In order to provide a more

⁵⁹ Ohio, Cause of Death Annual 2009

⁶⁰ 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

accurate comparison of the relative percentage of deaths caused by difference causes of pneumonia, Table 25 presents reorganized information.

The relative percent of deaths from influenza and pneumonia (excluding aspiration pneumonia) may be higher in Ohio figures due to a timeframe of reporting that included a national flu epidemic in early 2008. However, even with this understanding, it appears that pneumonia, particularly aspiration pneumonia, is a more significant source of mortality in Connecticut and Ohio than in Massachusetts and Louisiana for this time period. In 2009, Massachusetts saw relatively fewer deaths from aspiration pneumonia than in previous years, but a similar level of deaths from influenza and pneumonia as in 2008 with higher levels in young adults and those living at home independently or with family.⁴⁵

HEALTHY PEOPLE 2010 OBJECTIVES

The U.S. Department of Health and Human Services' Healthy People 2010 (HP2010) initiative contains a series of health-related goals and objectives for the nation to achieve by the year 2010. The initiative built upon recommendations in previous Surgeon General's reports and *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*. The initiative has two major goals: the first is to "help individuals of all ages increase life expectancy and improve their quality of life." The second goal is to "eliminate health disparities among different segments of the population." Within the objectives are mortality rate targets for the nation and individual states. The original objectives have been revised to reflect both the Healthy People 2010 Midcourse Review (October 2006) and more complete population estimates and prevalence data that became available since the original publication of the HP2010.

Table 26 below displays data associated with 22 of the mortality targets. These particular 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 HP2010 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 (2005-2009). 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 HP2010 targets or other populations, part of the difference will likely be due to the different age distributions of the base population.

Comparison of a five-year average of DDS data with the objectives contained in HP2010, 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. Statistics from 2007 were the most current figures available for the U.S. and Massachusetts populations.

Similar to previous years, crude mortality rates for adults served by the Massachusetts DDS meet many of the HP2010 targets. Because many of the causes of death targeted by the HP2010 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 HP2010 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 HP2010 goal, the population meets many of the goals for specific types of cancer and meets more cancer mortality goals than in previous years. In particular, rates for prostate cancer and melanoma fell. For female breast cancer, the mortality rate is within 25% of the target, largely due to a drop seen in 2008. However, the rate of death from colorectal cancer exceeds the HP2010 goal, and mortality rates from both causes are above state and national rates. In both of these types of cancer, early detection can improve survival rates; therefore continued efforts are recommended to advocate for mammography and colorectal cancer screening in this population.

While still below the HP 2010 targets, diabetes-related deaths saw an increasing trend from 2004 to 2008, but dropped in 2009 in the adults served by the MA DDS.

In 2009 the rate of death from stroke dropped substantially, bringing the 5-year average within 25% of the HP 2010 goal. Chronic Obstructive Pulmonary Disease (COPD) continues to be higher than goal and a substantial source of mortality.

The rate of deaths from unintentional injuries in 2009 was below the state and national rates. However, the 5-year average is higher than state and national rates, and exceeds the HP2010 goal. The majority of deaths from unintentional injury in the population served by the MA DDS are due to choking or aspiration.

Table 26
Target Status for Selected Healthy People 2010 Mortality Objectives⁶¹
Rates per 100,000 population

