JUNE 2009

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2007 MORTALITY REPORT

COMMONWEALTH OF MASSACHUSETTS

EXECUTIVE OFFICE OF HEALTH & HUMAN SERVICES

DEPARTMENT OF MENTAL RETARDATION

(DEPARTMENT OF DEVELOPMENTAL SERVICES AS OF 7/1/09)

PREPARED BY:

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June, 2009

Dear Colleagues and Friends:

Enclosed is the Department of Mental Retardation Annual Mortality Report (Department of Developmental Services as of July 1, 2009) for calendar year 2007. 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 2007 for all persons 18 years of age or older who have been determined to be eligible for DMR supports. This is the seventh year in which DMR has commissioned an independent review of all deaths.

The report is a significant component of the Department's quality management system and reflects DMR's ongoing commitment to reviewing and learning from critical information gathered regarding individuals within our system. DMR 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, DMR has made significant progress in improving our standardized reporting systems, strengthening our clinical mortality review process and improving the comparability of our data to state and national death statistics. For the first time, the 2007 report provides data regarding the location of a person's death as well as utilization of hospice services for end of life care.

This report is reviewed by the Statewide Mortality Review Committee as well as our Statewide and Regional Quality Councils to assist DMR in its ongoing commitment to supporting the health and quality of life of the individuals we support. I remain committed to the importance o 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 Howe
Commissioner

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

Tables

Figures

EXECUTIVE SUMMARY

The Massachusetts Department of Developmental Services (DDS), through an established process for mortality review and death reporting, reviews the causes and circumstances of the deaths of individuals it supports. Mortality findings are used to inform quality improvement efforts for supports provided by the Department. As part of this process, the University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER) has prepared annual reports on mortality within this population of Massachusetts citizens since the year 2000. This report represents population and mortality information for the period between January and December of 2007.

In the middle of calendar year 2007, the Massachusetts DDS served 32,682 individuals, 23,625 of whom were adults with intellectual disabilities[1] over the age of 18 years. Between June 2006 and June 2007, the DDS mid-year adult consumer population showed an increase of about 2.5%, or 572 people.

For the calendar year of 2007, DDS received death reports for 416 individuals who met the criteria outlined above, representing a crude adult death rate[2] of 17.6 individuals per thousand. The average age at death of adults in the DDS population during 2007 was 62.0 years of age.

Mortality rates vary in the DDS population and are related to a number of key factors. Age is one of the strongest predictors; the lowest death rates are in the younger age groups and the highest death rates are in the elderly populations. Residential settings also show distinct differences in mortality statistics. Individuals requiring the level of care provided in nursing homes have the highest mortality rates and are at the greatest risk for mortality due to advanced age and/or health status. Despite being the smallest residential grouping with about 4% of the adult population served by DDS, about one-fifth (22.1%) of the deaths in the DDS population occur within the DDS nursing home population.

In the 2007 Mortality Report two new sections were added, both of which reflect the enhanced analytic capability from the electronic death record system implemented by DDS in 2006. The first section discusses the place of death for people served by DDS. The second section contains information on hospice use by people who died in 2007, and compares hospice use statistics in the DDS population to other populations. Very little information is publicly available on hospice use for individuals with intellectual disabilities, an important option for those with terminal conditions.

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[1] The term "intellectual disability" is the preferred term in current literature and is used throughout this report. "At the heart of that shift [from "mental retardation"] is the understanding that this term covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability." 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.

Notable findings in 2007 include:

- Consistent with previous years, a proportional relationship exists between the crude mortality rate for the DDS population and advancing age. Mortality rates are lowest in the youngest age groups.

- The overall crude mortality rate for the population served by DDS showed a small increase from the 2006 rate, but is well within the range of past rates observed in the population served by DDS.

- The average age at death for the population served by DDS is similar to previous years. Average age at death was lowest for individuals living in their own home with family (51.6 years) and those in non-DDS settings (52.0 years) and highest for those residing in DDS facilities (71.7 years) and nursing homes (68.6 years).

- While the crude mortality rate for males is generally lower than for females in the population served by DDS, age-adjustment shows that other factors may differentially affect mortality across genders. After adjusting for age, mortality rates for males are higher relative to female mortality rates.

- Twenty-nine percent (29%) of DDS decedents utilized hospice services before their death, compared with 39% of decedents statewide in Massachusetts in 2006.

- 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 (based on most recently released data on hospice use).

- Decedents served by DDS who utilized hospice services were twice as likely to die in their own homes (Table 7), in comparison with the overall proportion of decedents served by DDS (Figure 7).

- Heart disease was the leading cause of death in 2007; the percent of deaths due to heart disease has decreased in 2007 and a relatively smaller portion of deaths are due to heart disease than in the Massachusetts and US populations.

- Cancer is the second leading cause of death for the DDS population, similar to years before 2006 and the Massachusetts and US populations.

- Septicemia is the third leading cause of death in 2007 for the DDS population, with 13% of deaths. The rate of death for this cause increased from a rate of 0.9 per thousand in 2006 to 2.3 per thousand in 2007.

- The rate of deaths due to unintentional injuries increased from a rate of 0.6 per thousand to a rate of 1.1 per thousand in 2007. Most accident-related deaths in 2007 were due to aspiration, followed by falls.

- More mortality-related investigations were conducted during 2007; however, the number of substantiated cases to date did not differ from 2006 levels.

2007 Mortality Report

The Massachusetts Department of Developmental Services (DDS) utilizes a formal process for reviewing and reporting of 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 within this population of Massachusetts citizens since the year 2000. This report represents population and mortality information for the period between January 1 and December 31 of 2007.

Mortality Review in DDS

2007 Mortality Report

This report includes information and data concerning all adults (individuals 18 years old and older) served by DDS who were listed in the Meditech Consumer System and who died during the 2007 calendar year. The data includes individuals, therefore, who do not always meet the specific criteria for formal review by the DDS Mortality Review Committee (see below).

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 page 41 for a more detailed description of the mortality review process.

DEPARTMENTAL NAME CHANGE

Effective July 1, 2009, the Massachusetts Department of Mental Retardation (DMR) will change 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. In anticipation of this name change, this report will use the new departmental name and abbreviation.

TRANSITION TO INTEGRATED ELECTRONIC QUALITY ASSURANCE DATA SYSTEM

In 2000, DDS began a strategic planning process to enhance the services provided to individuals with intellectual disabilities. One of the goals of this process was to develop an effective quality management system.

In 2002, DDS started the development of its DDS Information System (DDSIS). The initial phase concerned the development of the Meditech system, which is an internal system to DDS. Meditech is the system of record for all individuals eligible for DDS services. Components include the eligibility process, individual demographic information, notes, assessments, services and programs, risk management, contract information, and the individual service planning process. The goal of the DDSIS design is an integrated system that facilitates the management of information in key areas in a way that affords consistency across the state, expedites communication and processes and increases overall service effectiveness.

Continued Impact of System Upgrades

Prior to implementation of the Home and Community Services Information Systems (HCSIS) module of the DDSIS, the DDS's mortality reporting system utilized a stand-alone database where information was entered and tracked electronically. This database was not linked to other quality management components. With the use of the DDSIS system starting in June 2006, all deaths are now reported through the HCSIS module by each DDS Area Office and are reviewed at the Central Office level.

While the implementation of the new DDSIS system added a number of improvements into the death reporting process, some transitional data issues continue to affect the demographic data used to classify 2007 death reporting. The data integrity issues are limited to mismatches between a data field that describes a consumer's current living situation and program enrollment data that records the dates of a person's enrollment in a particular residential service. The program service enrollment data is normally used to verify a person's residential situation as the enrollment status is tied to service billing. A small portion of consumers in the mid-year of 2007 had a living situation listed, but did not have any enrollment for that period in a program. CDDER worked closely with the DDSIS team to understand the possible reasons for this mismatch, and has worked to approximate the living situation for these consumers. Footnotes will be used to specify how many consumers were classified in each living arrangement that did not have corresponding program enrollment data to verify this residential situation.

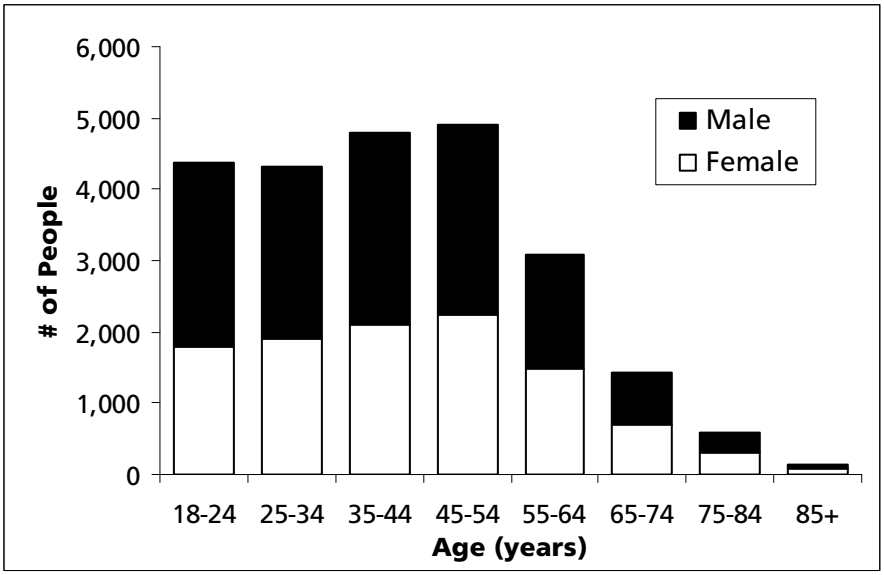
OVERVIEW OF POPULATION SERVED BY DDS

In the middle of calendar year 2007, the Massachusetts DDS served 32,682 individuals, 23,625 of whom were adults with intellectual disabilities over the age of 18 years. The mid-year population (June) is used to model the average population across the entire year, since the population served by DDS tends to increase as the year progresses. An increase of about 2.5%, or 572 people, was seen in the mid-year adult consumer population from June 2006 to June 2007. 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

Figure 1 displays the age distribution for the DDS population. The age groups between 18 and 54 years are of similar size. Age groups beyond this age decrease in size with increasing age.

Figure 1
Distribution of the Population Served by DDS by Age and Gender, 2007



2007 DDS Population (Figure 1, continued)

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1,808	1,904	2,113	2,242	1,472	693	313	87	**10,632**
Male	2,569	2,424	2,669	2,667	1,603	726	288	47	**12,993**
Total	4,377	4,328	4,782	4,909	3,075	1,419	601	134	**23,625**

The increase of 2.5% in the 2007 adult DDS population is larger than the 0.9% increase between 2005 and 2006. Table 1 shows the gross population change within each age

group. Deaths in each age group are taken into account when calculating the gross annual change.[3] Relative to the 2006 population, age groups of 65 - 84 years showed the largest increases. In contrast, the 35-44 age group showed a decrease of 2.8% for at least the second consecutive year. A much larger relative increase is shown in the 18-24 year old age group than in past years: between 2005 and 2006 this age group showed a 0.9% increase, whereas a 6.1% increase is seen between 2006 and 2007.

The adult population as a whole continues to age, driven by the relative increase of the "baby-boomer" population through the 55-64 age group and moving through to the 65-74 year old group.[4,5] Similar aging trends have been cited by other MR/DD agencies in the northeastern states.[6]

Table 1
Annual DDS Population Change within Age Group
A Comparison of 2006 and 2007

	Gross Population Fluctuation[7]		
Age Group	Individuals	% Change within Age Group	Resulting % Change in Overall DDS Consumer Population from 2006
18-24	253	6.1%	1.1%
25-34	122	2.9%	0.5%
35-44	-140	-2.8%	-0.6%
45-54	261	5.5%	1.1%
55-64	222	7.6%	1.0%
65-74	164	12.2%	0.7%
75-84	55	9.1%	0.2%
85-94	18	0.1%	0.1%
Total	955		4.1%

[3] The net increase in the DDS population was 572 individuals in 2007, while the gross population increase was 955 individuals. The gross population increase accounts for the people that died in the population, while the net difference only shows differences in the total population numbers without accounting for those that left the population due to death.

