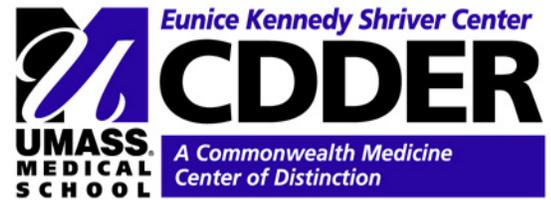


AUGUST 2010



2008 MORTALITY REPORT

COMMONWEALTH OF MASSACHUSETTS

EXECUTIVE OFFICE OF HEALTH & HUMAN SERVICES

DEPARTMENT OF DEVELOPMENTAL SERVICES

PREPARED BY:

CENTER FOR DEVELOPMENTAL DISABILITIES

EVALUATION AND RESEARCH (CDDER)



Prepared by:

Emily Lauer, MPH
Consultant Analyst
Center for Developmental Disabilities Evaluation and Research (CDDER)

Prepared with support from:

Steven Staugaitis, PhD
Assistant Professor
CDDER

Sharon Oxx, RN, CDDN
Director of Health Services
MA DDS

Alexandra Bonardi, MHA OTL/R
Assistant Director
CDDER

Gail Grossman
Assistant Commissioner for Quality
Management
MA DDS

Center for Developmental Disabilities Evaluation and Research

University of Massachusetts Medical School

Eunice Kennedy Shriver Center

200 Trapelo Rd., Waltham, MA 02452

Tel. (781) 642-0283 Fax. (781) 642-0162

www.umassmed.edu/cdder/ cdder@umassmed.edu



Deval L. Patrick
Governor

Timothy P. Murray
Lieutenant Governor

The Commonwealth of Massachusetts
Executive Office of Health & Human Services
Department of Developmental Services
500 Harrison Avenue
Boston, MA 02118-2439

September, 2010

JudyAnn Bigby, M.D.
Secretary

Elin M. Howe
Commissioner

Area Code (617) 727-5608
TTY: (617) 624-7590

Dear Colleagues and Friends:

Enclosed is the Department of Developmental Services Annual Mortality Report for calendar year 2008. 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 2008 for all persons 18 years of age or older who have been determined to be eligible for DDS supports. This is the seventh 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 health 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,

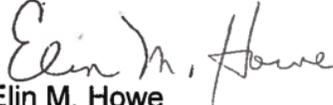

Elin M. Howe
Commissioner

TABLE OF CONTENTS

Executive Summary	iv
Introduction	1
Departmental Name Change	1
Overview of Population Served by DDS	2
Mortality During 2008	5
Age	5
Gender	6
Residence	8
Place of Death	12
Hospice	13
Age-adjusted Mortality Rates	17
Age-adjustment within the DDS Population	17
Gender-specific Age-adjustment within the DDS Population	18
Trends Over Time	19
Causes of Death	21
Causes of Death for Specific Groups	26
Mortality Review Process and Committee	29
Investigations	30
Benchmarks	31
Healthy People 2010 Objectives	37
Appendices	
A: Methodology for Mortality Review and Analysis	41
B: Residential Codes and Definitions	42
C: Demographic Data	44
D: Methods and Details of Age Adjustment	45
E: ICD-10 Codes Used in this Publication (Sorted by ICD-10 Codes)	50
F: ICD-10 Codes Used in this Publication (Sorted by Category)	51
G: ICD-10 Codes for Selected Healthy People 2010 Mortality Objectives Used in This Publication	52

LIST OF TABLES AND FIGURES

Tables

Table 1: Annual DDS Population Change within Age Group, a Comparison of 2007 and 2008	3
Table 2: Distribution of Deaths by Age Group, 2008	5
Table 3: No. Deaths, Average Age at Death and Death Rate by Gender, 2008	6
Table 4: Average Age at Death by Gender, DDS Population 2001-2008	7
Table 5: Age and Mortality by Type of Residential Setting, Adults Served by DDS, 2008	8
Table 6: Mortality Rate in Nursing Homes, A Comparison of US and MA DDS Populations	11
Table 7: Location of Death for Hospice Patients	15
Table 8: Diagnoses for Hospice Users	16
Table 9: Mortality Trends in DDS, 2000-2008	19
Table 10: Top 10 Leading Causes of Death	22
Table 11: Cause-specific DDS Mortality Rates, 2003-2008	23
Table 12: Top Primary Sites for Cancer Deaths in the DDS Population, 2008	24
Table 13: Cause of Death by Age Group for DDS, 2008	27
Table 14: Cause of Death by Age Group for Massachusetts Population, 2007	27
Table 15: Top Causes of Death for DDS Community	28
Table 16: Top Causes of Death for Individuals Served by DDS and Residing in Their Own Home	28
Table 17: Top Causes of Death for Individuals Served by DDS in Other Residential Settings	28
Table 18: Summary of Investigations, 2000 to 2008	30
Table 19: Findings in Cases Investigated by DDS or DPPC, 2000 to 2008	31
Table 20: Comparison of Crude Mortality Rates for Selected State ID/DD Systems	32
Table 21: Mortality Rates by Age for Three State ID/DD Agencies	33
Table 22: Comparison of the Percentage of Deaths by Gender for Three State ID/DD Systems	34
Table 23: Comparison of Mortality Rates by Residential Setting for the Massachusetts DDS and Connecticut DDS	35
Table 24: Comparison of the Top 5 Leading Causes of Death As Reported by Four State ID/DD Agencies	36
Table 25: Breakdown of Relative Percent of Annual Deaths by Pneumonia Type	37
Table 26: Target Status for Selected Healthy People 2010 Mortality Objectives	39
Table 27: Age and Residential Distribution of the 2008 DDS Adult population	44
Table 28: Age-adjusted Mortality Rates	46
Table 29: Crude Gender-specific Adult Mortality Rates	48
Table 30: Age-adjusted Gender-specific Adult Mortality Rates	48

Figures

Figure 1: Distribution of the Population Served by DDS by Age and Gender, 2008	2
Figure 2: Gender Distribution by Age, Adults Served by DDS 2008	3
Figure 3: Where People Live	4
Figure 4: Mortality Rate by Age Group, Adults Served in 2008	6
Figure 5: DDS Age at Death by Gender, 2001-2008	7
Figure 6: Relationship between Mortality Rate, Average Age at Death, and Type of Residence, 2008	9
Figure 7: Comparison of Place of Death in MA State and MA DDS Populations	12

Figure 8: Percentage of Decedents Who Utilized Hospice Services 14

Figure 9: Utilization of Hospice Services by Gender for 2008 Decedents Served by DDS..... 14

Figure 10: Utilization of Hospice Services by Age Group: National Medicare
Enrollees and DDS Decedents 15

Figure 11: Comparison of Crude and Adjusted Gender-specific Adult Mortality Rates..... 18

Figure 12: Statewide Mortality Rates, 2000-2008..... 19

Figure 13: Average Age at Death per Year, 2000-2008 19

Figure 14: Comparison of Mortality Rate by Age Group over Time, 2004-2008 20

Figure 15: National Trend of Pneumonia and Influenza Deaths..... 25

Figure 16: Mortality Rates by Age for Three State ID/DD Agencies..... 33

Figure 17: Comparison of 2008 MA DDS and U.S. Standard Populations Percentage of
Population by Age Group 45

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 2008.

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 2008, the Massachusetts DDS served 33,254 individuals, 24,052 of whom were adults with intellectual disabilities¹ over the age of 18 years. Between June 2007 and June 2008, the DDS mid-year adult consumer population showed a net increase of about 1.8%, or 427 people.

In calendar year 2008, there were 427 deaths of DDS consumers, representing a crude adult death rate² of 17.8 individuals per thousand. The average age at death of adults in the DDS population during 2008 was 61.5 years of age. Mortality statistics in 2008 do not show a significant change in the rate of death for the population since 2007.

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

Causes of Death:

- Heart disease remained the leading cause of death in 2008.
- Alzheimer's disease was the second leading cause, after moving up two ranks from 2007. The increasing impact of Alzheimer's disease on mortality is a trend that is mirrored in both the Massachusetts and U.S. populations, and may be seen more strongly in the population served by DDS due to the higher prevalence in people with Down syndrome.

¹ The term "intellectual disability" is the preferred term in current literature and is used throughout this report. This term replaces the previously used term of "mental retardation"; there is no change in the definition of the population. R. Shalock et al. *Intellectual and Developmental Disabilities*, Apr 2007, Vol 45(2): 116-124.

² 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 dividing the number of individuals who died during the year by the total number of individuals served by DDS during the same year and times multiplying one thousand. See Appendix A for details.

- Aspiration Pneumonia was the third leading cause of death, with a rate of death similar to previous years.
- Cancer and septicemia were tied for the fourth leading cause of death. Cancer deaths decreased from a rate of 2.5 per thousand in 2007 to 1.5 per thousand in 2008, which is the lowest crude mortality rate for cancer seen in this population since 2000. In 2008, cancer represented a far smaller percent of deaths for adults (8.7%) in the DDS population than for adults in the US population (24%) in 2007³ or for people (aged 15+) in the Massachusetts population (25%). More data is needed to determine whether this decrease in rate is part of a larger trend.
- The mortality rate for Influenza and Pneumonia, the sixth leading cause of death, almost doubled in 2008 to 1.1 per thousand. This increase may reflect the national flu epidemic in 2008, in which there was a significant increase in the incidence of pneumonia in the general population in Massachusetts, compared to 2007.

Other Key Findings in 2008:

- Examining the place of death for a population can be useful to inform questions about the setting and type of care received at the end of a person's life. The relative distribution of place of death is similar between the MA state population and the MA DDS. A slightly higher percent of DDS consumers die in their own home, and a smaller percentage die in nursing homes than the general population of MA.
- The percent of DDS decedents utilizing hospice services was higher in 2008 than in 2007 (29% or 121 people), bringing the utilization rate of 34% closer to the MA state rate of 39%. Consistent with 2007 data, a higher percentage of hospice users in the DDS population died in their own home than in the general population.
- There were fewer allegations, and fewer substantiated abuse/neglect in 2008 compared to previous years.
- 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.
 - For the first time since the application of the HP2010 benchmarks to this population in 2004, the 5-year average adult crude mortality rate for female breast cancer is within 25% of the HP2010 targeted mortality rate for all ages.
 - The mortality rates for lung, cervical, oropharyngeal and prostate cancer were also within the targets.
 - 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.

³ Approximated from the number of deaths per cause presented in Table 10. Number of deaths from 113 selected causes and Enterocolitis due to *Clostridium difficile*, by age: United States, 2007

2008 Mortality Report

INTRODUCTION

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 2008. The mortality information in this report includes all consumers who were eligible and active service recipients in the Meditech Consumer System during this period and who died during the 2008 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 individuals 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 this 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 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. This report includes both individuals whose deaths were reviewed, and those who were not. See the section on mortality review for a more detailed description of the process.

DEPARTMENTAL NAME CHANGE

Effective July 1, 2009, the Massachusetts Department of Mental Retardation (DMR) changed its name to the Department of Developmental Services (DDS). The name change was enacted through legislation in 2008 in order to promote dignity and respect for people with disabilities, and to better reflect the range of services and supports offered by the department. Although the name change did not occur until after the period covered in this report, the new departmental name and abbreviation will be used.

OVERVIEW OF POPULATION SERVED BY DDS

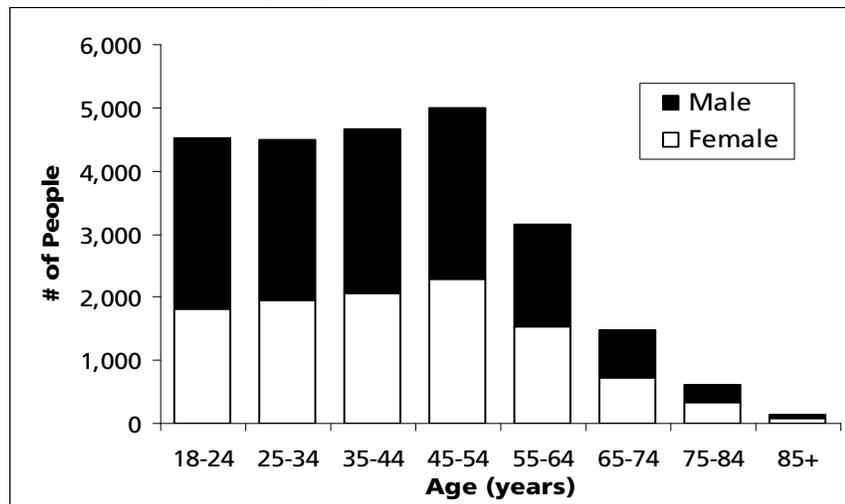
Because the population served by DDS fluctuates in the course of the calendar year, a snapshot of the population at a single point in time is used to estimate the calendar year population. Since the population served by DDS tends to increase as the year progresses, the mid-year population (June 2008) is used to model the average population across the entire year.