Objective Number	HEALTHY PEOPLE 2010 OBJECTIVE	TARGET 2010⁶²	DDS 2005-2009		MA 2007⁶²	US 2007⁶²
			Avg. Crude Rate	Target Status	age-adjusted	age-adjusted
3-1	Overall Cancer death rate	158.6	200.6	●	179.8	178.4
3-2	Lung Cancer	43.3	20.4	✓	50.8	50.6
3-3	Female Breast Cancer (per 100,000 females)	21.3	27.5	○	20.3	22.9
3-4	Cervical (per 100,000 females)	2.0	1.9	✓	1.1	2.4
3-5	Colorectal Cancer	13.7	24.5	●	16.0	16.9
3-6	Oropharyngeal Cancer	2.4	1.7	✓	2.5	2.5
3-7	Prostate Cancer (per 100,000 males)	28.2	9.2	✓	24.1	23.5
3-8	Malignant Melanoma	2.3	1.7	✓	3.0	2.7
5-5	Diabetes-related deaths	46	30.5	✓	54.0	73.0
12-7	Stroke deaths	50	61.4	○	37.0	42.0
26-3	Drug-induced deaths	1.2	1.4	○	15.1	12.6
13-14	HIV-infection deaths	0.7	1.7	●	NA	3.7
24-10	Chronic Obstructive Pulmonary Disease Deaths (age 45+)	62.3	160.9	●	87.8	112.4
	<u>Injuries</u>					
15-13	Unintentional injuries (Accidents)	17.1	56.2	●	30.8	40.0
15-27	Falls	3.3	4.2	●	6.1	7.0
15-3	Firearm-related	3.6	0.0	✓	3.6	10.2
15-8	Poisonings	1.5	2.5	●	14.7	13.1
15-9	Hanging, strangulation or suffocation	3.3	*	✓*	5.0	4.9
15-25	Residential fire deaths	0.2	5.0	●	0.4	0.9
15-29	Drownings	0.7	2.5	●	0.8	1.2
15-32	Homicide	2.8	2.5	✓	3.0	6.1
18-1	Suicide	4.8	*	✓*	7.6	11.3
✓ = YES, met target ○ = NO, but within 25% of target ● = NO, > 25% from target ✓* = Too few deaths from this cause to provide rate						

⁶¹ The HP2010 objective 12-1 Coronary Artery Disease was not presented in this table, as there was not sufficient information from all years to assess whether all deaths listed under Heart Disease were Coronary Artery Disease (ICD-10 codes I11 and I20-I25) or another type of Heart Disease. Cirrhosis is not presented, as there is not sufficient information for every death from "liver disease" to determine whether the cause originated from substance abuse.

⁶² Data 2010 the Healthy People 2010 Database. CDC Wonder website: <http://wonder.cdc.gov>. October 2011 Edition (Last update of database). Accessed October 2011.

Appendix A

Methodology for Mortality Review and Analysis

The 2009 Mortality report analyzes information on all deaths occurring in calendar 2009 for all individuals 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 individual's death according to DDS policy. The 2009 Mortality Report includes statistics on all deaths of individuals who died in calendar year 2009 and whose Death Report was received by DDS by the end of January 2010. A total of 421 deaths were reported to have occurred between January 1, 2009 and December 31, 2009.

The data used to calculate death rates per 1000 by age group and type of residence was supplied by the DDS Meditech System of June 30, 2009.⁶³ 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 individuals subject to clinical mortality review.

DDS provided the following information for deaths:

- Name of the individual
- 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:

$$\text{Crude Death Rate} = \frac{(\text{Number of individuals who died in calendar year 2009} \times 1000)}{(\text{No. Individuals in Meditech systems in June 2009})}$$

⁶³ CDDER relies on the accuracy of information about the number of individuals eligible for DDS services, their ages, region and type of residential placement. Inaccuracies in the CRS, if any, will be reflected in the numbers used to compute death rates in the DDS population. The number of individuals served by DDS by region and type of residence used in the calculations of death rates were based on data as of June 30, 2009.

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
3152	Community Residence
3153	Residential Supports
3155	Satellite Residential
3157	Staffed Apt I
3158	Staffed Apt II
3161	M.S.A. Residential Supports
3182	DDS Respite facility
3286	Ind. Support & Community Habilitation
3288	Placement Services Tier 1
3975 / zTEMPRES	Temporary Residence
4157	DDS State Operated Residential
5150	Self-Directed Supports – Shared Living/Home Share
5153	Self-Directed Supports – Residential Supports
5286	Self-Directed Supports – Ind. Support & Community Habilitation
5288	ISO-PLACEMENT SERVICES TIER 1

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

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 / zADFOSCARE	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)
MCBR	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

Out of State: Ricci class members that previously resided in Massachusetts, but have moved out of state and remain class members