[4] Before the Boom: Trends in Long-Term Supportive Services for Older Americans with Disabilities, October 2002, Public Policy Institute, AARP.

[5] U.S. Census Bureau, Census 2000 Summary file 1; 1990 Census Population, General Population Characteristics, United States (1990 CP-1-1).

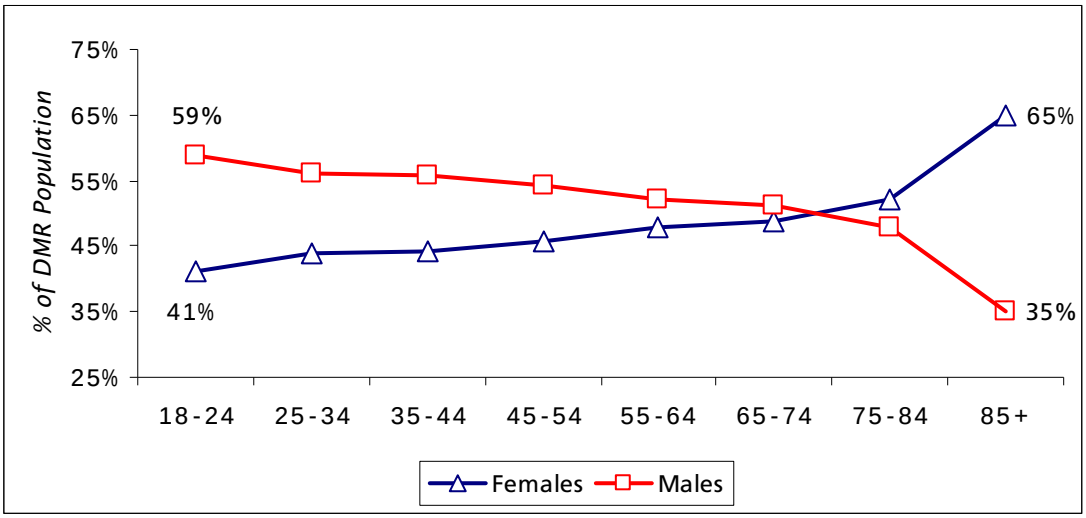
[6] State of Connecticut Department of Mental Retardation. *Aging Focus Team Report and Recommendations*, October 2003.

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

Gender Characteristics

The gender distribution in the 2007 adult DDS population is very similar to 2006 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. The gender proportions begin to equalize by age 55 and then steeply move toward a female majority starting at age 75. The shift in gender distributions in the elderly population is consistent with reports from other states.[8]

Figure 2
Gender Distribution by Age, Adults Served by DDS 2007



Residential Setting Characteristics

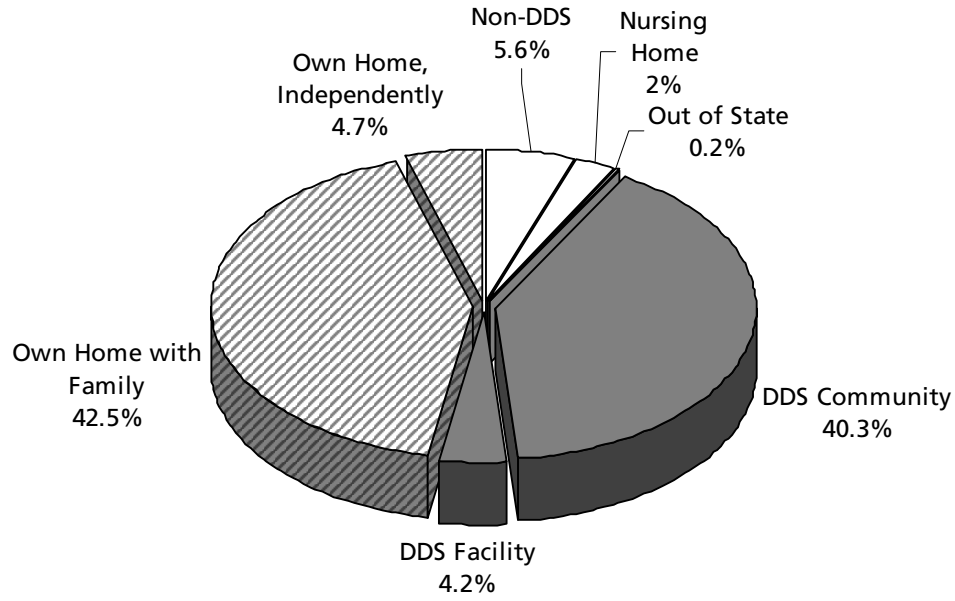
Adults receiving services from DDS reside in a variety of different residential settings. Many individuals live independently in their own homes or with their family, while others may receive residential supports directly from DDS or from another state agency. In this report, the various DDS residential 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. Individuals living in their own home are counted in one of two categories: those living independently and those living with their family. The sections representing people living in their own home are shown in grey stripes, and together represent 46.8% of the adult population served by DDS.

Residential programs operated, licensed/ certified or funded by DDS are shown in the sections shaded in solid grey, and provide residential services to almost half of the individuals served by DDS.

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,

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

Figure 3
Where People Live
(Adult population served by DDS, 2007)



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). [9]

[9] As mentioned in the introduction, data integrity issues existed for 2007 population data in that there were mismatches between a data field that describes a consumer's current living situation and program enrollment data that records the dates of a person's enrollment in a particular residential service. CDDER worked closely with the DDSIS team to approximate the living situation for these consumers. The following numbers of consumers were assigned to the following residential groups based upon historic placements and other information: DDS Community=609, DDS Facility=2, Non-DDS=336, Nursing Home=190, Out of State=51, Own Home Living with Family=267, Own Home Living Independently=14.

MORTALITY DURING 2007

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 determined to be eligible for DDS services and supports during calendar year 2007. Appendix A contains a detailed description of the methodology used to collect and analyze the information and data contained in this section.

For calendar year 2007, DDS received death reports for **416 individuals** who met the criteria outlined above, representing a crude adult mortality rate[10] of **17.6 individuals per thousand**.[11] The average age at death of adults in the DDS population during 2007 was **62.0 years of age**. The median age at death, or the middle age if all deaths were ranked by age, of adults in the DDS population during 2007 was **62.5 years of age.** Mortality statistics in 2007 show a slight increase since 2006 in both the number of individuals who died, and the rate of death for the population.

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. A proportional relationship exists between the crude mortality rate and advancing age. Mortality rates are lowest in the youngest age groups. Each ten-year age group between 45 and 85 represents approximately one-fifth of deaths.

Table 2
Distribution of Deaths by Age Group, 2007

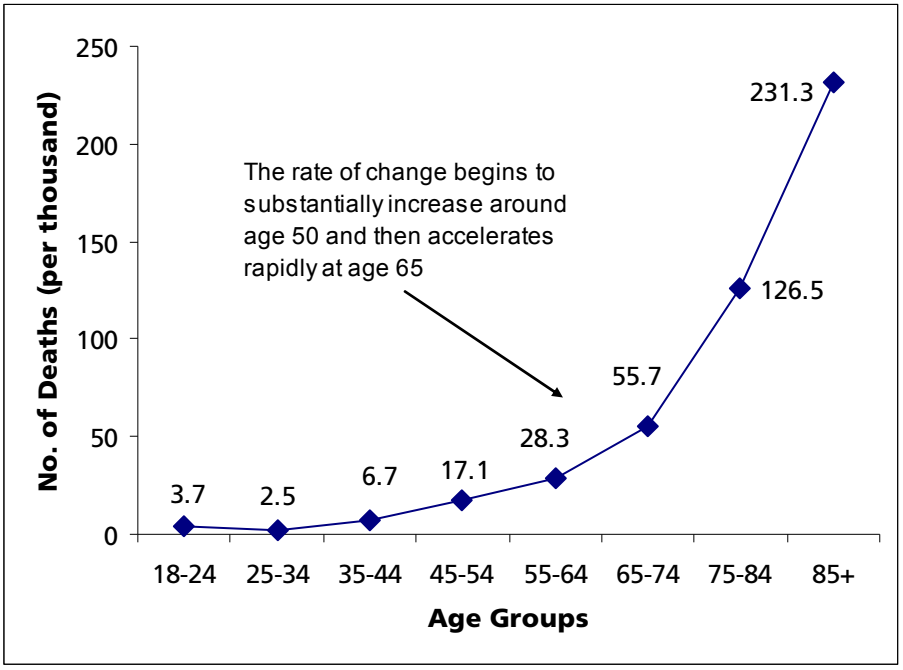
Age Range	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)
18-24 yrs	16	3.8%	3.7
25-34 yrs	11	2.6%	2.5
35-44 yrs	32	7.7%	6.7
45-54 yrs	84	20.2%	17.1
55-64 yrs	87	20.9%	28.3
65-74 yrs	79	19.0%	55.7
75-84 yrs	76	18.3%	126.5
85 yrs & older	31	7.5%	231.3
Total	**416**	**100%**	**17.6**

[10] 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.

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

The 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. 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 increase more sharply, reflecting the expected increase in risk of mortality for adults of advanced age.

Figure 4
Mortality Rate by Age Group
Adults Served in 2007



Gender

Because gender proportions vary with age in the population served by DDS, there is a complex relationship between gender and mortality. Table 3 displays the number of deaths, percent of overall deaths, average age at death and rate of death for each gender. Consistent with previous years, the number of deaths of males was greater than of females. 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.

Table 3
No. Deaths, Average Age at Death and Death Rate by Gender, 2007

Gender	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	197	47.4%	64.2	18.5
Male	219	52.6%	60.0	16.9

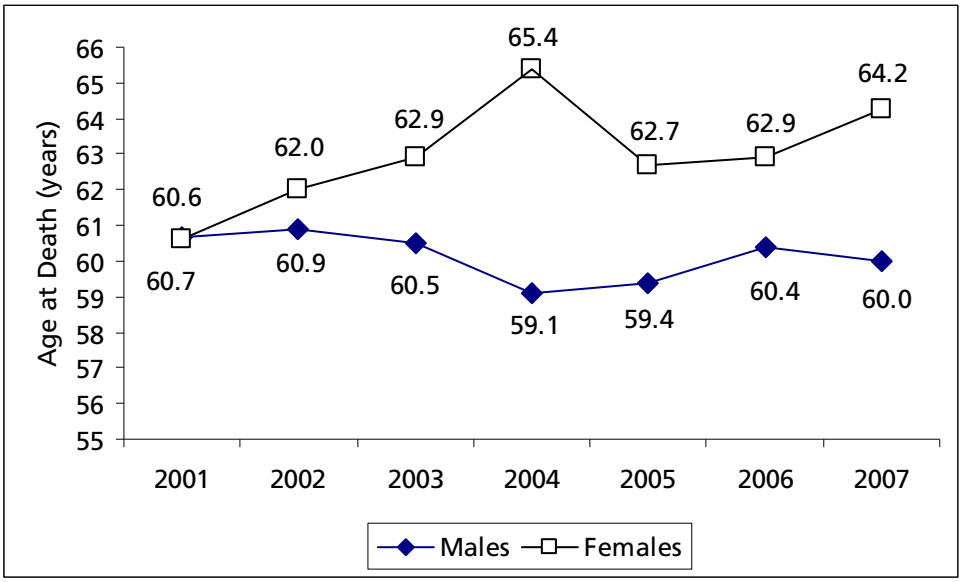
Because the age distribution within each gender differs, crude mortality rates should not be directly compared between genders in the DDS population. Males represent a higher proportion of consumers in younger age groups compared to females. Gender-specific, age-adjusted mortality rates have been calculated for 2001-2007, 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 2001-2007

	Age at Death (years)	
Calendar Year[12]	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