In the middle of calendar year 2008, the Massachusetts DDS served 33,254 individuals, 24,052 of whom were adults with intellectual disabilities over the age of 18 years. A net increase of about 1.8%, or 427 people, was seen in the mid-year adult consumer population from June 2007 to June 2008. In this report, population and mortality statistics are presented only for those individuals age 18 years and older who were eligible for services from DDS.

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, with a peak at the 45-54 year old age group. Over the age of 54, the numbers of people in each age band decreases with increasing age.

Figure 1
Distribution of the Population Served by DDS
by Age and Gender, 2008



2008DDS Population (Figure 1, continued)

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1,814	1,964	2,063	2,278	1,521	713	326	91	10,770
Male	2,703	2,517	2,589	2,716	1,641	778	292	46	13,282
Total	4,517	4,481	4,652	4,994	3,162	1,491	618	137	24,052

Table 1 presents the change in the DDS population between calendar years 2007 and 2008. 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. Increases of between 3% - 25% are seen in all age groups except for the 35-44 year old group, which had a 2% decline. The age groups with the largest relative increases are the oldest age groups; this pattern reflects the trend of aging within the DDS population.

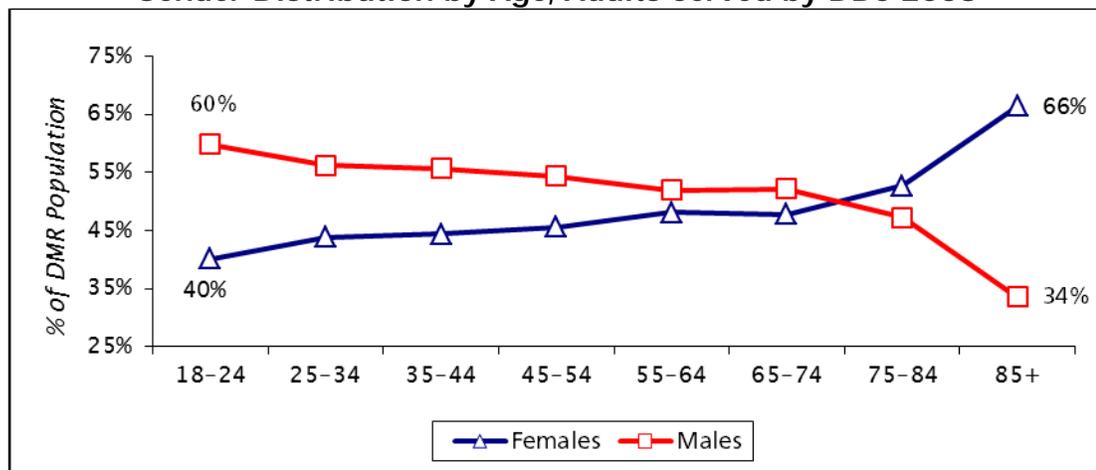
Table 1
Annual DDS Population Change within Age Group
A Comparison of 2007 and 2008

Age Group	Gross Population Fluctuation ⁴		
	Individuals	% Change within Age Group	Resulting % Change in DDS Consumer Population from 2007
18-24	156	3.6%	0.7%
25-34	164	3.8%	0.7%
35-44	-98	-2.0%	-0.4%
45-54	169	3.4%	0.7%
55-64	174	5.7%	0.7%
65-74	151	10.6%	0.6%
75-84	93	15.5%	0.4%
85+	34	25.4%	0.1%
Total	843	N/A	3.6%

Gender Characteristics

The gender distribution in the 2008 adult DDS population is very similar to 2007 and previous years. As Figure 2 shows below, the proportion of men and women served by DDS varies with age. Younger age groups have a larger proportion of men.

Figure 2
Gender Distribution by Age, Adults Served by DDS 2008



⁴ 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.

The gender proportions equalize by about age 55 and then steeply move toward a female majority. The shift in gender distributions in the elderly population is consistent with reports from other states.⁵

Residential Setting Characteristics

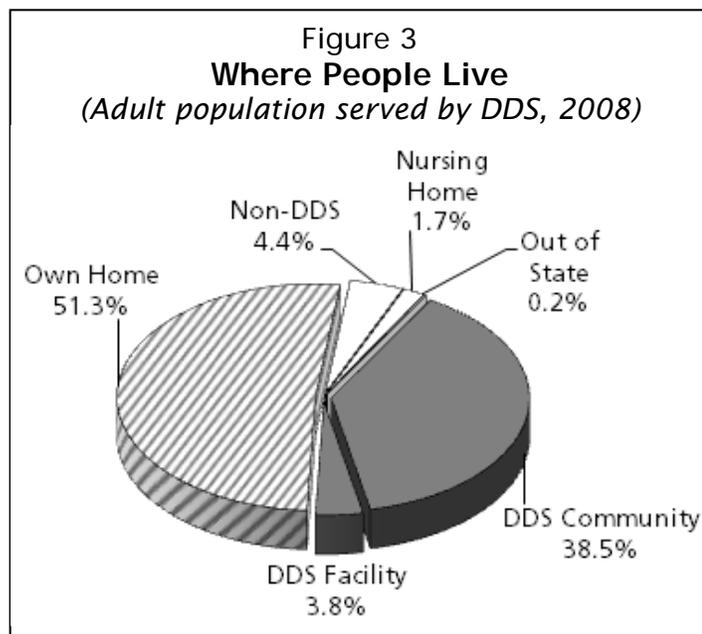
Adults receiving services from DDS reside in a variety of different residential settings. Many individuals live independently in their own homes or with their family, while others receive residential supports directly from DDS or from another state agency. In this report, the various DDS residential settings are grouped into one of six residential categories. The percent of people served by DDS living in each residential category is presented in Figure 3. Just over half of the adults served by DDS reside in their own home, which includes people living independently or with their family.⁶

Residential programs operated, licensed/ certified or funded by DDS are shown in the sections shaded in solid grey. About 39% of adults served by DDS live in community residential programs, and about 4% live in DDS facilities. The number of people living in DDS facilities continues to decline annually largely due to DDS’s efforts to plan transitions to community settings for these residents.

About 4% 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 3, or in nursing homes.

Individuals counted in the “out of state” category 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).



⁵ Gruman, C. and Fenster, J. *A Report to the Department of Mental Retardation: 1996 through 2002 Data Overview*, April 2002.

⁶ Due to changes in the electronic DDS tracking systems, the ‘own home’ category will no longer be broken out separately into people living independently and those living with their families.

MORTALITY DURING 2008

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 2008. Appendix A describes the methodology used to collect and analyze the information and data contained in this section.

A total of **427 deaths** occurred for active DDS service recipients in 2008, representing a crude adult mortality rate⁷ of **17.8 individuals per thousand**.⁸ DDS received death reports for 423 individuals who met the criteria outlined above for calendar year 2008. A validation exercise was conducted between the electronic DDS mortality reports filed for 2008, consumers listed in the agency's Meditech Consumer System, and the Social Security Death Index. An additional four deaths were confirmed of DDS consumers for whom a DDS death report had not yet been filed, bringing the total number of deaths to 427. 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 2008 was **61.5 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 **61.5 years**. Mortality statistics in 2008 do not show a significant change in the rate of death for the population since 2007⁹.

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 deaths across DDS, and the crude mortality rate.

Table 2
Distribution of Deaths by Age Group, 2008

Age Range	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)
18-24 yrs	19	4.4%	4.2
25-34 yrs	13	3.0%	2.9
35-44 yrs	39	9.1%	8.4
45-54 yrs	68	15.9%	13.6
55-64 yrs	108	25.3%	34.2
65-74 yrs	72	16.9%	48.3
75-84 yrs	75	17.6%	121.4
85 yrs & older	33	7.7%	240.9
Total	427	100%	17.8

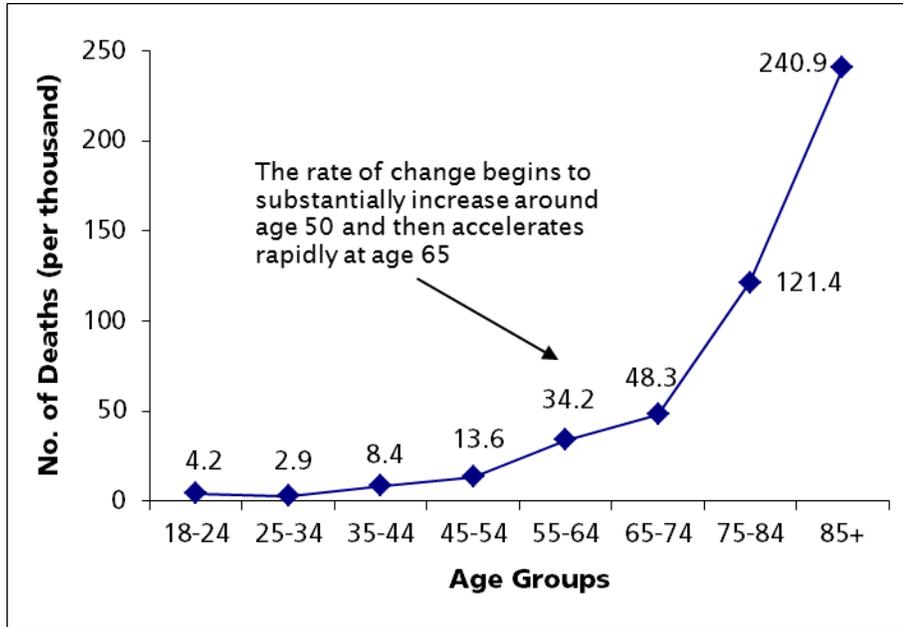
⁷ The crude death rate is a measure of how many people out of every thousand served by DDS died within the calendar year. It is determined by multiplying the number of individuals who died during the year times one thousand and dividing this by the total number of individuals served by DDS during the same year. The crude death rate can be useful when comparing deaths across populations of varying sizes.

⁸ 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.

⁹ χ^2 Test of Independence. $\chi^2 = 0.14$, d.f.=1

A proportional relationship exists between the crude mortality rate and advancing age. 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 relationship between age and mortality is seen in most other populations and is reflective of the increasing risk of mortality with advancing age.

**Figure 4
Mortality Rate by Age Group
Adults Served in 2008**



The relationship between age and rate of death for adults served by DDS is displayed in Figure 4. The use of a mortality rate (deaths per thousand individuals) controls for differences in the population size between age groups, and allows for the age groups to be compared to each other. The line in Figure 4 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 reflecting the expected increase in risk of mortality for adults of advanced age.

Gender

Because gender proportions vary with age in the population served by DDS, there is a complex relationship between gender and mortality.

**Table 3
No. Deaths, Average Age at Death and Death Rate by Gender, 2008**

Gender	Adult Population	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	10,770	205	48.0%	62.3	19.0
Male	13,282	222	52.0%	60.8	16.7

Table 3 displays the adult population, number of deaths, percent of overall deaths, average age at death and rate of death for each gender. More deaths occurred for men, but the population also has more men in it. Because there are fewer women than men in the DDS population, the female crude death rate is higher despite the fact that fewer women than men died during the year.

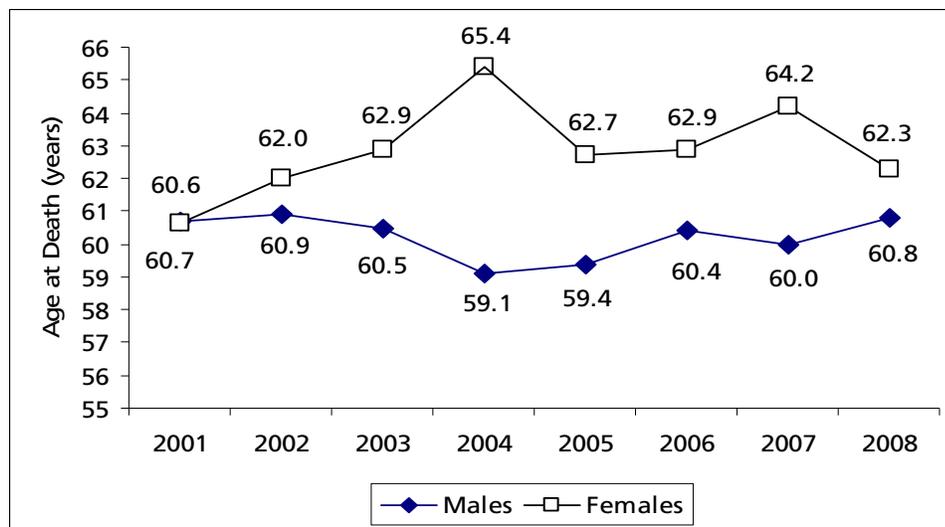
Because the age distribution within each gender differs, crude mortality rates should not be directly compared between genders in the DDS population. Males represent a higher proportion of consumers in younger age groups compared to females. Gender-specific, age-adjusted mortality rates have been calculated for 2001-2008, and appear later in the "Age-adjusted Mortality" section. Comparisons of the mortality rates between genders should be made using these adjusted rates, which control for the age differences between the populations.