Appendix C

Demographic Data

Table 27
Age and Residential Distribution of the 2009 DDS Adult population

Gender	Age	DDS-Funded Community	DDS Facility	Nursing / Rest Home	Own Home	Non-DDS	Out of State	Total
Males	18-24 yr	253	4	191	18	2,373	0	2,839
	25-34 yr	847	9	78	36	1,652	0	2,622
	35-44 yr	1,240	36	103	29	1,090	1	2,499
	45-54 yr	1,431	152	147	14	980	14	2,738
	55-64 yr	919	189	94	24	504	11	1,741
	65-74 yr	413	102	46	27	214	1	803
	75-84 yr	169	39	25	21	71	2	327
	85+ yr	24	5	1	7	8	1	46
Females	18-24 yr	171	2	104	14	1,590	0	1,881
	25-34 yr	604	4	80	30	1,300	0	2,018
	35-44 yr	881	29	101	36	974	1	2,022
	45-54 yr	1,101	105	116	18	915	6	2,261
	55-64 yr	801	105	133	25	489	7	1,560
	65-74 yr	353	75	48	36	228	3	743
	75-84 yr	144	28	32	37	70	0	311
	85+ yr	38	6	8	20	22	0	94
Total ⁶⁴		9,389	890	1,307	392	12,480	47	24,498

⁶⁴ 7 consumers have duplicate residential statuses listed in the DDS enrollment system. The total of 24451 reflects the count of unique consumers, but is not the sum of the population in each residential setting because of this duplication.

Appendix D

Methods and Details of Age Adjustment

As a standard practice, federal and state mortality reports typically perform age-adjustment using an estimate of the 2000 U.S. population called the “U.S. Standard Population.” This population estimate is also used as the basis for age-adjustment in this section of the report.

Comparison of the MA DDS 2009 & U.S. 2000 Standard Populations

Overall, the DDS population tends to be younger than the overall U.S. population with a relatively larger percentage of individuals within the younger age groups. In the process of age-adjustment (i.e., to statistically model the DDS population after the U.S. population), the mortality information for each age group is weighted according to the size of that age group in the U.S. Standard Population. Because the older age groups tend to be smaller in the DDS population than in the national population, these groups experience a heavier ‘weighting’ than in the crude DDS mortality rate. And because older age groups have the highest mortality rates, the weighting results in an age-adjusted mortality rate that is higher than the crude mortality rate for the DDS population.

Table 28
Age-adjusted Mortality Rates

Age Group	% population in age group		US 2007 Age-Specific Rate of Death ⁶⁵ (per thousand)	DDS 2009 rate of death (per thousand)	Weight	Weighted Rate (per thousand)
	US Standard	DDS				
18 to 24	9.6%	13.6%	0.8	5.8	0.129	0.57
25 to 34	13.6%	13.5%	1.0	7.3	0.183	1.06
35 to 44	16.3%	14.0%	1.8	17.2	0.219	1.60
45 to 54	13.5%	15.0%	4.2	32.1	0.182	3.13
55 to 64	8.7%	9.5%	8.8	34.3	0.118	3.77
65 to 74	6.6%	4.5%	20.1	114.4	0.089	3.05
75 to 84	4.5%	1.9%	50.1	157.1	0.060	6.91
85+	1.6%	0.4%	129.5	5.8	0.021	3.28
Adult Total						23.4

(Note, percentages are of total US population and total DDS population served and includes individuals of all ages.)

Age-adjusted Rate = 23.4 per thousand

⁶⁵ National Vital Statistics Reports, Vol. 58, No. 19, May, 2010. Table 9. Death rates by age and age-adjusted death rates for the 15 leading causes of death in 2007: United States, 1999-2007.

Weight = Count of US citizens in age group / Total US citizens
(also described as the proportion of the total population represented by each age group)

Weighted DDS Mortality Rate = 2009 DDS mortality rate for age group * Weight for age group

Adjusted Total DDS Adult Mortality Rate = Sum of weighted rates for each age group

Age-adjustment of the MA DDS Mortality Rate

Age-adjusted death rates are used to compare relative mortality rates between groups and should be viewed as *relative indexes* rather than as actual measures of mortality. As noted earlier, age-adjustment⁶⁶ examines the proportion of the population represented by each age group in the population. By weighting the mortality rates according to the standard age distribution, an adjusted mortality rate is created that shows what the DDS mortality rate “might be” if DDS had similar age structures to the general population. These results are presented in Table 28.

The overall age-adjusted adult mortality rate for the DDS population is approximately 23.4 per thousand, which is higher than the crude mortality rate of 17.2 per thousand due to the larger proportions of the population in younger age groups, which have low death rates. If the DDS population was structured more like the U.S. standard population, it would have a higher proportion of people in elderly age groups, which have the highest mortality rates of age group. The findings in the DDS client population are relatively consistent with the nationwide consensus for populations with similar disabilities; the average age at death and the lifespan both tend to be lower in individuals with intellectual disabilities.⁶⁷

Due to an alteration to the methodology used to calculate this rate, it cannot be compared with prior year age-adjusted rates.