Table 4 shows the average age at death for each gender from 2001 to 2007. The DDS population shows significant differences in average age at death between genders.[12] 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, 2001-2007



[12] One-tailed t-test with equal variance and hypothesized mean difference of zero. (T=2.56, df=413 p=0.005).
[13] 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 the 2007 report, the "own home" category is now separated by those that live independently (Own Home, Independently) and those that live with family (Own Home with Family). In addition, a small proportion of the population (0.2%) is made up of Ricci class members residing outside of the Commonwealth of Massachusetts. 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, 2007

Residential Setting	Adult Population[14] (No. People)	Percent of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home, Independently	1,102	12%	9	2.2%	**61.9**	**8.2**
Own Home with Family	10,033	3%	60	14.4%	**51.6**	**6.0**
DDS Community	9,511	11%	180	43.3%	**60.5**	**18.9**
Non-DDS	1,329	11%	22	5.3%	**52.0**	**16.5**
DDS Facility	984	26%	53	12.7%	**71.7**	**53.9**
Nursing Home	615	45%	92	22.1%	**68.6**	**149.6**
Out of State	51	16%	0	0.0%	**N/A**	**0.0**
Total (Statewide)	23,625	9%	416	100%		
Average					**62.0**	**17.6**

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

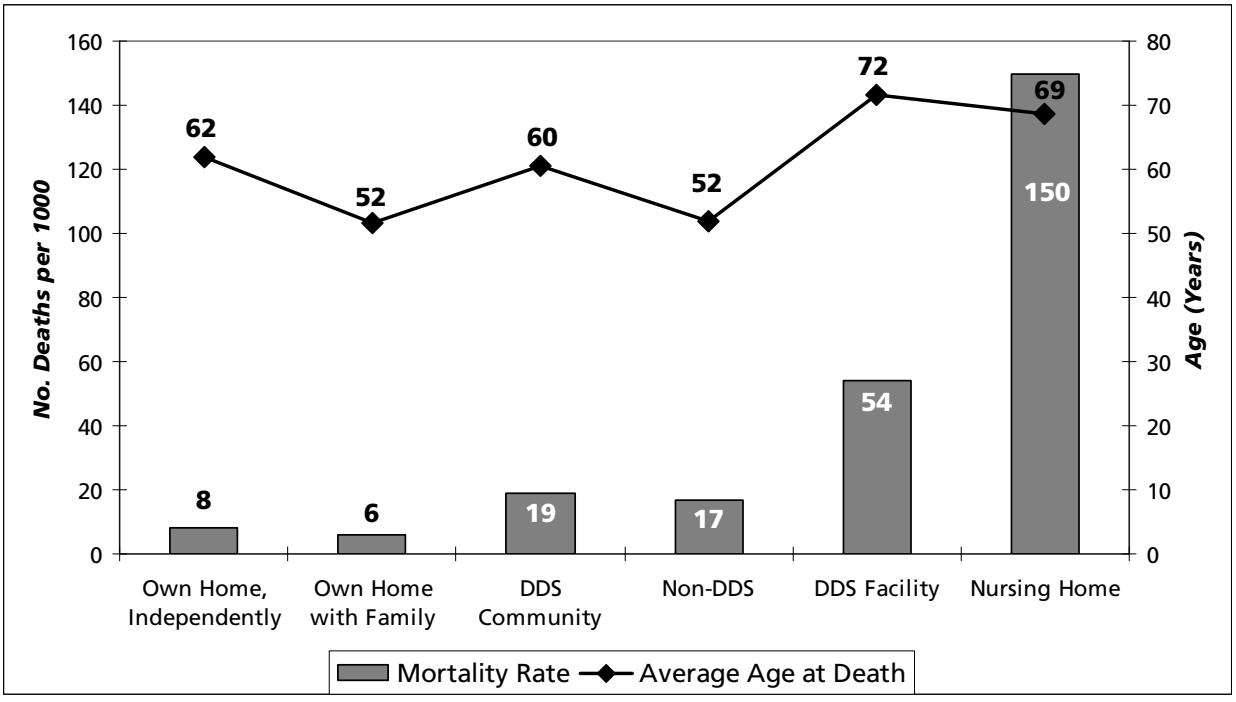
[14] As mentioned in the introduction, data integrity issues existed for 2007 population data in that there were mismatches between a data field that describes a consumer's current living situation and program enrollment data that records the dates of a person's enrollment in a particular residential service. CDDER worked closely with the DDSIS team to approximate the living situation for these consumers. The following numbers of consumers were assigned to the following residential groups based upon historic placements and other information: DDS Community=609, DDS Facility=2, Non-DDS=336, Nursing Home=190, Out of State=51, Own Home Living with Family=267, Own Home Living Independently=14.

for individuals living in their own home with family (51.6 years) and those in non-DDS settings (52.0 years) and highest for those residing in DDS facilities (71.7 years) and nursing homes (68.6 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 2007 continued to follow this pattern.

Individuals residing in nursing homes experienced the highest rate of death in 2007, 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.[15] This is because the average population age and health tends to vary by type of residential setting.[16] 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, 2007



Own Home

Individuals served by DDS living independently in their own home or with family had the lowest mortality rates in 2007, similar to previous years. In the 2007 report, the

[15] State of Connecticut. *Mortality Annual Report,* July 2007.

[16] 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.

own home residential category was split into those living independently and those living at home with family. This change was made because differences exist, on average, between these groups in age and other possible factors relevant to mortality statistics, such as health-related service needs and the ability to care for oneself independently.

The crude rate of death for those living independently in their own home was 8.2 per thousand in 2007. The crude rate of death for those living in their own home with family was 6.0 per thousand. Combined, the crude death rate was 6.2 per thousand for both groups, which is not significantly different from the 2006 crude death rate for this group.[17] The crude mortality rates for people living with family is lower than both the crude mortality rate of 8.3 per thousand and the age-adjusted rate of 7.2 per thousand for the general population in Massachusetts.[18] (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 at home with their family is the youngest on average of all residential subgroups and has the smallest percentage of individuals over the age of 65. Similarly, this group also had one of the youngest average ages at death of any residential subgroup.

DDS Community

The DDS Community is typically the most diverse residential subgroup in terms of both age and level of service need. This residential setting supports the second-largest residential subpopulation of DDS consumers in Massachusetts, after the group of individuals living independently in their own homes. The mortality rate for individuals served by DDS living in the DDS Community in 2007 was 18.9 per thousand. This rate has not changed significantly from 2006.[19]

Other Residential Settings

The remaining three residential settings, Non-DDS settings, DDS Facilities and Nursing Homes, represent in total less than 13% of the entire DDS population. It is important to note that such small population numbers can result in large annual fluctuations in the rate of death when compared by residential setting. Changes in rate should therefore be interpreted with caution.

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. The ages of people living in Non-DDS residences tend to cover a wide range of ages, with about one-third of the residents between the ages of 18-24, while the remainder falls within older age groups. Twenty-two (22) individuals served by DDS living in Non-DDS residences died in 2007, resulting in a crude mortality rate of 16.5 per thousand. No significant change in the mortality rate was seen from 2006.[20]

[17] Z-test between proportions of residential-specific deaths and populations, z = 0.076
[18] *Massachusetts Deaths 2006.* Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, April 2008.
[19] Z-test between proportions of residential-specific deaths and populations, z = 0.895
[20] Z-test between proportions of residential-specific deaths and populations, z = 0.002

DDS Facilities. DDS facilities serve an aging population that is decreasing in size, with the majority of residents over the age of 45 years. Because the risk of death increases with age, the age composition of the population in this residential setting is likely to cause it to experience a higher rate of death than other settings. It is also important to note that while the population served by DDS increased by 2.4% between 2006 and 2007, the size of the population living in DMR facilities decreased by 5.4%. In 2007, the mortality rate for individuals living in DDS facilities was 53.9 per thousand, a non-significant[21] change since 2006. The average age at death for individuals residing in DDS facilities increased to 71.7 years from the average of 64.9 years in 2006.

Nursing Homes. The population of individuals served by DDS living in nursing homes is, on average, the oldest of all the residential subpopulations. Forty-five percent (45%) of people served by DDS who live in nursing homes are age 65 or older. Between 2006 and 2007, the population served by DDS living in nursing homes showed a net decrease of 16%. As mentioned earlier, this is in contrast to the 2.5% increase in the total DDS population over the same time period.

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

Age Group	Rate of Death (per thousand)	
	US 2004[22] (estimated)	DDS 2007
65+	410.2	227.6
85+	397.6	230.8
Total	**363.5**	**149.6**

The 2007 crude mortality rate of 149.6 per thousand did not change significantly[23] from the 2006 rate. 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 (358.7 per thousand) in 2006[24] and U.S. nursing

[21] Z-test between proportions of residential-specific deaths and populations, z = 1.213

[22] 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, 2004, June 06, 2007, National Center for Health Statistics. 2004 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.

[23] Z-test between proportions of residential-specific deaths and populations, z = 0.822

[24] Approximate 2006 Crude Rate of Death in Massachusetts Nursing Homes calculated from a population in 2007 of 45,172 living in MA Nursing Homes (from *Across the States: Profiles of Long Term Care: Massachusetts, 2009,* Public Policy Institute, AARP) and a total number of 16,205 deaths in MA Nursing Homes from (*Massachusetts Deaths 2005,* Bureau of Health Statistics, Research and Evaluation Massachusetts Department of Public Health).

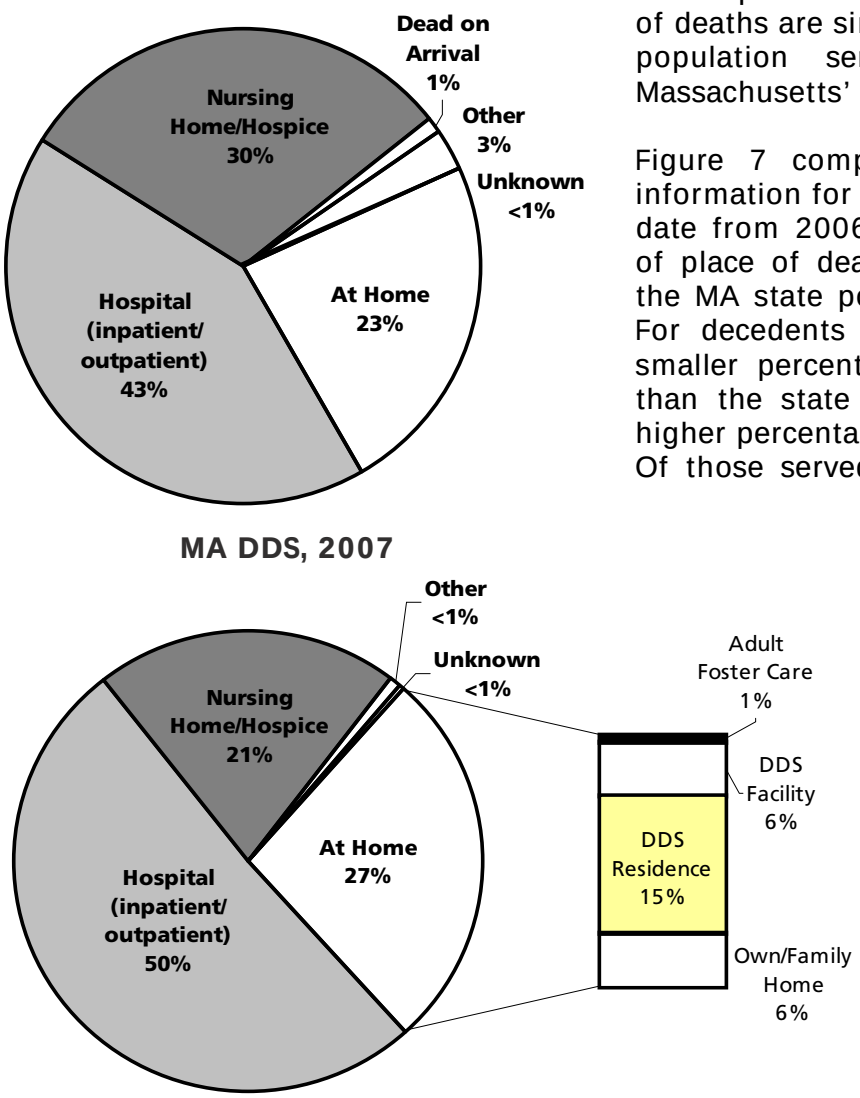
homes in 2004 (363.5 per thousand). Rate of death by age for both the MA DDS and the US population are shown in Table 6.[25]

Place of Death

The transition to the electronic data system has allowed for better aggregation of certain data fields that were previously not analyzed. For the first time in the series of DDS mortality reports, place of death data will be presented. The relative percentages of deaths are similar across settings for the population served by DDS and the Massachusetts' general population.