Table 4
Average Age at Death by Gender,
DDS Population
2001-2008

Calendar Year ¹²	Age at Death (years)	
	Males	Females
2001	60.7	60.6
2002	60.9	62.0
2003	60.5	62.9
2004	59.1	65.4
2005	59.4	62.7
2006	60.4	62.9
2007	60.0	64.2
2008	60.8	62.3

Table 4 shows the average age at death for each gender from 2001 to 2008. Figure 5 displays recent trends in average age at death by gender. The higher female to male average age at death is consistent with trends found in the general population both nationally and statewide.

Figure 5
DDS Age at Death by Gender, 2001-2008



¹⁰ Revised mortality information is presented for 2001 and 2002

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 5 and Figure 7.

Table 5
**Age and Mortality by Type of Residential Setting,
 Adults Served by DDS, 2008**

Residential Setting	Adult Population (No. People)	Percent of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home	12,349	5%	85	20.0%	49.8	6.9
DDS Community	9,260	12%	196	46.2%	62.6	21.2
Non-DDS	1,055	13%	15	3.5%	64.6	14.2
DDS Facility	925	27%	49	11.6%	63.3	53.0
Nursing Home	416	41%	81	19.0%	70.0	194.7
Out of State	51	16%	0	0.0%	N/A	0.0
Total (Statewide)¹¹	24,052	9%	427	100%		
Average					61.5	17.8

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. Average age at death was lowest for individuals living in their own home (49.8 years).¹² The average age at death is highest for those living in nursing homes (70.0 years) and those living in non-DDS settings (64.6 years). The average age of death for decedents from the DDS community (62.6 years) and from DDS facilities (63.3 years) was similar to the average

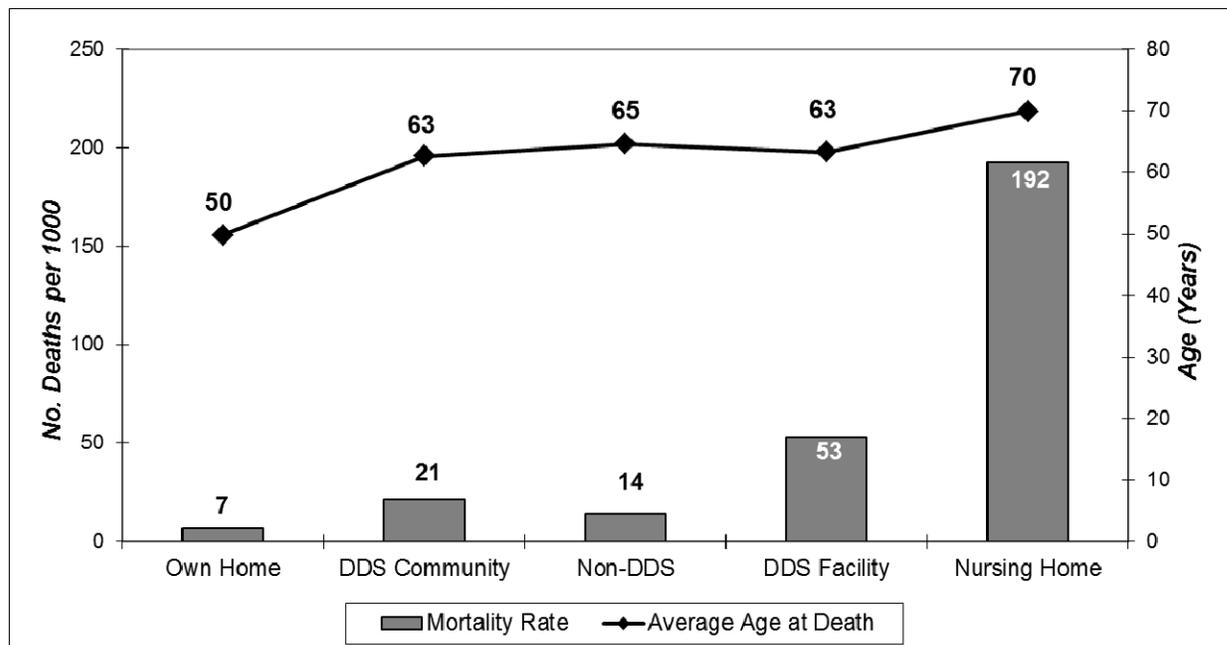
¹¹ 4 consumers had duplicate residential enrollments in 2008. Therefore, the total reflected here will be 4 less than the sum of each residential setting. 1 decedent in 2008 had an unknown residential setting at the time of this report.

¹² In the previous year’s mortality report (2007), people who lived at home with their family were listed separately from those that lived independently. Those living with their family are generally younger than those living independently; by combining the two populations, the average age at death will likely differ from previous data.

for the population (61.5 years). 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 2008 continued to follow this pattern with the exception of the Non-DDS setting. Because the non-DDS setting serves a small and varied population with few deaths annually, the average age at death fluctuates greatly for this residential group; in 2007, the average age at death was 52.0 years for the group.

Individuals residing in nursing homes experienced the highest rate of death in 2008, accounting for about one-quarter of all deaths despite having the smallest population of all residential settings. The relationship between type of residence and mortality are consistent with expectations and with trends present in other state intellectual disability systems.¹³ This is because the average population age and health tends to vary by type of residential setting.¹⁴ The relationship between age, mortality and type of residential setting is further illustrated in Figure 6.

Figure 6
 Relationship between Mortality Rate, Average Age at Death,
 and Type of Residence, 2008



Own Home

Individuals served by DDS living independently in their own home or with family had the lowest mortality rates in 2008, similar to previous years. The crude rate of death for those living in their own home, either independently or with family, was 6.9 per thousand in 2008, which is not significantly different from the 2007 crude death rate

¹³ State of Connecticut. *Mortality Annual Report*, July 2007.

¹⁴ 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.

for this group.¹⁵ The crude mortality rates for people living with family is lower than both the crude mortality rate for residents of 8.2 per thousand and the age-adjusted rate of 7.0 per thousand for the general population in Massachusetts.¹⁶ (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 48.8 years.

DDS Community

The DDS Community is a diverse residential subgroup in terms of both age and level of service need, and supports the second-largest residential subpopulation of DDS consumers in Massachusetts. The mortality rate for individuals served by DDS living in the DDS Community in 2008 was 21.2 per thousand. This rate has not changed significantly from 2007.¹⁷ The average age at death (62.6 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 less than 10% of the entire DDS population. The number of people living in these settings is decreasing annually, and is down from about 13% of the population in 2007. 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.

Additionally, DDS continued efforts in 2008 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.

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. Fourteen (15) individuals served by DDS living in Non-DDS residences died in 2008, resulting in a crude mortality rate of 14.2 per thousand. No significant change in the mortality rate was seen from 2007.¹⁸

DDS Facilities. In 2008, 49 people who were residing in DDS facilities died; the rate for this setting was 53.0 per thousand in 2008. The average age at death was 63.3 years, which is higher than the average age at death of 61.5 years for the entire

¹⁵ Z-test between proportions of residential-specific deaths and populations, $z = 0.65$

¹⁶ *Massachusetts Deaths 2007*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, April 2009. Table 1: Trends in Mortality Characteristics, Massachusetts: 1997 – 2007.

¹⁷ Z-test between proportions of residential-specific deaths and populations, $z = 1.09$

¹⁸ Z-test between proportions of residential-specific deaths and populations, $z = -0.46$

population served by DDS. This is reflective of the older age of the residents in facilities. Twenty-seven percent (27%) of residents were over the age of 65 in 2008.

Nursing Homes. In 2008, 81 people who were residing in nursing homes (for more than 30 days) died. This setting had a mortality rate of 194.7 per thousand and represented 19.0% of all deaths in the DDS community. The people residing in nursing homes are much older than those living in other settings, with 41% of residents over the age of 65.

Table 6
Mortality Rate in Nursing Homes
A Comparison of US and MA DDS Populations

Age Group	Rate of Death (per thousand)	
	US 2005 ¹⁹ (estimated)	DDS 2008
65+	420.7	23.2
85+	414.3	102.9
Total	373.4	194.7

The 2008 crude mortality rate increased with moderate significance²⁰ from the 2007 rate. This was partly due to the 32% decline in the number of people residing in nursing homes between 2007 and 2008. The rate of death in nursing homes is consistently the highest among the various residential categories. It is important to note that the crude mortality rate continues to be lower than the general population approximate rate of death in Massachusetts nursing homes (352.5 per thousand) in 2007²¹ and U.S. nursing homes in 2005 (373.4 per thousand). Rate of death by age for both the MA DDS and the US population are shown in Table 6.

¹⁹ US Nursing Home Mortality Rate estimates are based upon 2004 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.

²⁰ Z-test between proportions of residential-specific deaths and populations, $z = 1.87$

²¹ 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 15,924 deaths in MA Nursing Homes from (*Massachusetts Deaths 2007*, Bureau of Health Statistics, Research and Evaluation Massachusetts Department of Public Health).

Place of Death

Examining the place of death for a population can be useful to inform questions about the setting and type of care received at the end of a person's life. The home environment is often the desired place to pass away, as opposed to 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 7
Comparison of Place of Death in
MA State and MA DDS Populations

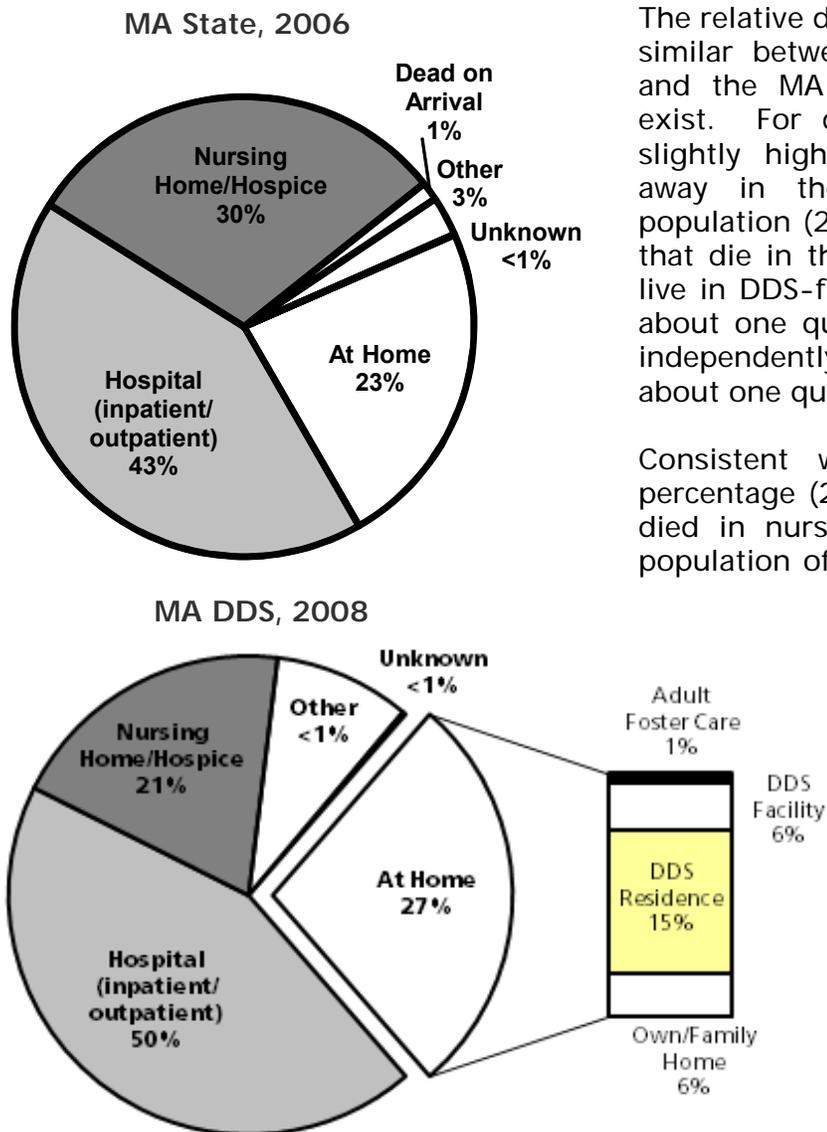


Figure 7 compares place of death for the MA DDS to the MA state data from 2006. The relative distribution of place of death is similar between the MA state population and the MA DDS, but some differences exist. For decedents served by DDS, a slightly higher percentage (27%) passed away in their homes than the state population (23%). Of those served by DDS that die in their own home, just over half live in DDS-funded community residences, about one quarter live in their own home independently or with their family, and about one quarter live in a DDS facility.