Calculations for the Age-Adjusted Adult Mortality Rate

Age adjustment examines the proportion of the population represented by each age group in the population. A “direct method” of calculation was used for the age adjustment, where the adjusted adult rate of death is calculated by weighting age-specific mortality rates with the age-specific proportions of the U.S. standard population. The weighted mortality rates for each age group are summed to calculate an overall age-adjusted rate for the adult DDS population.

$$R' = \sum_i \frac{P_{Si} R_i}{P_S}$$

Where
 R' = age-adjusted rate,
 P_{Si} = standard population for age group i ,
 P_S = adult U.S. standard population

⁶⁶ A “direct method” of calculation was used for the age-adjustment, where the adjusted rate of death is calculated by weighting age-specific mortality rates with the age-specific proportions of the U.S. standard population. The weighted mortality rates for each age group are summed to calculate an overall age-adjusted rate for the adult DDS population.

⁶⁷ Eyman RK, Grossman HJ, Chaney RH, Call TL. The life expectancy of profoundly handicapped people with mental retardation. N Engl J Med. 1990 Aug 30;323(9):584-9.

Appendix E

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 F

ICD - 10 Codes Used in this Publication

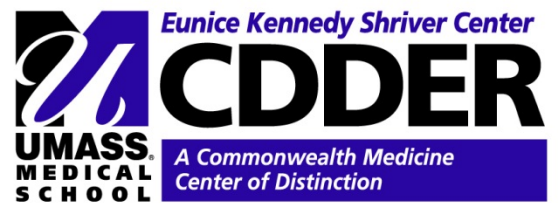
(Sorted by Category)

<u>Cause of Death</u>	<u>ICD - 10 Code</u>
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 Diseases¹	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 G
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
3-1	Cancer (all sites)	C00-C97
3-2	Lung cancer	C33-C34
3-3	Female breast cancer	C50
3-4	Uterine Cervix cancer	C53
3-5	Colorectal cancer	C18-C21
3-6	Oropharyngeal cancer	C00-C14
3-7	Prostate cancer	C61
3-8	Malignant melanoma	C43
5-5	Diabetes-related deaths	E10 – E14
12-7	Stroke	I60-I69 (including underlying or multiple causes)
13-14	HIV infection	B20-B24
15-3	Firearm-related deaths	U01.4, W32-W34, X72-X74, X93-X95, Y22-Y24, Y35.0.
15-8	Poisoning	X40-X49, X60-X69, X85-X90, Y10-Y19, Y35.2
15-9	Hanging, strangulation or suffocation	W75-W84, X70, X91, Y20
15-13	Unintentional injuries (Accidents)	V01-X59, Y85-Y86
15-25	Residential fire deaths	X00, X02
15-27	Falls	W00-W19
15-29	Drownings	W65-W74, X71, X92, Y21, V90, V92
15-32	Homicides	X85-Y09, Y87.1
18-1	Suicide	X60-X84, Y87.0
24-10	Chronic Obstructive Pulmonary Disease Deaths (age 45+)	J40-J44, and excludes asthma
26-3	Drug-induced deaths	D52.1, D59.0, D59.2, D61.1, D64.2, E06.4, E16.0, E23.1, E24.2, E27.3, E66.1, F11.0F11.5, F11.7-F11.9, F12.0-F12.5, F12.7-F12.9, F13.0-F13.5, F13.7-F13.9, F14.0-F14.5, F14.7F14.9, F15.0-F15.5, F15.7-F15.9, F16.0-F16.5, F16.7-F16.9, F17.0, F17.3-F17.5, F17.7-F17.9, F18.0-F18.5, F18.7-F18.9, F19.0-F19.5, F19.7F19.9, G21.1, G24.0, G25.1, G25.4, G25.6, G44.4, G62.0, G72.0, I95.2, J70.2-J70.4, L10.5, L27.0, L27.1, M10.2, M32.0, M80.4, M81.4, M83.5, M87.1, R78.1-R78.5, X40-X44, X60-X64, X85, Y10-Y14

These Healthy People 2010 objectives use data on underlying causes of death.



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