Figure 7 compares the place of death information for the MA DDS to the MA state date from 2006. The relative distribution of place of death is very similar between the MA state population and the MA DDS. For decedents served by DDS, a slightly smaller percentage die in nursing homes than the state population, and a slightly higher percentage die in hospital settings. Of those served by DDS that die in their own home, about half live in DDS-funded residences, about one quarter live in their own home independently or with their family, and about one quarter live in a DDS facility.

Figure 7
Comparison of Place of Death in MA State and MA DDS Populations



[25] 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, 2004, June 06, 2007, National Center for Health Statistics. 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.

Hospice

Background

A new section has been added to the 2007 DDS mortality report on hospice care. This section has been added to quantify the use of hospice care among decedents in the population served by DDS. System improvements on data collection within the new DDSIS system have allowed the aggregation and reporting of this service utilization.

Hospice draws 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. Recent efforts to find information on the use of hospice services on a population-level by people with intellectual disabilities yielded no results.

The majority of people served by DDS are dually eligible for Medicaid and Medicare benefits. 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.

Hospice is an important care option for the terminally ill patients 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.[26] 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."[26]

This section on hospice care has been added to provide more information on 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.

More education about the availability and use of hospice services is needed. In a 2005 survey on end of life care of Massachusetts residents age 35 and older, the Massachusetts Commission on End of Life Care found that "only 6 percent of survey respondents have never heard of hospice, and 55 percent report they have heard a lot about hospice, yet only 33 percent are aware that Medicare & Medicaid pay for hospice services."[27]

[26] 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.

[27] The Massachusetts Commission on End of Life Care, End-of-Life Care Survey, published September 2005.

Findings

In 2007, 121 people, or 29% of DDS decedents, utilized hospice services before their death, as shown in Figure 8. For 4% of the DDS population, it is not known whether hospice services were utilized. 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 approximately 38.8% {930.000 / 2,400,000} of all deaths in the United States were under the care of a hospice program.[28]

Figure 8
Percentage of Decedents Who Utilized Hospice Services

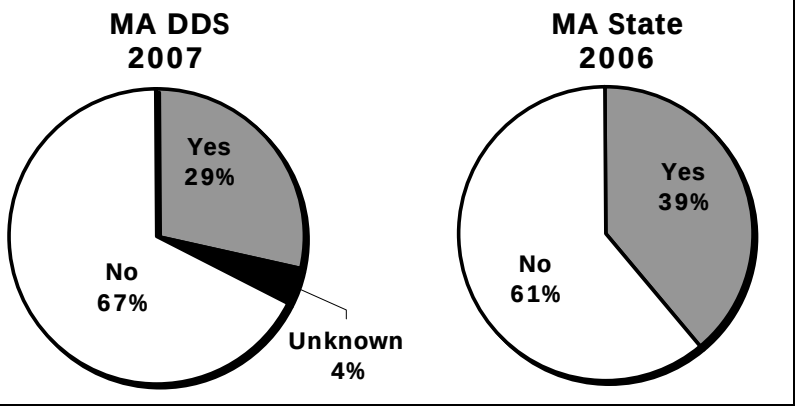


Figure 9 shows the percentage by gender of people served by DDS who died in 2007 and used hospice services before their death. The relative portion of consumers who used hospice services is similar across gender in the DDS population.

Figure 9
Percent by Gender of 2007 Decedents Served by DDS Who Used Hospice

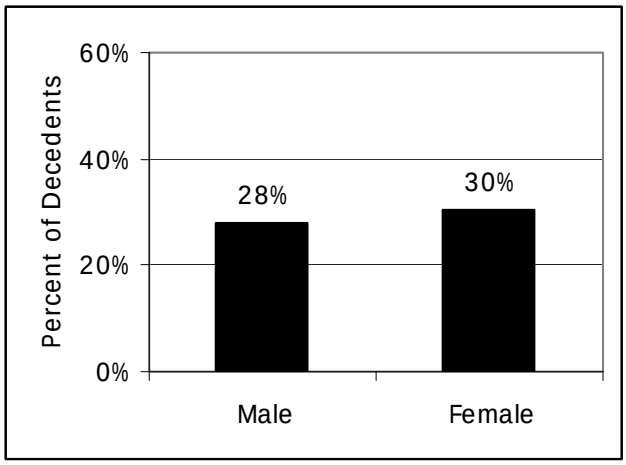


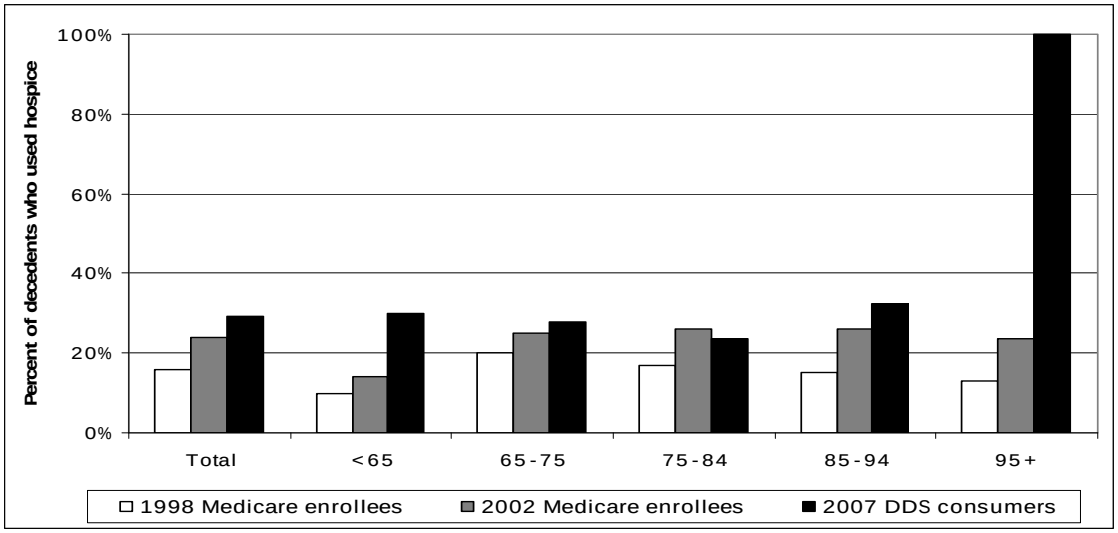
Figure 10 examines the percentage of decedents in each age group that utilized hospice services. In general, the use of hospice services has increased in the national population of Medicare enrollees over time. The most recently released data on hospice use (2002) is shown in Figure 10 for Medicare enrollees; 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.

[28] NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, October 2008.

Because this information is not known, the comparisons of use must be viewed with caution.

Figure 10
Percent of Decedents by Age Group Who Used Hospice: National Medicare Enrollees[29] and DDS Consumers



The percent of decedents using hospice services is similar between national Medicare enrollees and those served by DDS for those aged 75 to 94 years. The use rate was 100% for the two decedents that were age 95 and above in the population served by DDS.

Table 7
Location of Death, 2007 Hospice Patients

United States[30]			MA DDS	
Patient's Place of Residence	70%		Patient's Place of Residence	85%
Private Residence	*42%*		Own Home or DMR Residence	*47%*
Nursing Facility	*23%*		Nursing Home	*28%*
Residential Facility	*6%*		DMR Facility	*10%*
Hospice Inpatient Facility	19%		Hospice Inpatient Facility	0%
Acute Care Hospital	11%		Acute Care Hospital	12%
			Other	20%
Total	100%		Total	100%

Table 7 compares the location of death for 2007 decedents using hospice between those served by the DDS population and the general population of the United States. Of hospice users served by DDS that died in their own home, almost half were living in their own home or a DDS residence. A higher percentage of hospice users in the DDS

[29] 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.

[30] NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, October 2008. Table 1: Location of Death

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.

In comparison with the place of death for all 2007 decedents in the DDS population presented in Figure 7, the proportion of people dying in their own homes was twice as high for hospice users. Only 12% of hospice users died in an acute care setting, compared with 50% who died in this setting in the entire group of DDS deaths. These comparisons show that the hospice efforts to provide supports in the person's home until their death were generally successful.

When the option of hospice was created, 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.[31] 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."[31]

Table 8
Primary Diagnoses for Hospice Users

	National 2007[32] Admissions	DDS 2007 Deaths
Cancer (malignancies)	**41.3%**	**29.8%**
Non-Cancer Diagnoses	**58.7%**	**70.2%**
Heart Disease	11.8%	11.6%
Debility Unspecified	11.2%	0.0%
Dementia, including Alzheimer's Disease	10.1%	27.3%
Lung Disease, including COPD/CLRD	7.9%	3.3%
Stroke or Coma	3.8%	<1%
Kidney Disease, including End Stage Renal Disease	2.6%	<1%
Motor Neuron Diseases, including ALS	2.3%	<1%
Liver Disease	2.0%	0.0%
HIV / AIDS	0.6%	0.0%
Other Diagnoses	6.5%	6.6%
Total	**100%**	**100%**

Table 8 shows the terminal diagnoses for hospice admissions nationally in 2007, and for hospice users served by DDS that died in 2007. It is important to note that these two groups are slightly different, and the relative percentages of terminal diagnoses in hospice admissions for those served by DDS may differ from the relative percentages for those that were using hospice and died in 2007. Because any differences between

[31] 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.

[32] NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, October 2008. Table 6: Percentage of Hospice Admissions by Primary Diagnosis

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.

A larger proportion of hospice decedents in the population served by DDS had non-cancer diagnoses than in 2007 admissions nationally. Of these non-cancer diagnoses, the incidence of a primary terminal condition of dementia or Alzheimer's Disease was almost three times as higher in the hospice decedents served by DDS. This may be related to the higher incidence, earlier onset, and more rapid progression of Alzheimer's Disease in people with Down's Syndrome.

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, this report (2007 DDS Mortality Report) includes an *age-adjusted rate of death* 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).

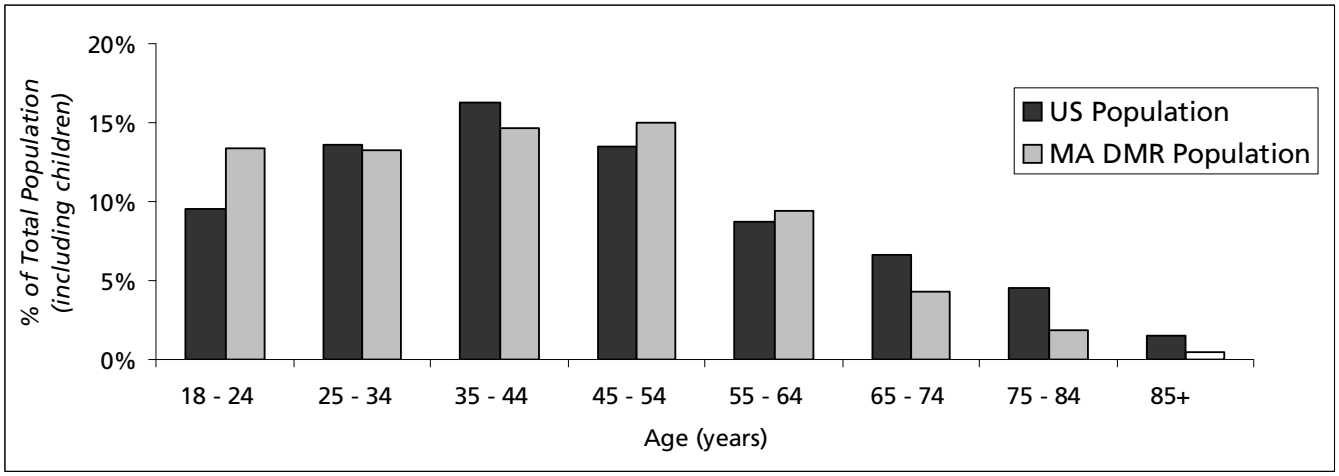
As a standard practice, federal and state mortality reports typically perform age-adjustment using an estimate of the 2000 U.S. population called the "U.S. Standard Population." This population estimate is also used as the basis for age-adjustment in this section of the report.