Consistent with 2007 data, a smaller percentage (21%) of people served by DDS died in nursing homes than the general population of MA (30%). It is important to

note that the information presented in Figure 7 regarding deaths in nursing homes is not the same as what is presented in Table 5 and Figure 6 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 8 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%) die in hospital settings, either inpatient or outpatient, in the DDS community than in the Massachusetts population.

Hospice

Background

In the 2007 mortality report, a section was added to the DDS mortality report to quantify the use of hospice care among decedents in the population served by DDS. 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.

Hospice services are an important and potentially under-utilized option for patients with terminal conditions that can prolong and improve the quality of their lives. In a recent study, the mean survival was 29 days longer for hospice patients than for non-hospice patients.²² In particular, "terminally ill patients with either congestive heart failure or cancer of the colon, lung, pancreas that received hospice care showed significant increases in mean survival time over other terminally ill patients with the same conditions in other care settings."²² Recent efforts to find information on the use of hospice services on a population-level by people with intellectual disabilities yielded no results.

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.

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 2008, 146 people, or 34% of DDS decedents, utilized hospice services before their death as shown in Figure 8. For 6% of decedents (26 people) served by DDS, it is not known whether hospice services were utilized. The percent of DDS decedents utilizing hospice services was higher in 2008 than in 2007 (29% or 121 people). This usage rate compares to 39% of decedents statewide in Massachusetts who used hospice in 2006. Nationally, the National Hospice and Palliative Care Organization estimates that

²² Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three year window. *J Pain Symptom Manage.* 2007 Mar;33(3):238-46.

approximately 39% {963,000 / 2,500,000} of all deaths in the United States were under the care of a hospice program.²³

Figure 9 shows the percentage by gender of people served by DDS who died in 2008 and used hospice services before their death. The relative portion of consumers who used hospice services is similar across gender in the DDS population.

Figure 10 examines the

percentage of decedents in each age group that utilized hospice services. In general, the use of hospice services has increased in the national population of Medicare enrollees over time. The most recently released data on hospice use (2002) is shown in Figure 10 for Medicare enrollees; however, it should be noted that the current figures on hospice use for Medicare enrollees may be higher than the 2002 figures shown as evidenced by trends of increasing use.

In the under 65 age group, a higher percentage of decedents in the DDS population used hospice services in 2007 than for 2002 Medicare enrollees. It is not known whether people under 65 experience similar rates of terminal conditions in the two populations. Given the higher incidence of complex medical issues in the DDS population on average, it is possible that the incidence of terminal conditions may not be the same in both groups, especially for this younger age group. Because this information is not known, the comparisons of use must be viewed with caution.

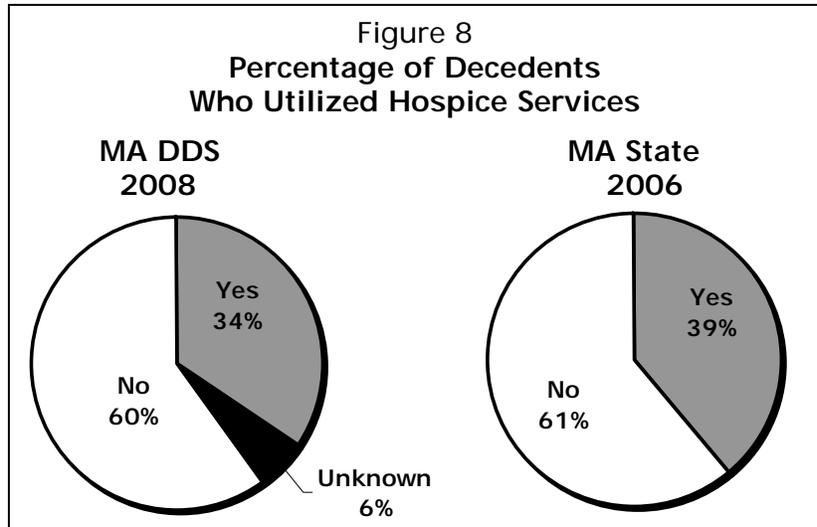
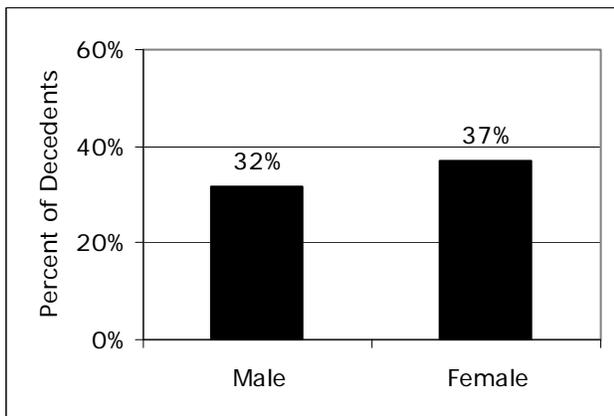


Figure 9

Utilization of Hospice Services by Gender for 2008 Decedents Served by DDS



Much of the increase in hospice use for 2008, compared to 2007, was in age groups over 65. In general, the age distribution of hospice utilization is similar to the utilization in national Medicare enrollees, with a slightly higher representation from those aged 75 years and older in the DDS population.

²³ NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, October 2009.

Figure 10
**Utilization of Hospice Services by Age Group:
 National Medicare Enrollees²⁴ and DDS Decedents**

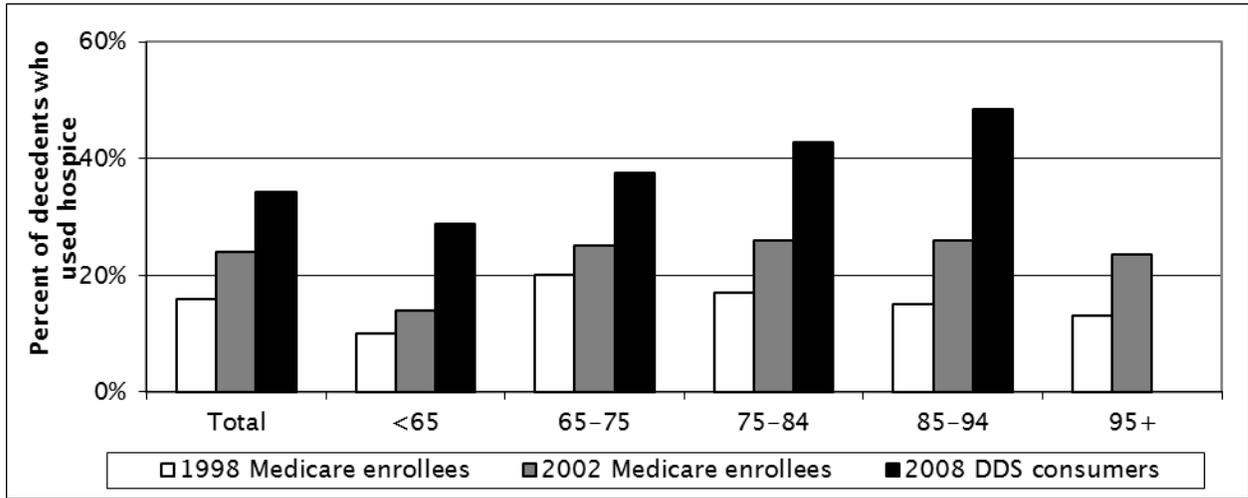


Table 7 compares the place of death for 2008 decedents using hospice between those served by the DDS population and the general population of the United States. Three-quarters (75%) of hospice users served by DDS died at their place of residence. Within this category are decedents who were living in a nursing home (40%), people living in their own home or a DDS-funded community residence (32%), or a DDS facility (10%). Consistent with 2007 data, a higher percentage of hospice users in the DDS population died in their own home than in the general population. None of the DDS hospice users died in inpatient hospice facilities, and a similar percentage died in acute care hospitals.

Table 7
Location of Death for Hospice Patients

United States 2008 ²⁵		2008 MA DDS	
Patient's Place of Residence	69%	Patient's Place of Residence	75%
Private Residence	41%	Own Home or DDS Residence	32%
Nursing Facility	22%	Nursing Home	34%
Residential Facility	6%	DDS Facility	10%
Acute Care Hospital	10%	Acute Care Hospital	8%
Other	21%	Other	11%
Total	100%	Total	100%

A higher proportion of hospice users die in their own homes (34%), compared to the entire population served by DDS (27%) as presented in Figure 7. Eight percent (8%) of hospice users died in an acute care setting, compared with 50% who died in this setting in the entire group of DDS deaths. However, a larger relative percent of

²⁴ Hospice Facts and Statistics, Hospice Association of America, February 2007. Medicare enrollees exclude beneficiaries in managed care. 2002 Data from a MedPAC analysis of 5 percent enrollee database from CMS, 2003.

²⁵ NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, October 2009. Table 1: Location of Death

hospice users died in nursing homes (34%) than in the entire population served by DDS (21%). These comparisons show that the hospice efforts to provide supports in the person’s home until their death were generally successful. Though, more hospice users served by DDS died in nursing homes in 2008 than in 2007.

When the option of hospice was created nationally, the vast majority of initial users were cancer patients. 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.²⁶ One of the reasons this distinction is important is that 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, and have more expensive hospice stays.”²⁶

**Table 8
Diagnoses for Hospice Users**

	National 2008 ²⁷ Admissions (Primary Diagnosis)	DDS 2008 (Underlying Cause of Death)
Cancer (malignancies)	38.3%	19.2%
Non-Cancer Diagnoses	61.7%	80.8%
Heart Disease	11.7%	11.0%
Debility Unspecified	15.3%	0.0%
Dementia, including Alzheimer’s Disease	11.1%	26.0%
Lung Disease, including COPD/CLRD	7.9%	6.8%
Stroke or Coma	4.0%	3.4%
Kidney Disease, including End Stage Renal Disease	2.8%	3.4%
Liver Disease	1.5%	2.7%
HIV / AIDS	0.5%	0.0%
Other Diagnoses	6.9%	21.2%
Total	100%	100%

Table 8 shows the terminal diagnoses for hospice admissions nationally in 2008, and the primary cause of death for hospice users served by DDS that died in 2008. It is important to note that the information presented is slightly different for the two groups. The primary 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. Differences may arise from the length of time between hospice admission and death that vary for certain diagnoses. Because any differences between these two groups are not expected to be large, the comparison in Table 8 is still useful to understand diagnostic differences between the two groups; however the data must be viewed with caution.

²⁶ 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.

²⁷ 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

Eighty percent (80%) of hospice decedents served by DDS had non-cancer diagnoses. This is a larger proportion of conditions other than cancer than seen in 2007 for DDS decedents (70%) and for 2008 admissions nationally (61.7%). Of these non-cancer diagnoses, the incidence of a primary terminal condition of dementia or Alzheimer's Disease continued to be higher in hospice decedents served by DDS 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 similar to national admissions.

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 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. population (2000).

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 death rate** for the DDS population is approximately **19.3 per thousand**. The age-adjusted rate is higher than the crude mortality rate of 17.8 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.

This age-adjusted mortality rate for the DDS population is higher than the 2007 age-adjusted U.S. overall mortality rate of 8.0 per thousand²⁸ and the age-adjusted adult 2007 mortality rate for Massachusetts of 7.0 per thousand²⁹. The findings in the DDS

²⁸ Deaths: Final Data for 2007. National Vital Statistics Reports Volume 58, Number 19, May 2010

²⁹ 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.

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.³⁰

Gender-specific Age-adjustment within the DDS Population

Differences in age distributions exist between males and females in both the DDS and national populations. In general, the male population served by DDS has a greater percentage of people in younger age groups compared to the females. Because age, a major risk factor for mortality, is not distributed the same way in each gender, it may be informative to examine adjusted mortality statistics where the effects of age and gender have been controlled (or effect caused by any difference is removed).

Figure 11
Comparison of Crude and Adjusted Gender-specific Adult Mortality Rates

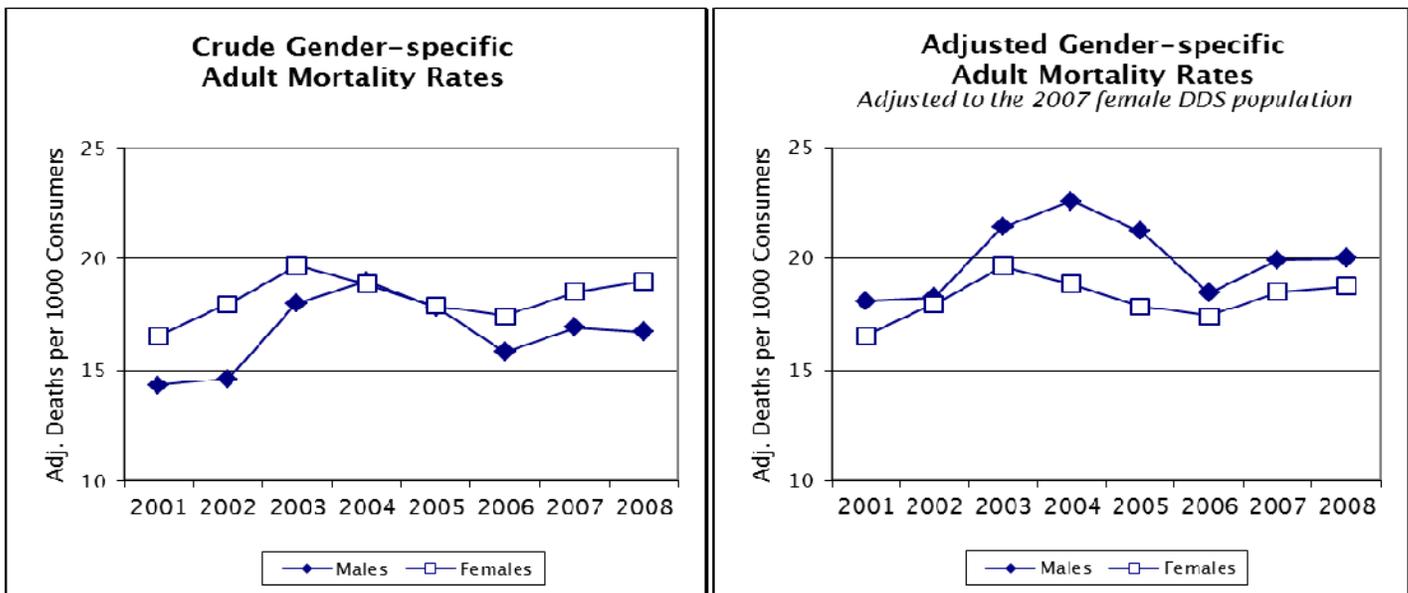


Figure 11 graphs the mortality rates by gender and displays the crude mortality rates on the left, and the adjusted mortality rates on the right. In the comparison of crude rates, the female mortality rates generally appear to be higher than the males for most years. However, when age is controlled (or, when the difference in age distributions is removed), the male mortality rates are higher than females.

In 2008, the age-adjusted rates suggest that there may be differences in the mortality rates between genders due to factors other than age. While the crude rate of death for males is lower than females in 2008, the age adjusted rate shows that the mortality rate would be higher for males when the difference in age is removed.

³⁰ 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.

TRENDS OVER TIME

Mortality Statistics

In comparison with calendar year 2007, the number of deaths and mortality rate for those served by DDS was about the same in 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 9 and illustrated in Figure 12.

Table 9
Mortality Trends in DDS³¹, 2000 - 2008

Year	No. Deaths	Mortality Rate ³² (No. Deaths/1000)	Ave. Age at Death (in years)
2000	322	15.1	60.2
2001	362	16.5	60.7
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

Figure 12³²
Statewide Mortality Rates, 2000-2008
(Deaths per 1000)

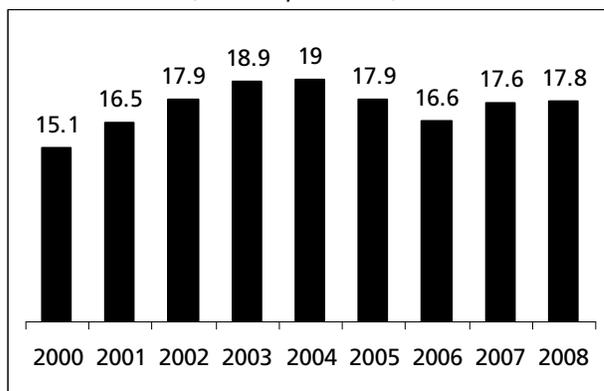
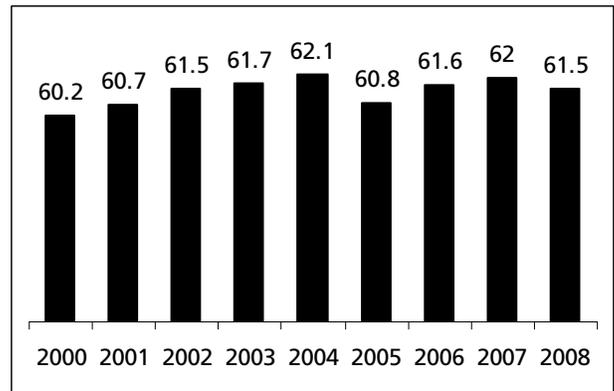


Figure 13
Average Age at Death per Year
2000-2008

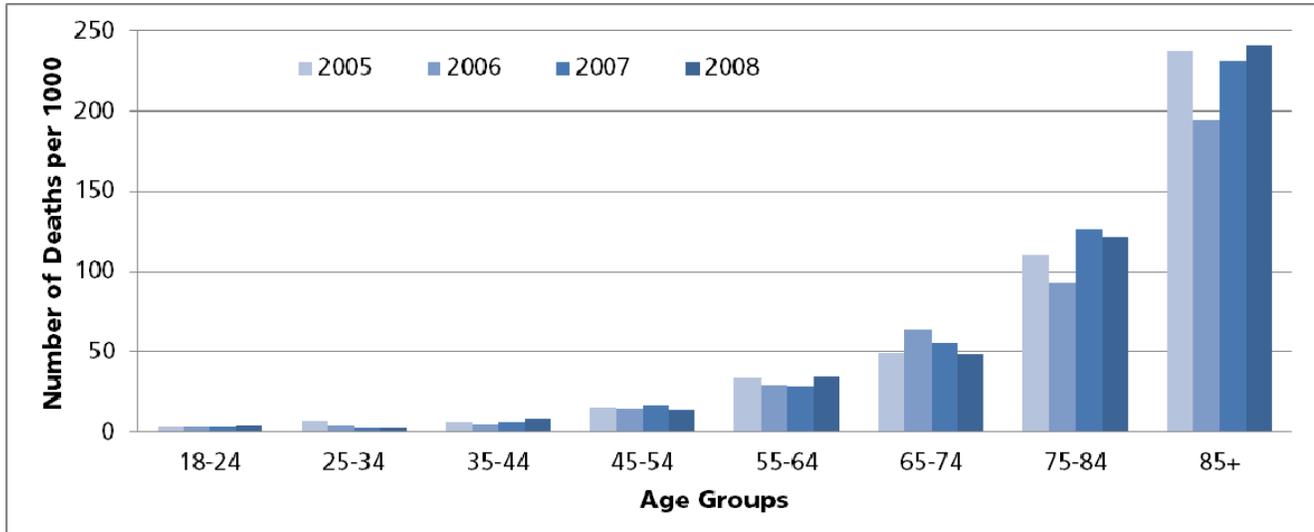


³¹ Rates for 2000-2002 have been adjusted by using the current methodology (adopted in the 2003 mortality report) to calculate the overall client population (denominator for calculating rates). The number of deaths was unchanged (numerator). These adjusted rates are provided to increase the validity 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.

³² The mortality rates for 2000, 2001 and 2002 are adjusted from previous reports. The adjusted calculation uses a revised client population based on the methodology employed in the 2003 report. This adjustment allows a more valid comparison of rates from 2000-2002 to rates from 2003 and future years.

The average age of death, as presented in Figure 13, remains similar to previous years.

Figure 14³²
Comparison of Mortality Rate by Age Group Over Time, 2005-2008



Mortality rates for each age group are displayed in Figure 14 for the past four calendar years. As expected, the age-specific mortality rates increase 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 2008. 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 was confirmed by the DDS Mortality Review Committee.³³ [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."³⁴

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). To allow for more accurate comparisons with other state and ID/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 2008 are compared with data from five previous years and with state and national data in Table 10. Table 11 displays cause-specific mortality rates for the major causes of death in the DDS population for the six year time period between 2003-2008.³⁵

Heart Disease. Heart disease is the leading cause of death in 2008 for people served by DDS, consistent with data from previous years and with data from the Massachusetts and U.S. general populations. The rate of death from Heart disease was 3.3 per thousand in 2008 and this was the underlying cause for 18.7% of deaths.

³³ In some cases, additional reports were available to confirm the cause of death, such as toxicology, autopsy or medical examiner reports.

³⁴ 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.

³⁵ 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.

Table 10
Top 10 Leading Causes of Death

Rank	U.S. 2007 ³⁶	MA 2007 ³⁷	DDS 2003	DDS 2004	DDS 2005	DDS 2006	DDS 2007	DDS 2008
Age inclusion	All ages	15+	18+	18+	18+	18+	18+	18+
1	Heart Disease 25.4%	Cancer 24.8%	Heart Disease 22.3%	Heart Disease 18.5%	Heart Disease 16.4%	Heart Disease 21.9%	Heart Disease 16.8%	Heart Disease 18.7%
2	Cancer 23.2%	Heart Disease 24.4%	Cancer 13.5%	Cancer 12.5%	Cancer 12.0%	Alzheimer's Disease 14.4%	Cancer 13.7%	Alzheimer's Disease 14.1%
3	Stroke 5.6%	Stroke 5.2%	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 11.2%	Influenza and Pneumonia 10.8%	Cancer 9.9%	Septicemia 13.0%	Aspiration Pneumonia 11.2%
4	CLRD 5.3%	CLRD 4.5%	Septicemia 9.0%	Influenza and Pneumonia 10.9%	C-P Arrest/ Seizure ³⁸ 10.8%	Aspiration Pneumonia 8.4%	Alzheimer's Disease 11.3%	Cancer 8.7%
5	Unintentional Injuries 5.1%	Unintentional Injuries 4.0%	C-P Arrest/ Seizure ³⁸ 7.2%	Alzheimer's 7.5%	Aspiration Pneumonia 9.3%	CLRD 5.7%	Aspiration Pneumonia 10.6%	Septicemia 8.7%
6	Alzheimer's Disease 3.1%	Alzheimer's Disease 3.2%	CLRD 6.0%	C-P Arrest/ Seizure ³⁸ 6.8%	Alzheimer's Disease 8.6%	C-P Arrest/ Seizure ³⁸ 5.5%	Unintentional Injuries 6.5%	Influenza and Pneumonia 6.3%
7	Diabetes 2.9%	Influenza and Pneumonia 2.9%	Alzheimer's Disease 5.3%	Septicemia 6.6%	Septicemia 5.9%	Stroke 5.2%	C-P Arrest/ Seizure ³⁸ 3.6%	CLRD 4.9%
8	Influenza and Pneumonia 2.2%	Nephritis 2.6%	Influenza and Pneumonia 4.6%	CLRD 5.7%	CLRD 4.6%	Septicemia 5.2%	Influenza and Pneumonia 3.4%	Stroke 4.0%
9	Nephritis 1.9%	Diabetes 2.3%	Stroke 4.2%	Nephritis 3.6%	Stroke 4.2%	Influenza and Pneumonia 3.9%	Stroke 2.9%	Unintentional Injuries 3.7%
10	Septicemia 1.4%	Septicemia 1.7%	Nephritis 2.6%		Stroke 3.6%	Unintentional Injuries 3.4%	Unintentional Injuries 3.7%	CLRD 2.6%
							Congenital anomalies 2.6%	C-P Arrest/ Seizure ³⁸ 3.3%

**CLRD = Chronic Lower Respiratory Disease

³⁶ 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

³⁷ Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2007, *Massachusetts Deaths 2007*. Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, April 2009. (Most recent data available)

³⁸ Includes sudden deaths reported as cardio-pulmonary arrest whether or not seizure was present.