Comparison of the MA DDS 2007 & 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 11 displays the relative percentage of the U.S. population and the MA DDS

Figure 11
Comparison of MA DDS and U.S. Standard Populations
Percentage of Population by Age Group



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 9
Age-adjusted Mortality Rates

Age Group	% population in age group US	% population in age group DDS	US 2005 Age-Specific Rate of Death[33] (per thousand)	DDS 2007 rate of death (per thousand)	Weight	Weighted Rate (per thousand)
18 to 24	9.6%	13.4%	0.81	3.7	0.096	0.35
25 to 34	13.6%	13.2%	1.04	2.5	0.136	0.34
35 to 44	16.3%	14.6%	1.93	6.7	0.163	1.09
45 to 54	13.5%	15.0%	4.32	17.1	0.135	2.31
55 to 64	8.7%	9.4%	9.07	28.3	0.087	2.47
65 to 74	6.6%	4.3%	21.4	55.7	0.066	3.68
75 to 84	4.5%	1.8%	52.6	126.5	0.045	5.67
85+	1.6%	0.4%	138.0	231.3	0.016	3.59
Adult Total						19.49

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

Age-adjusted Rate[34] = 19.5 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 = 2007 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-adjustment[35] 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

[33] National Vital Statistics Reports, Vol. 56, No. 10, April 24, 2008. Table 9. Death rates by age, and age-adjusted death rates for the 15 leading causes of death in 2005: United States, 1999–2005.

[34] 95% Confidence Interval = (19.36, 19.63)

[35] 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.

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 19.5 per thousand. The age-adjusted rate is higher than the crude mortality rate of 17.6 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 2006 age-adjusted U.S. overall mortality rate of 7.8 per thousand[36] and the age-adjusted adult 2006 mortality rate for Massachusetts of 7.1 per thousand[37]. 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.[38]

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 greater percentages 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 had the same age distribution as females in 2007. Similarly, the past mortality rates for females have been adjusted to the current age distribution of females in the DDS population. By standardizing the male mortality rate and past female mortality rates to the current 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

[36] National Vital Statistics Reports, Vol. 56, No. 16, June 11, 2008. *Deaths: Preliminary Data for 2006..* Table A. Deaths, age-adjusted death rates, and life expectancy at birth, by race and sex, and infant deaths and mortality rates, by race: United States, final 2005 and preliminary 2006.

[37] Estimate of adult age-adjusted rate from populations and number of deaths per age group presented in the 2006 Massachusetts Mortality Report. Also, "adult" defined as 15 years +, as a 15-24 year old age group is presented in the report.

[38] 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.

mortality rates because we have removed the expected differences due to the different age distributions.

Table 10 displays the un-adjusted mortality rates for each gender from 2001-2007. Table 11 shows the adjusted mortality rates, after they were standardized to the age distribution of the 2007 females.

Table 10
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

Table 11
Age-adjusted Gender-specific Adult Mortality Rates

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

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.

Figure 12
Comparison of Crude and Adjusted Gender-specific Adult Mortality Rates

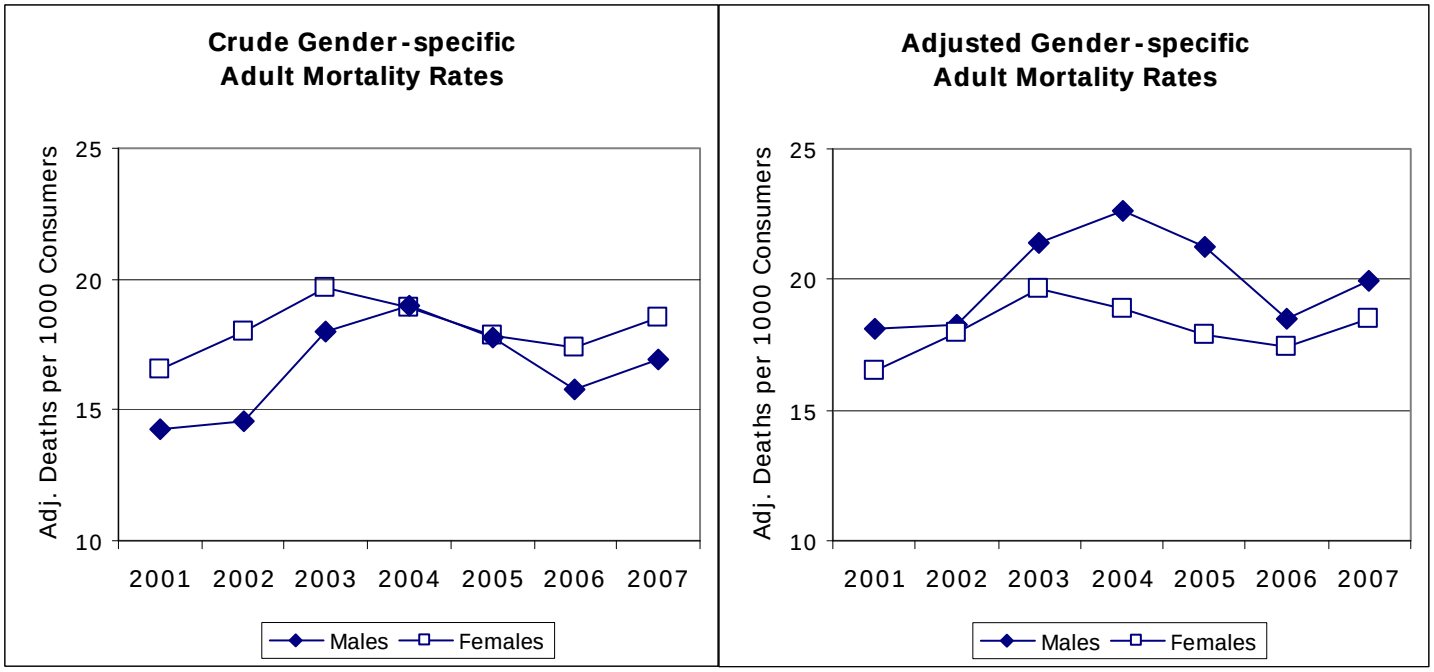


Figure 12 graphs the mortality rates by gender and displays the crude mortality rates on the left, and the adjusted mortality rates on the right. In the comparison of crude rates, the female mortality rates generally appear to be higher than the males for most years. However, when age is controlled (or, 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 2007, 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 2007, the age adjusted rate shows that the mortality rate would be higher for males when the difference in age is removed.

TRENDS OVER TIME

Mortality Rate

In comparison with calendar year 2006, the number of deaths and mortality rate for those served by DDS increased slightly in 2007. 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 12 and illustrated in Figure 13. The average age of death remains similar to previous years.

Table 12
Mortality Trends in DDS[39], 2000 - 2007

Year	No. Deaths	Mortality Rate[40] (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

Figure 13[40]
Statewide Mortality Rates, 2000-2007
(Deaths per 1000)

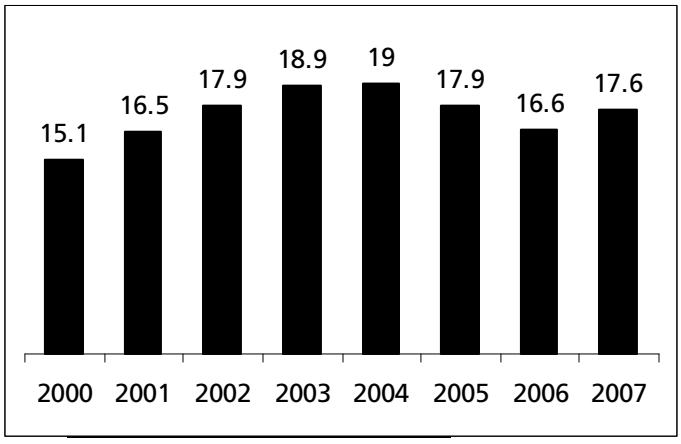
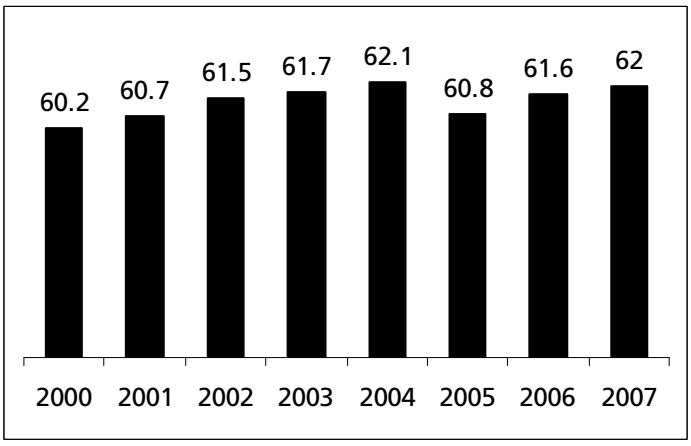


Figure 14
Average Age at Death per Year 2000-2007



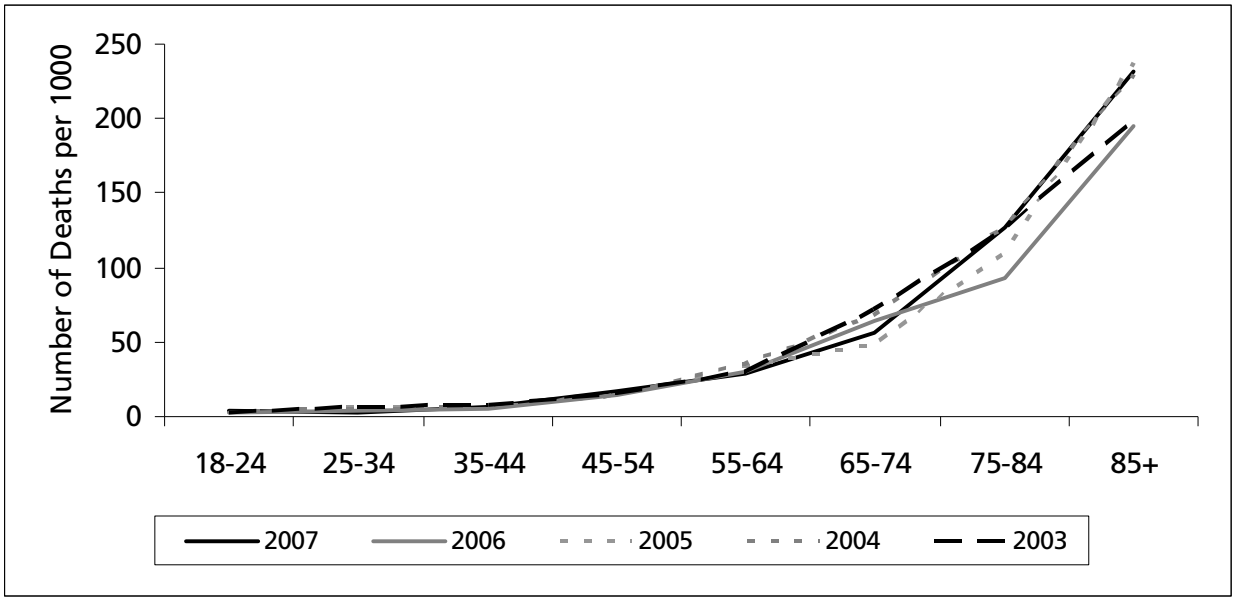
[39] Rates for 2000-2002 have been adjusted by using the current methodology (adopted in the 2003 mortality report) to calculate the overall client population (denominator for calculating rates). The number of deaths was unchanged (numerator). These adjusted rates are provided to increase the validity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

[40] 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.

Average age at death, as presented in Figure 14, is similar to past years.

Mortality rates for each age group are displayed in Figure 15 for the past five 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.

Figure 15[40]
Comparison of Mortality Rate by Age Group Over Time, 2003-2007



CAUSES OF DEATH

The following section presents information about the causes of death for adults served by the Massachusetts DDS during 2007. 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 (either a paper or an electronic system, as described on page 6) 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.[41] [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 reports 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."*[42]

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 MR/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 2007 are compared with data from five previous years and with state and national data in Table 13. Table 14 displays cause-specific mortality rates for the major causes of death in the DDS population for the seven year time period between 2002-2007.[43,44]

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

[42] 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.

[43] Cause-specific mortality rates are unavailable for 2000.

[44] 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 13
Top 10 Leading Causes of Death

Rank	U.S. 2004[45]	MA 2005[46]	DDS 2002	DDS 2003	DDS 2004	DDS 2005	DDS 2006	DDS 2007
1	Heart Disease *27.2%*	Heart Disease *24.6%*	Heart Disease *21.2%*	Heart Disease *22.3%*	Heart Disease *18.5%*	Heart Disease *16.4%*	Heart Disease 21.9%	Heart Disease 16.8%
2	Cancer *23.1%*	Cancer *24.5%*	Aspiration Pneumonia *12.3%*	Cancer *13.5%*	Cancer *12.5%*	Cancer *12.0%*	Alzheimer's Disease 14.4%	Cancer 13.7%
3	Stroke *6.3%*	Stroke *5.5%*	Cancer & Septicemia[47] *10.1%*	Aspiration Pneumonia *12.3%*	Aspiration Pneumonia *11.2%*	Influenza and Pneumonia *10.8%* C-P Arrest/ Seizure *10.8%*	Cancer 9.9%	Septicemia 13.0%
4	CLRD *5.1%*	CLRD *4.9%*	C-P Arrest/ Seizure[48] *9.4%*	Septicemia *9.0%*	Influenza and Pneumonia *10.9%*		Aspiration Pneumonia 8.4%	Alzheimer's Disease 11.3%
5	Unintentional Injuries *4.75%*	Influenza and Pneumonia *3.6%*	Alzheimer's Disease *7.2%*	C-P Arrest/ Seizure[48] *7.2%*	Alzheimer's *7.5%*	Aspiration Pneumonia *9.3%*	CLRD 5.7%	Aspiration Pneumonia 10.6%
6	Diabetes *3.1%*	Unintentional Injuries *3.5%*	CLRD *6.2%*	CLRD *6.0%*	C-P Arrest/ Seizure[48] *6.8%*	Alzheimer's Disease *8.6%*	C-P Arrest/ Seizure[48] 5.5%	Unintentional Injuries 6.5%
7	Alzheimer's Disease *2.8%*	Alzheimer's Disease *3.0%*	Influenza and Pneumonia *4.7%*	Alzheimer's Disease *5.3%*	Septicemia *6.6%*	Septicemia *5.9%*	Stroke 5.2% Septicemia 5.2%	C-P Arrest/ Seizure 3.6%
8	Influenza and Pneumonia *2.5%*	Nephritis *2.6%*	Nephritis *4.0%*	Influenza and Pneumonia *4.6%*	CLRD *5.7%*	CLRD *4.6%*		Influenza and Pneumonia 3.4%
9	Nephritis *1.8%*	Diabetes *2.4%*	Stroke *3.5%*	Stroke *4.2%*	Nephritis *3.6%* Stroke *3.6%*	Stroke *4.2%*	Influenza and Pneumonia 3.9%	Stroke 2.9%
10	Septicemia *1.4%*	Septicemia *1.8%*	Congenital Defects *2.5%*	Nephritis *2.6%*		Unintentional Injuries *3.4%*	Unintentional Injuries 3.7%	CLRD 2.6% Congenital anomalies 2.6%

**CLRD = Chronic Lower Respiratory Disease

[45] Table C. Percentage of total deaths, death rates, age-adjusted death rates for 2004, percentage change in age-adjusted death rates from 2003 to 2004, and ratio of age-adjusted death rates by race and sex for the 15 leading causes of death for the total population in 2004: United States. Deaths: Final Data for 2004. National Vital Statistics Reports, Vol. 55, No. 19, August 21, 2007, October 10, 2007 Revision.

[46] Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2005, *Massachusetts Deaths 2005.* Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, March 2007. (Most recent data available)

[47] Septicemia and Cancer were tied for 3rd leading cause of death among DMR clients in 2002.

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

Heart disease is the leading cause of death in 2007 for people served by DDS, consistent with data from previous years and with data from the Massachusetts and U.S. general populations. The percent of deaths due to heart disease has decreased in 2007 to 16.8%; while still the leading cause of death for those served by DDS, a relatively smaller portion of deaths are due to heart disease than in the Massachusetts and U.S. populations. Cancer is the second leading cause of death for the DDS population, similar to years before 2006 and the Massachusetts and U.S. populations. Similar to heart disease, the proportion of deaths due to cancer is smaller in the DDS population than in the state or nation.

Septicemia is the third leading cause of death in 2007 for the DDS population, with 13% of deaths, substantially higher than for the U.S. and the Massachusetts general populations (<2%). In 2007, a moderate increase in the frequency of deaths due to septicemia and its relative ranking among other causes were observed. In past years, deaths from septicemia had shown a decline to a low of 0.9 deaths per thousand in 2006, as shown in Table 14. In 2007, the cause-specific crude mortality rate for septicemia was 2.3 per thousand.

Table 14
Cause-specific DDS Mortality Rates, 2001-2007

2007 Rank	Previous Ranking	Cause of Death	DDS Rates of Death (per thousand)					
			2002	2003	2004	2005	2006	**2007**
1	1	Heart Disease	3.8	4.2	3.5	2.9	3.6	**3.0**
2	3	Cancer	1.8	2.5	2.4	2.1	1.6	**2.4**
3	8	Septicemia	1.8	1.7	1.3	1.1	0.9	**2.3**
4	2	Alzheimer's Disease	1.3	1.0	1.4	1.5	2.4	**2.0**
5	4	Aspiration Pneumonia	2.2	2.3	2.1	1.7	1.4	**1.9**
6	10	Unintentional Injury[49]	0.4	0.7	0.6	0.6	0.6	**1.1**
7	6	CP Arrest/ Seizure[48]	1.7	1.4	1.3	1.9	0.9	**0.6**
8	9	Influenza and Pneumonia	0.8	0.9	2.1	1.9	0.7	**0.6**
9	7	Stroke	0.6	0.8	0.7	0.7	0.9	**0.5**
10	5	Chronic Lower Respiratory Disease	1.1	1.1	1.1	0.8	1.0	**0.5**
10	12	Congenital Anomalies	0.4	0.4	0.3	0.4	0.5	**0.5**

Alzheimer's Disease, which was the second leading cause of death in 2006, declined to the fourth leading cause of death in 2007. The rate of death for this cause decreased slightly to 2.0 per thousand, which is still the second highest rate of death from this cause seen in the DDS population since 2001. The higher rates of Alzheimer's Disease are similar to trends in the Massachusetts and the U.S.; Between 2000 and 2025, the Commonwealth of Massachusetts is projected to experience a 17% increase in adults with Alzheimer's Disease between 2000 and 2025.[50] In addition, the shift in death reporting to use the underlying causes of death has increased the reporting of this

[49] Category codes includes 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.

[50] *Across the States: Profiles of Long Term Care: Massachusetts, 2006,* Public Policy Institute, *AARP*, Pg W-14

disease as the final cause of death. The ranking for Alzheimer's Disease is higher for the population served by DDS than the state or the nation. This is partly due to the increased risk of early-onset Alzheimer's Disease in people with Down's Syndrome. Almost 90% of the deaths from Alzheimer's Disease in individuals between the ages of 44 and 64 were in individuals with Down Syndrome.

Aspiration Pneumonia was the fifth leading cause of death, down slightly from its rank of fourth in 2006. Despite this decrease in ranking, the rate of death from this cause rose slightly from 1.4 per thousand in 2006 to 1.9 per thousand in 2009.

Unintentional injuries increased in both rank and rate in 2007. Unintentional injuries were ranked tenth or below in all previous reporting years; in 2007, this cause was ranked sixth and increased from a rate of 0.6 per thousand to a rate of 1.1 per thousand. Most deaths from unintentional injuries were due to aspiration/choking (16 of 25 deaths)[51] or falls (5 of 25 deaths). Other unintentional injuries causing two or fewer deaths in 2007 include motor-vehicle related accidents, burns, poisoning, suffocation and drowning. The increase in unintentional injuries is due partly to an increase in the number of deaths due to aspiration/choking, and a small increase in deaths due to falls. The number of motor-vehicle related deaths was lower in 2007 than in past years.

Mortality rates for influenza and pneumonia continued to be lower than in previous years at a rank of eighth and a rate of death of 0.6 per thousand, after a substantial decline in 2006. Rates of death from cardiopulmonary arrest and seizure decreased in 2007 to 0.6 per thousand.

Cancer

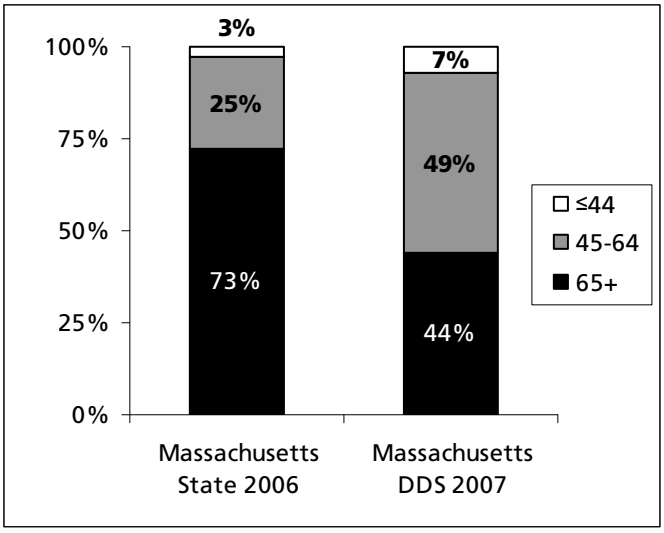
Primary sites of cancers causing death in 2007 are ranked in Table 15. Cancer of the colon, rectum or anus was the most common primary site (9 deaths), similar to previous years. Cancer of the trachea, bronchus and lungs was the second most common primary site for deaths due to cancer, with 8 deaths. Four deaths were each associated with leukemia and stomach cancer. Fewer deaths were seen at the sites of the female breast, and the meninges, brain and the central nervous system and the esophagus than in previous years. Variation does exist across years with the primary sites of cancers resulting in death in this small population and changes must be viewed with caution due to the size of the population.