Table 11
Cause-specific DDS Mortality Rates, 2003-2008

2008 Rank	Previous Ranking	Cause of Death	DDS Rates of Death (per thousand)					
			2003	2004	2005	2006	2007	2008
1	1	Heart Disease	4.2	3.5	2.9	3.6	3.0	3.3
2	4	Alzheimer's Disease	1.0	1.4	1.5	2.4	2.0	2.5
3	5	Aspiration Pneumonia	2.3	2.1	1.7	1.4	1.9	2.0
4	2	Cancer	2.5	2.4	2.1	1.6	2.4	1.5
4	3	Septicemia	1.7	1.3	1.1	0.9	2.3	1.5
6	8	Influenza and Pneumonia	0.9	2.1	1.9	0.7	0.6	1.1
7	10	Chronic Lower Respiratory Disease	1.1	1.1	0.8	1.0	0.5	0.9
8	9	Stroke	0.8	0.7	0.7	0.9	0.5	0.7
9	6	Unintentional Injury ³⁹	0.7	0.6	0.6	0.6	1.1	0.7
10	7	CP Arrest/Seizure	1.4	1.3	1.9	0.9	0.6	0.6

Alzheimer's Disease. Alzheimer's disease was the second leading cause of death with 14.4% of deaths, moving up two ranks from its placement in 2007 with a rate of 2.5 per thousand in 2008. This is the highest rate of death from Alzheimer's disease seen in the adult population served by DDS since the start of this reporting in 2000. The increasing impact of Alzheimer's disease on mortality is a trend that is mirrored in both the Massachusetts and U.S. populations. In 2007, Alzheimer's disease increased by one rank in the US population to sixth with 3.1% of deaths. This move in relative rank in the U.S. population was due both to an increase in the proportion of deaths due to Alzheimer's disease and a decrease in those due to diabetes (ranked seventh). Alzheimer's disease moved up two ranks to sixth in the MA population in 2007, representing 3.2% of deaths.

Alzheimer's disease is more common and occurs at younger ages for individuals with Down Syndrome.^{40,41,42} Symptoms of Alzheimer's disease can develop at ages as young as 35 in people with Down Syndrome, and it is estimated that by the age of 60, up to three-quarters of people with Down Syndrome will develop Alzheimer's disease.⁴³ 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. There is also evidence to

³⁹ 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.

⁴⁰ Mann, D. M. A. (1988) Alzheimer's disease and Down's syndrome. *Histopathology*, 13, 125-127.

⁴¹ 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.

⁴² 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.

⁴³ 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.

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.⁴⁴

Aspiration Pneumonia. In 2008, 11.2% of deaths in the DDS population were due to Aspiration Pneumonia, making it the third leading cause of death. The rate of Aspiration Pneumonia deaths in 2008, 2.0 per thousand, was similar to the rate in 2007. Its move up in relative rank was due largely to the substantial decrease in the rate of death from Cancer in the DDS population in 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 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.⁴⁵

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 ID/DD. The benchmarking section, later in this report, discusses the impact of these issues in other ID/DD systems.

Cancer. Cancer deaths decreased from a rate of 2.5 per thousand in 2007 to 1.5 per thousand in 2008 and represented 8.7% of deaths in 2008. This is the lowest crude mortality rate for cancer seen in this population since 2000. Additionally, cancer represents a far smaller percent of deaths for adults (8.7%) in the DDS population than it does for adults in the US population (24%) in 2007⁴⁶ or for people (aged 15+) in the Massachusetts population

Table 12
**Top Primary Sites for Cancer Deaths
 in the DDS Population, 2008**

Primary Site	Number of Deaths	Rate (per thousand)	Average Age at Death
Pancreas	4	0.17	67.4
Female breast	3	0.28	70.5
colon, rectum, rectum and anus	3	0.12	63.4
Esophagus	3	0.12	66.4
Liver	3	0.12	49.1
Stomach	3	0.12	70.3
Trachea, bronchus and lung	3	0.12	75.1

⁴⁴ 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.

⁴⁵ 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.

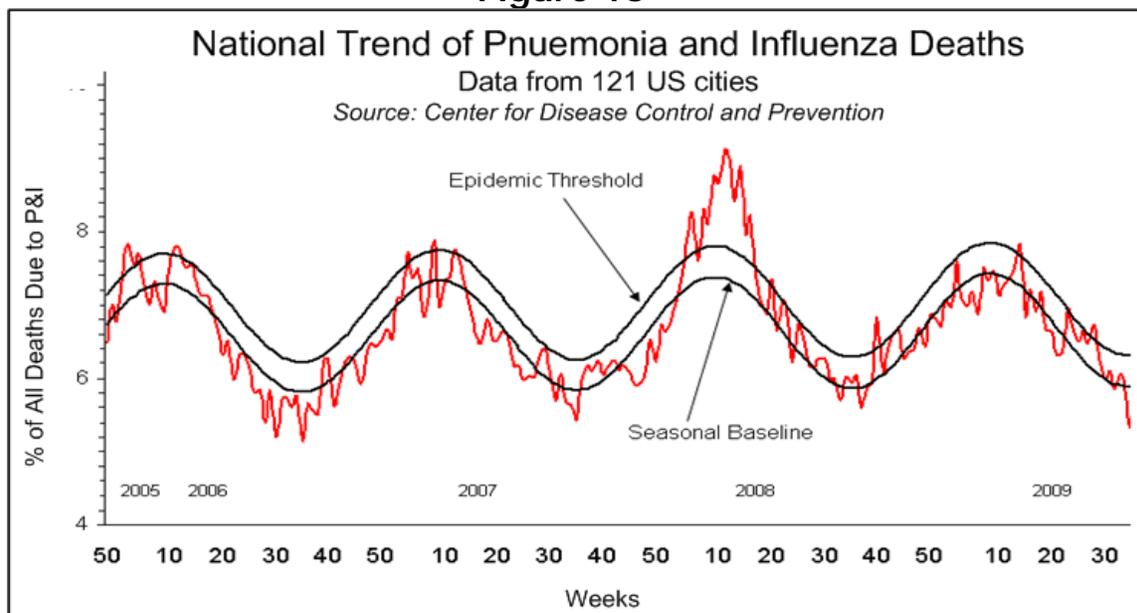
⁴⁶ Approximated from the number of deaths per cause presented in Table 10. Number of deaths from 113 selected causes and Enterocolitis due to *Clostridium difficile*, by age: United States, 2007

(25%).⁴⁷ The rate of death from cancer in this population has fluctuated between 2005-2007 and more information is needed to understand whether this fluctuation is anything other than a normal balancing for this small population. The primary sites of cancers causing death in 2008 are ranked in Table 12.

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^{48,49,50,51} and the appearance of cancers at significantly younger ages (e.g. colorectal cancer around age 35⁴⁸) in individuals with intellectual disabilities of certain etiologies.

Other Causes. The rate of death from septicemia dropped to 1.5 per thousand in 2008, making it the fourth leading cause of death (tied with cancer).

Figure 15⁵²



⁴⁷ National and Massachusetts cancer rates from *Massachusetts Deaths 2007*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, April 2008.

⁴⁸ 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.

⁴⁹ 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.

⁵⁰ 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.

⁵¹ Patja K, Eero P & Livanainen M. Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research*. 2001 Aug 45(4):300-307.

⁵² 2009-2010 Influenza Season Week 20 ending May 22, 2010. Center for Disease Control and Prevention

The rate of death from Influenza and Pneumonia increased in 2008 to 1.1 per thousand from a rate of 0.6 per thousand in 2007, making it the sixth leading cause of death. This increase was likely due to the flu epidemic seen in the US in 2008. Figure 15 shows the relative percent of deaths per week due to influenza and pneumonia for 122 US cities from 2005 to 2009. Early in 2008, a large spike can be seen in the weekly percent of deaths due to pneumonia and influenza, bringing the US to epidemic levels. The US epidemic was also seen in Massachusetts: the number of cases of influenza identified by rapid diagnostic testing statewide increased by 400% between 2007 (4,389 cases) and 2008 (16,202 cases).⁵³

Chronic Lower Respiratory Disease (CLRD) was the seventh leading cause of death in 2008 with 4.9% of deaths and a crude mortality rate of 0.9 per thousand. Stroke was the eight leading cause of death in 2008, representing 4.0% of deaths and a crude mortality rate of 0.7 per thousand.

The rate of death from Unintentional Injuries showed a decline in 2008 in the DDS population, from 1.1 per thousand in 2007 to 0.7 per thousand in 2008. It was the ninth leading cause of death in 2008 with 3.7% of deaths. This brings the mortality rate from this cause back to a rate that is more typical for the population served by DDS, as shown in Table 11. Interestingly, the rate of death from unintentional injuries increased in the MA population in 2007 and the cause moved up by 1 place in ranking. Data is not yet available to determine if the 2008 dropped in a way similar to the DDS population.

CP Arrest/Seizure was the tenth leading cause of death in 2008 with 3.3% of deaths and a crude mortality rate of 0.6 per thousand.

Cause of Death by Age Group

Age-specific causes of death for the 2008 population served by DDS and the 2007 Massachusetts population are presented in Tables 13 and 14.⁵⁴ 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). In contrast, the most frequent causes of death for this age group in the population served by DDS is congenital anomalies, followed by other natural causes of death. The population served by DDS has a lower rate of death from external causes for all age groups than in the general population.

In older age groups, some similarities do exist between the two populations, such as the increasing 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. Cancer is less prevalent as a leading cause in the DDS population than in the general population. 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.

⁵³ 2003-2008 Influenza Activity in Massachusetts, Massachusetts Department of Public Health. Available at: http://www.mass.gov/Eeohhs2/docs/dph/cdc/flu/activity_table.rtf

⁵⁴ The most current data available for the Massachusetts general population was for the year 2007.

Table 13
Cause of Death by Age Group for DDS, 2008
(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	Congenital anomalies	Congenital anomalies	Heart Disease	Alzheimer's Disease	Alzheimer's Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease
2	<i>Multiple Causes</i>	<i>Multiple Causes</i>	CP Arrest/Seizure	Aspiration Pneumonia	Heart Disease	Cancer	Aspiration Pneumonia	Stroke	Alzheimer's Disease
3			<i>Multiple Causes</i>	Cancer	Septicemia	Alzheimer's Disease, Aspiration Pneumonia	CLRD	Aspiration Pneumonia, Nephritis	Aspiration Pneumonia

Table 14
Cause of Death by Age Group for Massachusetts Population, 2007⁵⁵

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

Cause of Death by Residence

Mortality statistics tend to vary across the DDS subpopulations living in different residential settings. This may be 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 15.

⁵⁵ Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2007, *Massachusetts Deaths 2007*. Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, April 2008. (Most recent data available)

Table 15
Top Causes of Death for DDS Community⁵⁶

Rank	Cause of Death	Number of Deaths	Rate of Death
1	Alzheimer's Disease	34	3.7
2	Heart Disease	32	3.5
3	Septicemia	23	2.5
4	Aspiration Pneumonia	21	2.3
5	Cancer	17	1.8

As shown in Table 16, the top two causes of death for individuals residing in their own home or with family are similar to the common causes of mortality in the Massachusetts general population.

Table 16
Top Causes of Death for Individuals Served by DDS and Residing in Their Own Home⁵⁷

Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)
1	Heart Disease	22	1.8
2	CP Arrest/Seizure	10	0.8
3	Alzheimer's Disease	8	0.6
4	Aspiration Pneumonia	7	0.6
5	Influenza and Pneumonia	6	0.5

Table 17 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 17*
Top Causes of Death for Individuals Served by DDS in Other Residential Settings

Rank	Nursing Home (Total 81 deaths)	Non-DDS (Total 14 deaths)	DDS Facility (Total 49 deaths)
1	Alzheimer's Disease, Heart Disease	Heart Disease	Aspiration Pneumonia, Heart Disease
2		Alzheimer's Disease, CLRD, Septicemia	
3	Aspiration Pneumonia		Septicemia

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

⁵⁶ The individual may have passed away in a setting other than the DDS Community, however, individuals are listed by their primary residential setting.

⁵⁷ The individual may have passed away in a setting other than their own home, however, individuals are categorized by their primary residential setting.

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 reviews required by DDS policy were completed, resulting in 100% compliance. A total of 245 mortality reviews were completed for 2008 deaths: 243 of these reviews were required by DDS policy and 2 were requested. A mortality review is required for one additional 2008 decedent for whom a DDS death certificate was not completed at the time of the writing of this report. The death was identified during a validation exercise between the DDS Meditech Consumer System and the Social Security Death Index.

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.⁵⁸

Table 18
Summary of Investigations, 2000 to 2008

Type of Activity	2000	2001	2002	2003	2004	2005	2006	2007	2008
DDS Investigation	5	5	14	9	5	10	2	9	8
DPPC Investigation	1	2	2	4	6	5	3	10	5
Refer to Other Agency	1	8	10	10	9	4	2	7	0
District Attorney/Law Enforcement Investigation	3	1	3	2	4	4	2	9	10
Other/dismissed ⁵⁹	3	5	4	2	1	2	3	5	4
Resolved Fairly and Efficiently								1	0
Total Number of Deaths Investigated	13	21	33	27	20	19	9	34	18

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.

During 2008 there were 18 deaths investigated by one or more of the agencies identified above. DDS conducted 8 investigations on 2008 deaths; judgment was deferred to a law enforcement investigation for five of these cases. A total of 5 investigations were conducted by DPPC. In 4 of these cases, the judgment was

⁵⁸ "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."