Table 15
Top Cancer Causes in the DDS Population, 2007

Primary Site	Number of Deaths	Average Age at Death
Colon, Rectum and/or Anus	9	68.7
Trachea, Bronchus and Lungs	8	69.5
Leukemia	4	73.3
Stomach	4	59.7

[51] Deaths within the MRDD population due to choking and aspiration are experiencing increased attention nationally as evidenced by special notations in mortality reports within other states (e.g., State of Tennessee Division of Mental Retardation Services Annual Report FY 2005, Arizona Division of Developmental Disabilities Annual Mortality Report for October 2003 to September 2004, Connecticut Department of Mental Retardation Annual Mortality Report for 2006)

Figure 16[43]
Age Distribution of Cancer Deaths



The age distribution of deaths from cancer differs between the Massachusetts DDS and the Massachusetts general population, as shown in Figure 16. In Massachusetts, almost two-thirds of deaths from cancer occur in adults over the age of 65. The population served by the Massachusetts DDS has a higher proportion of deaths from cancer at younger ages than in the general population. This finding is consistent with medical literature, which finds both a predisposition for certain types of cancers[52,53,54,55] (e.g. leukemia, colorectal, oropharygeneal, thyroid, testicular, gastrointestinal) and the appearance of cancers at significantly younger ages (e.g. colorectal cancer around age 35[52]) in individuals with intellectual disabilities of certain etiologies.

In 2007, the crude mortality rate from cancer in the DDS population (2.4 per thousand) was slightly higher than the 2006 national (1.9 per thousand)[56] and 2005 statewide (1.9 per thousand) general population rates.[57] The incidence of cancer in individuals with intellectual disabilities has been shown in the literature to be similar to rates in the general population, despite lower rates of tobacco smoking, a major cause of cancer in the general population.

Cause of Death by Age Group

Age-specific causes of death for the 2007 DDS population and the 2006 Massachusetts population are presented in Tables 16 and 17.[58] Similar to previous years, the causes of death in the younger DDS age group vary from statewide general population findings. In younger individuals served by DDS, the primary causes of death are related to medical conditions. In the general population, accidents and

[52] 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.

[53] 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.

[54] 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.

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

[56] National Vital Statistics Reports, Vol. 56, No. 16, June 11, 2008. *Deaths: Preliminary Data for 2006.* Table B. Deaths and death rates for 2006 and age-adjusted death rates and percentage changes in age-adjusted rates from 2005 to 2006 for the 15 leading causes of death: United States, final 2005 and preliminary 2006.

[57] National and Massachusetts cancer rates from *Massachusetts Deaths 2006.* Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, April 2008.

[58] The most current data available for the Massachusetts general population was for the year 2006.

homicide are the most common causes of death for younger individuals. In contrast, the rate of death from accidents is low across all age groups in the DDS population; one of the sixteen deaths in the 18-24 year old group occurred from an accident (unintentional injury) for the DDS population. Findings over the past six years suggest deaths from accidents in the DDS population are most likely to occur for individuals over the age of 55 and are most often related to aspiration/choking, falls or motor vehicles.

Table 16
Cause of Death by Age Group for DDS, 2007
(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	*Multiple Causes*	Septicemia	Alzheimer's Disease	Alzheimer's Disease	Cancer	Heart Disease	Heart Disease	Heart Disease
2	*Multiple Causes*		Cancer, Unintentional injuries, CP arrest	Septicemia	Cancer	Septicemia	Aspiration Pneumonia	Aspiration Pneumonia	Cancer
3				Heart Disease, Cancer	Heart disease	Heart Disease	Septicemia	Septicemia, Stroke	Septicemia

Table 17
Cause of Death by Age Group for Massachusetts Population, 2006[59]

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	Heart Disease
2	Homicide	Cancer	Heart Disease	Heart Disease	Heart Disease	Cancer	Cancer
3	Suicide	Heart Disease	Unintentional Injuries	CLRD*	Stroke	Stroke	Stroke

* CLRD = Chronic Lower Respiratory Disease

Deaths in the 35-44 year old age group were spread across several causes. Septicemia ranked as the leading cause of death in this age group, representing six of the 32 deaths in this age group. Cancer, unintentional injuries, and CP arrest each represent four deaths in this group.

Septicemia ranked higher across many age groups in the DDS population. By contrast, it is not one of the top causes of death in the Massachusetts general population.

Alzheimer's Disease was a leading cause of death in the 45-54 and 55-64 year old age groups for the MA DDS population in 2007. This ranking is similar to 2006. However, Alzheimer's Disease does not rank as a leading cause at any age in the general

[59] Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2006, *Massachusetts Deaths 2006.* Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, April 2008. (Most recent data available)

population. Many of the deaths related to Alzheimer's Disease in the population served by DDS are of individuals with Down Syndrome, who experience an increased risk of early-onset Alzheimer's Disease.

Cancer ranked as one of the top three causes of death in age groups between 35 and 74 years in the DDS population. Interestingly, cancer is not one of the top causes for deaths of people aged 75 and above in the DDS population, as it has been in past years. Cancer ranks consistently higher in the MA population than in the MA DDS population, particularly in the older age groups.

In older age groups (75+), aspiration pneumonia ranks as a top cause of death for the population served by DDS; however, this is not seen in the MA population. Swallowing difficulties are more prevalent in the population served by DDS. Swallowing disorders can be caused by a variety of factors, many of which are experienced in a higher frequency by the population served by DDS. These include central nervous disorders including Alzheimer's Disease, structural abnormalities, and muscular disorders. The development of swallowing disorders may also be a long-term side effect of anti-seizure medications.

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.

Table 18
Major Causes of Death for DDS Community[60]

Rank	Cause of Death	Number of Deaths	Rate of Death
1	Heart Disease	29	3.0
2	Alzheimer's Disease	28	2.9
3	Septicemia	26	2.7
4	Cancer	23	2.4
5	Aspiration Pneumonia	17	1.8

Mortality causes with the highest frequency for people living in the DDS Community are presented in Table 18. In this residential setting, the ranking for causes of death were similar to those in 2006. Heart disease was the leading cause of death, with a crude mortality rate 3.0. This rate is in between the range of rates for this cause seen in previous years. Alzheimer's Disease ranked second and the rate of death remained steady from 2006 levels at 2.9 per thousand. Septicemia ranked third, an increase from previous years and had a rate of death of 2.7 per thousand. Cancer was the fourth cause of death with a rate of 2.4 deaths per thousand. The rate of death from aspiration pneumonia increased slightly in 2007 to 1.8 per thousand. However, the relative rank dropped to fifth from a ranking of third in 2006.

[60] The individual may have passed away in a setting other than the DMR Community, however, individuals are listed by their primary residential setting.

Table 19
Major Causes of Death for Individuals Served by DDS and Residing in Their Own Home[61]

Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)
1	Cancer	14	1.3
2	Heart Disease	9	0.8
3 & 4	Alzheimer's Disease	6	0.5
	Unintentional Injuries	6	0.5
5	Septicemia	5	0.4

As shown in Table 19, 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. Alzheimer's Disease and unintentional injuries were tied for the third rank. Rates of death from septicemia increased slightly and brought this cause up to a ranking of fifth for people residing in this residential setting.

Table 20*
Major Causes of Death for Individuals Served by DDS in Other Residential Settings

Rank	Nursing Home *(Total 92 deaths)*	Non-DDS *(Total 22 deaths)*	DDS Facility *(Total 52 deaths)*
1	Heart Disease *(21 deaths)*	Congenital anomalies *(5 deaths)*	Aspiration Pneumonia *(13 deaths)*
2	Aspiration Pneumonia *(13 deaths)*	Cancer, Septicemia *(4 deaths each)*	Heart Disease *(9 deaths)*
3	Septicemia *(11 deaths)*		Septicemia *(8 deaths)*

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

Table 20 presents the most frequent causes of death for the smaller residential settings. Although the population of individuals served by DDS in Nursing Homes is small (732 individuals or 3.2% of the DDS population), about one quarter of all DDS deaths occurred in this type of residential setting. Both the population size of people served by DDS in nursing homes and the proportion of overall deaths in nursing homes declined in 2007. As in past years, individuals served by DDS in nursing homes experienced the highest mortality rate from heart disease. Similar to the previous year, Alzheimer's Disease was the second leading cause of death for nursing home residents. However, cancer fell out of the top rankings for this group, and was replaced by septicemia.

In DDS facilities, aspiration pneumonia and heart disease are the top ranked causes, which is consistent with previous years. The rate of deaths from cancer also fell in this

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

group, and the rates of septicemia increased, bringing it up to the third leading cause of death.

Due to the small population size corresponding small number of deaths, the ranking of leading cause of death tends to be variable from year to year. In 2007, congenital anomalies were the most common cause, which is different from previous years. Alzheimer's Disease and heart disease were less common in 2007 in this group, and deaths from septicemia were seen more frequently.

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 223 mortality reviews were completed for 2007 deaths, 218 of these reviews were required by DDS policy.

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), 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.[62]

Some deaths may involve more than one investigation by more than one state agency. For example, DPH is charged with investigating allegations of abuse, mistreatment or neglect in certain licensed health facilities including hospitals, rehabilitation hospitals and nursing facilities. Therefore DPPC or DDS may conduct an investigation of issues in a DDS funded or licensed setting and DPH may conduct a separate, non-duplicative investigation of the care of the individual received while in an acute care hospital.

Table 21
Summary of Investigations, 1999 to 2007

Type of Activity	1999	2000	2001	2002	2003	2004	2005	2006	2007
DDS Investigation	7	5	5	14	9	5	10	2	9
DPPC Investigation	5	1	2	2	4	6	5	3	10
Refer to Other Agency	2	1	8	10	10	9	4	2	7
District Attorney/Law Enforcement Investigation	0	3	1	3	2	4	4	2	9
Other/dismissed[63]	5	3	5	4	2	1	2	3	5
Resolved Fairly and Efficiently									1
Total Number of Deaths Investigated	19	13	21	33	27	20	19	9	34

During 2007 there were thirty-four (34) deaths investigated by one or more of the agencies identified above. DDS conducted nine investigations on 2007 deaths. In five

[62] "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."

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

of these cases, the judgment was deferred to a law enforcement investigation. A total of ten investigations were conducted by DPPC. In three of these cases, the judgment was deferred to a law enforcement investigation. Investigations of seven deaths were referred to another agency. The cases listed as "other/dismissed" either had an administrative review by DDS (1 case) or were dismissed (5 cases). One allegation was resolved fairly and efficiently.

Table 22
Findings in Cases Investigated by DDS or DPPC, 1999 to 2007

Findings	1999	2000	2001	2002	2003	2004	2005	2006	2007
No. Substantiations	0	0	1	2	2	1	4	2	3
Pending								3	3

Table 22 presents the findings of investigations by either DDS or DPPC. Investigations about three of the deaths occurring in 2007 were found to be substantiated. Three investigations are still pending, all of which are cases that have been assigned to DPPC for review. Thirteen 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 intellectual disabilities/developmental disabilities 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 2006 Massachusetts findings. Direct comparisons of specific data should NOT be made.

NOTE: In this section, mortality data for the MA DDS will be shown with data from the CT DMR. There is an important difference between the two populations: the CT DMR includes children in their mortality statistics, and the MA DDS includes only adults. Therefore the mortality rate and average age at death for CT DMR are expected to be lower than the adult-only statistics presented from the MA DDS.

Mortality Rate Benchmarks

A review of selected state MRDD reports and data regarding mortality identified six state systems that included information on crude mortality rates (no. deaths/population served). Findings from these reports are presented below in Table 22. Once again, 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 MRDD systems difficult. As shown in Table 21, the reported crude death rate for the MA DDS appears to be higher than that reported by the other five states for their entire populations. However, it is similar to the CT adult-only crude mortality rate. **Given that age is the single most important risk factor for mortality, it is to be expected that adult-only mortality rates (such as the rate reported for MA) will be higher than mortality rates that include populations of both children and adults.** The exact nature of the differences due to age and disability composition cannot be determined without formal risk adjustment of all the data from all of the state systems.