⁵⁹ Complaint was Dismissed, Resolved w/o Investigation or Referred to the Regional Office for administrative review.

deferred to a law enforcement investigation. The cases listed as “other/dismised” had an administrative review by DDS (four cases).

Table 19
Findings in Cases Investigated by DDS or DPPC, 2000 to 2008
(Includes cases deferred to law enforcement)

Findings	2000	2001	2002	2003	2004	2005	2006	2007	2008
No. Substantiations	0	1	2	2	1	4	2	3	1
Pending							3	3	2

Table 19 presents the findings of investigations by either DDS or DPPC. Investigations about 1 of the deaths occurring in 2008, out of the 13 deaths reviewed, was found to be substantiated. The substantiated case was referred to law enforcement for further action, where it is still pending. Two investigations that were deferred to law enforcement are still pending due to the timeline of the law enforcement investigation. Ten investigations were found to be unsubstantiated allegations.

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 ID/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 2008 Massachusetts findings. Direct comparisons of specific data should NOT be made, especially where important differences are noted.

NOTE: In this section, mortality data for the MA DDS will be shown with data from the other state ID/DD systems. There is an important difference between the states: 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 ID/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 ID/DD reports and data regarding mortality identified seven state systems that included information on crude mortality rates (no. deaths/population served). Findings from these reports are presented below in Table 20.

Table 20
Comparison of Crude Mortality Rates for Selected State ID/DD Systems

Comparative Mortality Rates	MA DDS 2008	CT DDS⁶⁰ FY2008		VT DDS⁶¹ FY2009	OH⁶² 2008	LA OCDD⁶³ FY2009	CA FY2008	SD DDS⁶⁴ 2008
Population Served	ID only	ID only		DD	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	children and adults
No. Deaths	427	205	216	32	751	114	1622	34
Mortality Rate (no./1000)	17.8	16.3	13.9	8.6	9.2	12.2	6.5	13.7

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 ID/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

⁶⁰ State of Connecticut DDS Mortality Annual Report, FY 2008, Issued May 2009
⁶¹ 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.
⁶² Number of deaths taken from: Cause of Death Summary 2008. Rate of death calculated with population served in 2008 as listed in: Reporting Rates per MUIS per 1000 individuals 2008, available at <http://test.mr.state.oh.us/health/MUIReport/2008/report08.htm>
⁶³ Louisiana OCDD Waiver Services 2009 Mortality Review Report – Issued 04/01/2010.
⁶⁴ *Trend Analysis: 2008 Unusual Incident Report* available at: <http://dhs.sd.gov/dd/Division/documents/UIRAnnualReport2008.doc>

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.

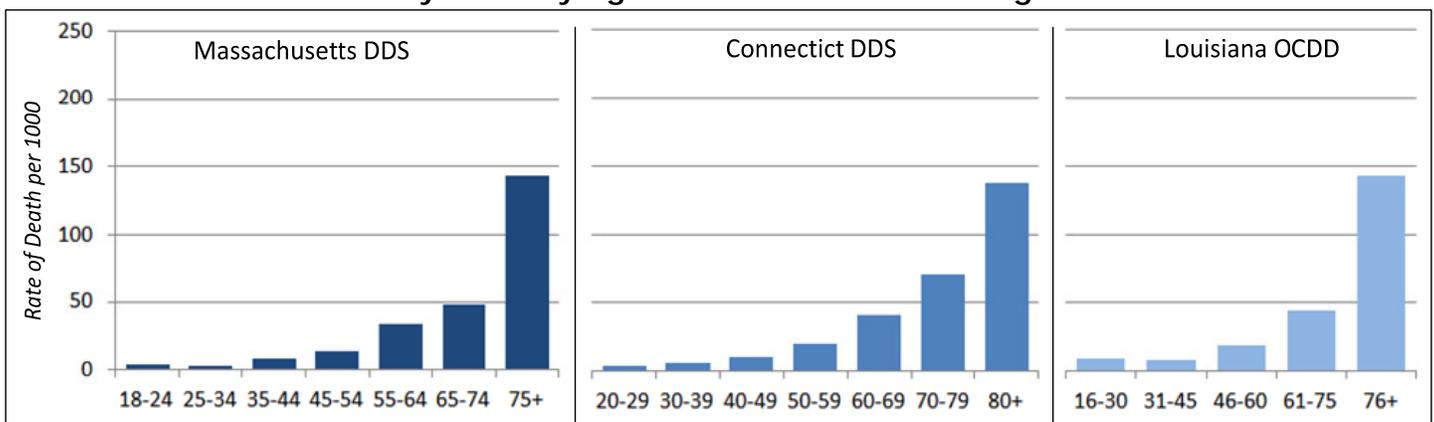
Mortality and Age Benchmarks

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 21 and Figures 16 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).

Table 21
**Mortality Rates by Age
 for Three State ID/DD Agencies**

Crude Mortality Rate by Age					
MA DDS (CY2008)		CT DDS ⁶⁰ (FY2008)		LA OCDD ⁶³ (FY2009)	
Age Range	Mortality Rate	Age Range	Mortality Rate	Age Range	Mortality Rate
18-24	4.2	0-19	3.3	0-15	8.7
25-34	2.9	20-29	3.9	16-30	9.2
35-44	8.4	30-39	6.2	31-45	8.0
45-54	13.6	40-49	10.0	46-60	19.1
55-64	34.2	50-59	20.0		
65-74	48.3	60-69	41.0	61-75	44.8
75+	143.0	70-79	70.4	76+	142.9
		80+	137.6		

Figure 16
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 22.

Both Massachusetts and Louisiana 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 in Louisiana, as it is Massachusetts which affects the average risk of mortality. In Connecticut, the gender distribution in the population served by DDS is very similar to the proportion of deaths. 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 the higher relative crude mortality rates in Massachusetts, and higher average age at death.

Table 22
**Comparison of the Percentage of Deaths by Gender
 for Three State ID/DD Systems**

Gender	Measure	MA DDS 2008 (Adults)	CT DDS⁶⁰ 2008 (All ages)	LA OCDD⁶³ FY2009 (All ages)
Male	Population Percentage	55%	57%	56%
	Percentage of Deaths	52%	56.5%	53%
	Death Rate	19.0	13.8	11.4
	Ave. Age of Death	62.3	56.4	
Female	Population Percentage	45%	43%	44%
	Percentage of Deaths	48%	43.5%	47%
	Death Rate	16.7	14.0	13.2
	Ave. Age of Death	60.8	58.7	

Mortality and Residence Benchmarks

Important differences exist in the populations served and residential groupings utilized by different state ID/DD agencies that make direct comparisons of mortality by residential setting difficult.⁶⁵ 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.

⁶⁵ 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 23
**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 2008 (adults)	CT DDS ⁶⁰ FY 2008 (all ages)
At Home/Family, Independent & Supported Living	6.8	5.6
Community Group Home, Community Training Home	21.1	14.6
Facility-ICF/ID	53.0	41.6
Nursing Facility	192.3	172.4

Table 23 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 adult crude mortality rate is slightly higher in Massachusetts for community settings, and for facilities than the crude mortality rate for all ages in Connecticut for the same settings. 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 ID/DD system for Massachusetts than Connecticut. In 2007, it was lower in Massachusetts than Connecticut, but the crude mortality rate for this setting increased in Massachusetts in 2008. While the majority of people living in nursing homes in the Connecticut ID/DD system are older, it is not known how many children were living in this setting in FY08.

Cause of Death Benchmarks

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

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% - 18.9%) in Massachusetts, Connecticut and Louisiana. Heart disease represents a much higher proportion of deaths in Connecticut (31%). Cancer represents a similar proportion of deaths in populations served the state ID/DD systems in Massachusetts, Connecticut and Ohio (8.7%-10.7%), but represents a much smaller proportion of deaths in the population served by Louisiana OCDD (3.8%)⁶³.

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

Rank	MA DDS CY2008 (adults)	CT DDS ⁶⁰ FY2008 (all ages)	OH OMRDD ⁶⁶ 2008 (all ages)	LA OCDD FY2009 (all ages)
Method	Underlying	Primary	Unknown	Unknown
1	Heart Disease 18.7%	Heart Disease 31.0%	Heart Disease 18.9%	Diseases of the Heart 14.9%
2	Alzheimer's Disease 14.1%	Aspiration Pneumonia 15.2%	Pneumonia 11.0%	Influenza and Pneumonia 14.9%
3	Aspiration Pneumonia 11.2%	Respiratory Disease ⁶⁷ 12.3%	Cancer 10.0%	Septicemia 10.5%
4	Cancer 8.7%	Cancer 10.7%	Aspiration Pneumonia 9.7%	Cerebrovascular Diseases (Stroke) 6.1%
5	Septicemia 8.7%	Pneumonia (non-Aspiration) and Septicemia 7.8% each	Congenital Diseases 6.4%	Chronic Lower Respiratory Diseases 5.3%

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.

While Alzheimer's disease appears as a common cause of death in the Massachusetts state ID/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 24% 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 CT as it does in Massachusetts. In Louisiana, 1.8% deaths are reportedly due to Alzheimer's Disease. It is not known if the counting

⁶⁶ Ohio, Cause of Death Annual 2008

⁶⁷ Includes Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma

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.

Aspiration Pneumonia is a significant cause of mortality in Massachusetts, Connecticut and Ohio, representing between 9.7% and 15.2% of deaths. While these three states count aspiration pneumonia separately from influenza and pneumonia (consistent with ICD-10 classification), the Louisiana OCDD mortality report appears to combine all pneumonias into the category of 'influenza and pneumonia'. In order to provide a more accurate comparison of the relative percentage of deaths caused by difference causes of pneumonia, Table 25 presents reorganized information.

Table 25
Relative Percent of
Annual Deaths by Pneumonia Type

% of annual deaths	MA DDS CY2008 (adults)	CT DDS ⁶⁰ FY2008 (all ages)	OH OMRDD 2008 ⁶⁸ (all ages)	LA OCDD FY2009 (all ages)
Aspiration Pneumonia	11.2%	15.2%	9.7%	Unknown
Influenza and Pneumonia	6.3%	7.8%	11.0%	Unknown
Total	17.5%	23%	20.7%	14.9%

The relative percent of deaths from influenza and pneumonia (excluding aspiration pneumonia) would be expected to be higher in Massachusetts, Connecticut and Ohio figures due to the timeframe of reporting (see Influenza and Pneumonia above for information about the 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 Massachusetts, Connecticut and Ohio than in Louisiana. The population served by OH OMRDD saw a more substantial percent of deaths from aspiration in 2008 than in previous years.

HEALTHY PEOPLE 2010 OBJECTIVES

The Healthy People 2010 (HP2010) initiative was promulgated by the U.S. Department of Health and Human Services in November 2000 and 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

⁶⁸ Ohio, Cause of Death Annual 2008

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 relatively small population (about 24,052 adults) relative to state and national populations. Smaller populations such as this are 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 (2004-2008). 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 2006 were the most current figures available for the U.S. and Massachusetts populations.

Overall the crude adult mortality rates for individuals served by the Massachusetts DDS meet many of the HP2010 targets, more than the age-adjusted mortality rates for general Massachusetts population or the national population. 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.

As discussed earlier in the cause of death section, the population served by the MA DDS saw a substantial decrease in the crude rate of death from cancer. While still above the HP2010, the 2008 rate is closer to this goal. More data will be required to understand whether this is part of a trend, or a normal fluctuation of the population. For the first time since the application of the HP2010 benchmarks to this population in 2004, the 5-year average adult crude mortality rate for female breast cancer is within

Table 26
 Target Status for Selected Healthy People 2010 Mortality Objectives⁶⁹
 Rates per 100,000 population

Objective Number	HEALTHY PEOPLE 2010 OBJECTIVE	TARGET 2010 ⁷⁰	DDS 2004-2008		MA 2006 ⁷⁰ age-adjusted	US 2006 ⁷⁰ age-adjusted
			Avg. Crude Rate	Target Status		
3-1	Overall Cancer death rate	158.6	202.4	●	186.7	180.7
3-2	Lung Cancer	43.3	21.4	✓	52.7	51.5
3-3	Female Breast Cancer (per 100,000 females)	21.3	24.8	○	23.4	23.5
3-4	Cervical (per 100,000 females)	2.0	1.9	✓	1.3	2.4
3-5	Colorectal Cancer	13.7	26.6	●	17.1	17.2
3-6	Oropharyngeal Cancer	2.4	1.7	✓	2.5	2.5
3-7	Prostate Cancer (per 100,000 males)	28.2	15.5	✓	24.5	23.5
3-8	Malignant Melanoma	2.3	2.6	○	3.0	2.7
5-5	Diabetes-related deaths	46	29.0	✓	53.0	74.0
12-7	Stroke deaths	50	70.3	●	38.0	44.0
26-3	Drug-induced deaths	1.2		✓	14.9	11.3
13-14	HIV-infection deaths	0.7	2.6	●	2.7	4.0
24-10	Chronic Obstructive Pulmonary Disease Deaths (age 45+)	62.3	158.4	●	95.6	111.2
	<u>Injuries</u>					
15-13	Unintentional injuries (Accidents)	17.1	79.6	●	32.0	39.8
15-27	Falls	3.3	6.0	●	5.5	6.6
15-3	Firearm-related	3.6	0.0	✓	3.2	10.2
15-8	Poisonings	1.5	1.7	○	15.3	12.4
15-9	Hanging, strangulation or suffocation	3.3	1.7	✓	4.2	4.7
15-25	Residential fire deaths	0.2	3.4	●	0.3	0.9
15-29	Drownings	0.7	2.6	●	0.8	1.3
15-32	Homicide	2.8	0.9	✓*	2.9	6.2
18-1	Suicide	4.8	0.8	✓*	6.7	10.9

✓ = YES, met target ○ = NO, but within 25% of target ● = NO, > 25% from target
 ✓* = Too few deaths from this cause to provide rate

⁶⁹ 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.

⁷⁰ Data 2010 the Healthy People 2010 Database. CDC Wonder website: <http://wonder.cdc.gov>. January, 2010 Edition, Accessed 6/14/10.

25% of the HP2010 target for the mortality rate for all ages. The population served by DDS has not seen any deaths due to cervical cancer in the past three years, bringing the 5-year average of the adult crude mortality rate under the HP2010 target for the mortality rate for all ages. The average adult crude mortality rate for oropharyngeal cancer is also within the HP2010 targets for all ages, and the rate for malignant melanoma is with 25% of the HP2010 target.

While still below the HP 2010 targets, there is an increasing trend of diabetes-related deaths from 2004 to 2008 in the adults served by the MA DDS.

The average adult crude mortality rate from unintentional injuries has increased slightly from past averages for the MA DDS population. However, the five-year average of the crude mortality rate from falls in adults served by MA DDS continued to decline. This average crude rate for adults is now lower than the age-adjusted mortality rate for all ages in the general population in Massachusetts. The majority of deaths from unintentional injury in the population served by the MA DDS are due to choking or aspiration.

Appendix A

Methodology for Mortality Review and Analysis

The 2008 Mortality report analyzes information on all deaths occurring in calendar 2008 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 2008 Mortality Report includes statistics on all deaths of individuals who died in calendar year 2008 and whose Death Report was received by DDS by the end of January 2009. A total of 427 deaths were reported to have occurred between January 1, 2008 and December 31, 2008.

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, 2008.⁷¹ 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 all 420 of the 427 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:

$$\text{Crude Death Rate} = \frac{(\text{Number of individuals who died in calendar year 2008} \times 1000)}{(\text{No. Individuals in CRS in June 2008})}$$

⁷¹ 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, 2006.

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
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

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

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
3950 / zADFOS CARE	Adult Foster Care
3951 / zHOMELESS	Homeless/Homeless Shelter
3952 / zINCAR	Incarceration
3953 / zDMHCOMRES	Community Residential Program
3977 / zDOERES	766 Residential Program
3978 / zREHABHOSP	Rehab Hospital (non-DMH)
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 2008 DDS Adult population

SEX	Age	DDS- Funded Community	DDS Facility	Nursing / Rest Home	Own Home	Non-DDS	Out of State	Total
M	18-24 yr	266	3	2256	156	22	0	2703
F	18-24 yr	167	1	1543	95	8	0	1814
M	25-34 yr	833	11	1586	56	31	0	2517
F	25-34 yr	570	5	1303	54	33	0	1965
M	35-44 yr	1277	48	1144	89	30	1	2589
F	35-44 yr	915	31	998	87	32	1	2064
M	45-54 yr	1432	173	968	115	15	14	2717
F	45-54 yr	1104	122	930	98	18	6	2278
M	55-64 yr	854	179	496	70	29	13	1641
F	55-64 yr	775	103	506	101	28	8	1521
M	65-74 yr	392	99	218	39	28	2	778
F	65-74 yr	333	74	226	34	44	3	714
M	75-84 yr	143	38	64	21	24	2	292
F	75-84 yr	147	25	82	31	41	0	326
M	85+ yr	18	7	7	2	11	1	46
F	85+ yr	34	6	22	7	22	0	91
Total ⁷²		9260	925	12349	1055	416	51	24052

⁷² 4 consumers have duplicate residential statuses listed in the DDS enrollment system. The total of 24052 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 2008 & 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.

Figure 17
**Comparison of 2008 MA DDS and U.S. Standard Adult Populations
 Percentage of Population by Age Group**

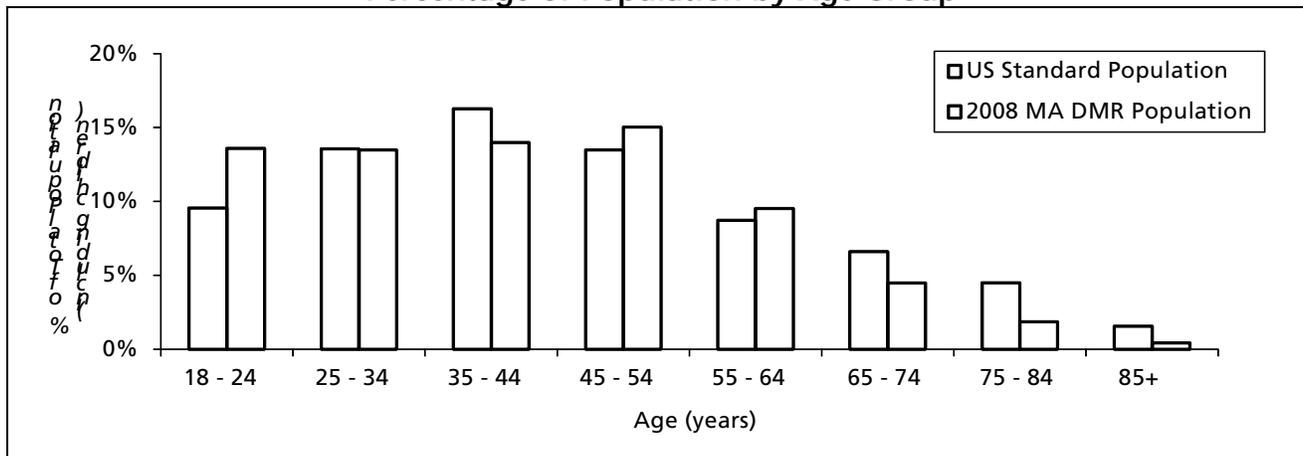


Figure 17 displays the relative percentage of the U.S. population and the MA DDS population in each age group. As described previously, higher percentages of younger individuals and smaller percentages of older individuals are present in the DDS population compared to the U.S. Standard Population. The age distribution in the DDS population has not changed substantially from 2006.

Table 28
Age-adjusted Mortality Rates

Age Group	% population in age group		US 2007 Age-Specific Rate of Death ⁷³ (per thousand)	DDS 2007 rate of death (per thousand)	Weight	Weighted Rate (per thousand)
	US Standard	DDS				
18 to 24	9.6%	13.6%	0.8	4.2	0.096	0.40
25 to 34	13.6%	13.5%	1.0	2.9	0.136	0.39
35 to 44	16.3%	14.0%	1.8	8.4	0.163	1.36
45 to 54	13.5%	15.0%	4.2	13.6	0.135	1.84
55 to 64	8.7%	9.5%	8.8	34.2	0.087	2.98
65 to 74	6.6%	4.5%	20.1	48.3	0.066	3.19
75 to 84	4.5%	1.9%	50.1	121.4	0.045	5.44
85+	1.6%	0.4%	129.5	240.9	0.016	3.74
Adult Total						19.34

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

Age-adjusted Rate⁷⁴ = 19.3 per thousand

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 = 2008 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-adjustment⁷⁵ 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 9. See Appendix D for more information on the calculations involved in the direct method of age-adjustment.

The overall adjusted death rate for the DDS population is approximately 19.3 per thousand. The age-adjusted rate is higher than the crude mortality rate of 17.8 per thousand due to the larger proportions of the population in younger age groups, which

⁷³ 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.

⁷⁴ 95% Confidence Interval = (19.36, 19.63)

⁷⁵ 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.

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 crude rate of death was the same between 2007 and 2008 for the DDS population, and the age-adjusted rate of death in 2008 was also similar at 19.3 per thousand, compared to the 2007 rate of 19.4 per thousand.

This age-adjusted mortality rate for the DDS population is higher than the 2007 age-adjusted U.S. overall mortality rate of 8.0 per thousand⁷⁶ and the age-adjusted adult 2007 mortality rate for Massachusetts of 7.0 per thousand⁷⁷. 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.⁷⁸

Gender-specific Age-adjustment within the DDS Population

Differences in age distributions exist between males and females in both the DDS and national populations. In general, the male population served by DDS has a greater percentage of people in younger age groups compared to the females. Because age, a major risk factor for mortality, is not distributed the same way in each gender, it may be informative to examine adjusted mortality statistics where the effects of age and gender have been controlled (or effect caused by any difference is removed).

For the purposes of comparison, the male-specific DDS adult mortality rates and female-specific DDS adult mortality rates from previous years have been adjusted to the 2007 age distribution of females in the DDS population. This means that the mortality rate for males is adjusted to show what it might be if males and females in 2008 had the same age distribution as females in 2007. The year 2007 was chosen because gender-specific age-adjustment was introduced in the series of DDS mortality reports, and continued use of this year allows for comparison with previous reports. Similarly, the past mortality rates for females have been adjusted to the 2007 age distribution of females in the DDS population. By standardizing the male mortality rate and past female mortality rates to the 2007 female age distribution, the expected difference in mortality due to the different age distributions has been removed, allowing for a more direct comparison.

Also, smaller variations in the age distributions within gender are seen year-to-year in the population served by DDS. By standardizing past female mortality rates to the female 2007 age distribution, we can directly compare the gender-specific adjusted mortality rates because we have removed the expected differences due to the different age distributions.

⁷⁶Deaths: Final Data for 2007. National Vital Statistics Reports Volume 58, Number 19, May 2010

⁷⁷ 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.

⁷⁸ 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.

Table 29
Crude Gender-specific
Adult Mortality Rates

Calendar Year	Males	Females
2001	14.3	15.9
2002	14.6	18.4
2003	18.0	20.0
2004	19.0	18.9
2005	17.8	18.1
2006	15.8	17.6
2007	16.9	18.5
2008	16.7	19.0

Table 30
Age-adjusted Gender-specific
Adult Mortality Rates
Standardized to 2007 female population

Calendar Year	Males	Females
2001	18.1	16.5
2002	18.3	18.0
2003	21.4	19.7
2004	22.6	18.9
2005	21.3	17.9
2006	18.5	17.4
2007	19.9	18.5
2008	20.0	18.8

Table 29 displays the unadjusted mortality rates for each gender from 2001-2008. Table 30 shows the adjusted mortality rates, after they were standardized to the age distribution of the 2007 females. In general, the population of females served by DDS is older than the population of males served. Adjustment of the male mortality rates to the female age distribution results in a higher adjusted mortality rate because the older age groups are weighted more heavily in the males.

See Figure 11 graphs the mortality rates by gender and displays the crude mortality rates on the left, and the adjusted mortality rates on the right. In the comparison of crude rates, the female mortality rates generally appear to be higher than the males for most years. However, when age is controlled (or, when the difference in age distributions is removed), the male mortality rates are higher than females. For example, in 2002, there appears to be a moderately sized difference in crude mortality rates between genders. After an adjustment for age, the adjusted rates are very similar. This suggests that the reason for the difference between the gender-specific mortality rates is due to age. In contrast, crude gender-specific mortality rates appear similar in 2004 and 2005. However, the age adjusted mortality rates show much larger differences between genders. For these years, other factors may be contributing to the gender differences.

In 2008, the age-adjusted rates suggest that there may be differences in the mortality rates between genders due to factors other than age. While the crude rate of death for males is lower than females in 2008, the age adjusted rate shows that the mortality rate would be higher for males when the difference in age is removed.

Calculations for the Age-Adjusted 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 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 = total U.S. standard population (all ages combined)

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	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 Diseases ¹	J40-J47
Congenital malformations, deformations, and Chromosomal abnormalities	Q00-Q99
Diabetes Mellitus	E10-E14
Heart Disease	I00-I09, I11, I13, I20-I51
Influenza and Pneumonia	J10-J18
Nephritis	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.



Eunice Kennedy Shriver Center
200 Trapelo Road, Waltham, MA 02452-6319
Tel. (781) 642-0283 Fax. (781) 642-0162
www.umassmed.edu/cdder/ cdder@umassmed.edu