Table 23
Comparison of Crude Mortality Rates for Selected State MRDD Systems

Comparative Mortality Rates	**MA DDS** 2007	**CT DMR** FY 2008	**CT DMR** FY 2008	**VT DDS** FY2005	**OH**[64] 2007	**MN MHDD**[65] **2006-2007**
Population Served	MR only	MR only	MR only	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	Adults in services paid by state
No. Deaths	416	205	216	26	693	470 (2 yrs)
Mortality Rate (no./1000)	**17.6**	**16.3**	13.9	8.4	8.7	~168

Mortality and Age Benchmarks

Crude mortality rates by age range are presented in mortality reports for both Connecticut and Massachusetts; however, the age groupings each state uses are different. Therefore, a direct comparison is not possible. Table 24 and Figures 17 illustrate that the general pattern of mortality by age is similar between Connecticut and Massachusetts, 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 is 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).

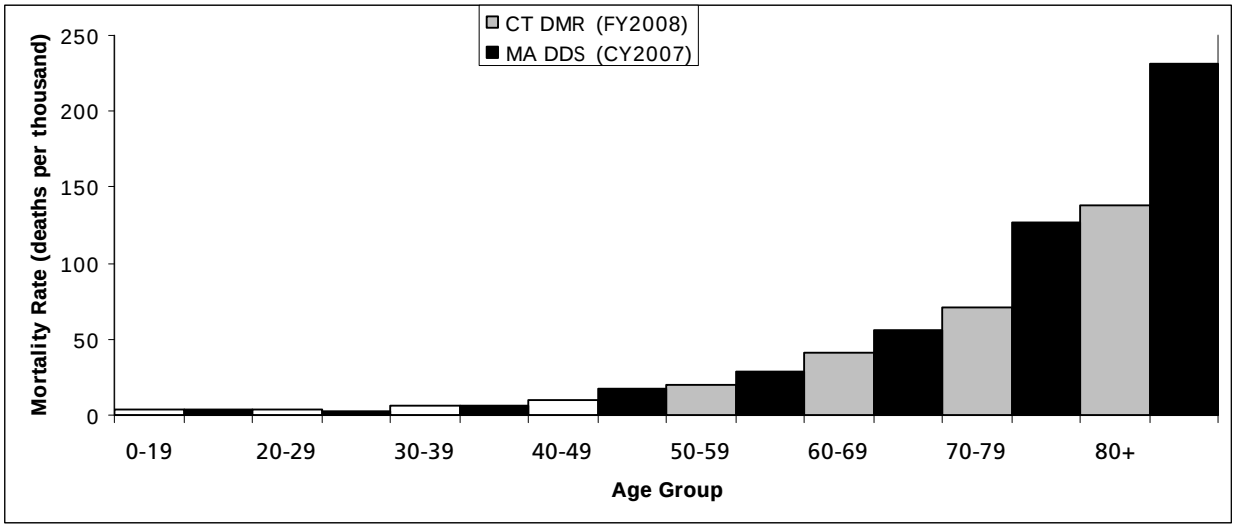
[64] Cause of Death Summary 2007, 3/10/08

[65] 2006/2007 Biennium Report to the Governor. Rate calculated from reported figures. 44% of the 1069 reported deaths were of people with developmental disabilities, yielding 470 deaths in the 2 year span. Of the 7,169 contacts reported during this time, approximately 2800 were contacts with people with developmental disabilities.

Table 24
Comparison of the Mortality Rate by Age
For the Massachusetts DDS and Connecticut DMR

Crude Mortality Rate by Age (Not Age Adjusted)			
CT DMR (FY2008)		MA DDS (CY2007)	
Age Range	Mortality Rate	Age Range	Mortality Rate
0-19	3.3	18-24	3.7
20-29	3.9	25-34	2.5
30-39	6.2	35-44	6.7
40-49	10.0	45-54	17.1
50-59	20.0	55-64	28.3
60-69	41.0	65-74	55.7
70-79	70.4	75-84	126.5
80+	137.6	85+	231.3

Figure 17
Connecticut DMR and Massachusetts DDS Mortality Rates by Age



Mortality and Gender Benchmarks

In addition to the Massachusetts DDS, the Connecticut DMR is one of the few state agencies that serve adults with intellectual disabilities to publish mortality statistics by gender. Connecticut and Massachusetts are compared by gender in Table 25. Similar ratios of male to female deaths are present in both state systems. It should be noted that the relative mortality rate by gender for Connecticut includes 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.

Table 25
Comparison of the Percentage of Deaths by Gender for Two State MRDD Systems

Gender	Measure	MA DDS 2006 (Adults)	CT DMR 2006 (All ages)
Male	Percentage of Deaths	53%	56%
	Death Rate	16.9	13.8
	Ave. Age of Death	60.0	56.4
Female	Percentage of Deaths	47%	44%
	Death Rate	18.5	14.0
	Ave. Age of Death	64.2	58.7

Note: Death Rate for CT includes children. MA only includes adults.

Mortality and Residence Benchmarks

Significant differences exist in the populations served and residential groupings utilized by different state MRDD agencies that make direct comparisons of mortality by residential setting difficult.[66] Of special concern are the differences in population characteristics, e.g., the Connecticut DMR 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.

Table 26
Comparison of the Mortality Rate by Residential Setting For the Massachusetts DDS and Connecticut DMR

Type of Residential Setting	Mortality Rate *(per thousand)*	
	MA DDS CY 2007	CT DMR FY 2008
At Home/Family, Independent & Supported Living	6.2	5.6
Community Group Home, Community Training Home	18.9	14.6
Facility-ICF/MR	53.9	41.6
Nursing Facility	149.6	172.4

[66] For example, in addition to Massachusetts, only five other states have a specific MRDD 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. A search of state reports was only able to identify one other state, Connecticut, that presented current mortality data according to this variable. Through collaboration, Massachusetts and Connecticut have worked to organize mortality information in categories that are more directly comparable. In addition, Connecticut provides some residential services for children, whereas Massachusetts serves an adult population.

Table 26 provides crude mortality rates (no. of deaths per 1000 people served) by type of residential setting for the Connecticut DMR and Massachusetts DDS state systems. Consistent with previous years, the facility (ICF/MR) crude mortality rates for the Massachusetts DDS appear to be somewhat higher than for the Connecticut system. However, mortality rates for persons served within nursing facilities appear to be lower. Crude mortality rates in the Massachusetts DDS system for community residence had a small increase in 2007; however, the rate is still similar to the Connecticut mortality rate for this setting. The absence of age-adjusted rates compromises the ability to make valid and direct comparisons between these two states, particularly because the mortality statistics for the Connecticut DMR include children. Nonetheless, the general patterns are similar with the highest rates present for persons residing in nursing facilities, followed, in order, by facilities and community residences, with the lowest rates occurring for persons residing at home (with family or independently).

Cause of Death Benchmarks

Comparisons of the top five leading causes of death as reported by the MR/DD state agencies in Connecticut, Ohio and Vermont are presented in Table 27.

Table 27
Comparison of the Top 5 Leading Causes of Death
As Reported by Four State MR/DD Agencies

Rank	MA DDS 2007	CT DMR 2007[67]	OH OMRDD 2006[68]	VT DDS 2005[69]
Method	**Underlying**	**Primary**	**Unknown**	**Underlying**
1	Heart Disease 16.8%	Heart Disease 31.0%	Heart Disease 18.4%	Respiratory Disease/ Pneumonia 23%
2	Cancer 13.7%	Aspiration Pneumonia 15.2%	Pneumonia 10.2%	Alzheimer's Disease, Cancer and Heart Disease 12% each
3	Septicemia 13.0%	Respiratory Disease[70] 12.3%	Cancer 9.7%	
4	Alzheimer's Disease 11.3%	Cancer 10.7%	Congenital Diseases 9.5%	
5	Aspiration Pneumonia 8.4%	Pneumonia (non-Aspiration) and Septicemia 7.8% each	Accidents and Adverse Actions 7.2%	Seizure Disorder and Diabetes 8% each

[67] CT DMR Mortality Annual Report, FY 2008, published May 2009
[68] Ohio, Cause of Death Annual 2006
[69] Mortality Among People in Vermont Receiving Developmental Disability Services (DDS) FY 2005
[70] Includes Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma

It is important to note that the Connecticut DMR does 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 DMR report. The underlying cause of death is used in the mortality reports for both the general population in Massachusetts and the U.S. Without additional information, it is not possible to determine which methodology was employed from the data released by Ohio MRDD. The Vermont DDS categorizes cause of death by underlying cause, and is therefore more directly comparable with Massachusetts.

Rank order is a general and relative comparison that can be very sensitive to small changes in the number of deaths within each category due to the small population size and the relatively small number of deaths within any given state. Despite this, some similarities do exist across state MR/DD systems in terms of the most common causes for death in the MRDD population served by public agencies. For example, as in Massachusetts, heart disease, respiratory diseases – especially pneumonia – and cancer consistently represent top causes of death for four state systems. The most common primary site of cancer resulting in death in Connecticut was the lung, followed by the ties for the larynx and lymphoma. The colorectal region was the most common primary site of cancer in the adult population served by the MA DDS population, followed by lung cancer. The frequency of death from lung cancer for people with intellectual disabilities appears to be increasing in both states.[67]

The number of deaths from Alzheimer's Disease continues to increase, and has been a leading underlying cause of death for both Vermont and Massachusetts. Connecticut reported an increased prevalence of Alzheimer's disease in people with Down Syndrome; in fact, the majority of people with Down Syndrome had a diagnosis of Alzheimer's Disease at the time of their death (59%) in FY 2008 in this state. As discussed earlier in this report, individuals with Down Syndrome are more likely to develop Alzheimer's Disease at younger ages than the general population[50].

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.

Table 28 below displays data associated with 23 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 objectives have recently been revised (October 2006) to reflect changes suggested by the Healthy People 2010 Midcourse Review. The objectives also have been adjusted due to more complete population estimates and prevalence data that became available since the original publication of the HP2010.

The objectives related to mortality rates in Healthy People 2010 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 23,500 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 (2003-2007). This method allowed 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, rates are not reported for causes of death with only 1 or 2 reported deaths across the five years.

Comparison of a five-year average of DDS data with the objectives contained in Healthy People 2010, 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 2005 were the most current figures available for the U.S. population.

Overall, rates for individuals in the Massachusetts DDS population meet more HP2010 targets than the general Massachusetts population or the national population. While reviewing the table, it should be kept in mind that the risk of cancer significantly

Table 28

Target Status for Selected Healthy People 2010 Mortality Objectives[71]

Objective Number	HEALTHY PEOPLE 2010 OBJECTIVE *Rates per 100,000 population; MA and US are Age-adjusted*	TARGET 2010[72]	DDS 2003-2007	DDS TARGET STATUS	MA 2006[72]	US 2005[72]
3-1	Overall Cancer death rate	158.6	222.5	●	186.3	183.8
3-2	Lung Cancer	43.3	21.6	✓	52.6	52.6
3-3	Female Breast Cancer (per 100,000 females)	21.3	30.9	●	23.2	24.1
3-4	Cervical (per 100,000 females)	2.0	3.9	●	1.4	2.4
3-5	Colorectal Cancer	13.7	29.3	●	17.1	17.5
3-6	Oropharyngeal Cancer	2.4	4.4	●	2.5	2.5
3-7	Prostate Cancer (per 100,000 males)	28.2	15.7	✓	24.5	24.5
3-8	Malignant Melanoma	2.3	3.5	●	3.4	2.7
5-5	Diabetes-related deaths	46	26.8	✓	54.0[73]	77.0
12-7	Stroke deaths	50	72.0	●	37.4	47.0
26-3	Drug-induced deaths	1.2	0.0	✓	14.9	11.3
13-14	HIV-infection deaths	0.7	2.6	●	2.7	4.2
24-10	Chronic Obstructive Pulmonary Disease Deaths (age 45+)	62.3	167.8	●	97.6[73]	118.8
	Injuries					
15-13	Unintentional injuries (Accidents)	17.1	73.3	●	31.4	39.1
15-27	Falls	3.3	7.8	●	5.7	6.4
15-3	Firearm-related	3.6	0.0	✓	3.2	10.2
15-8	Poisonings	1.5	--[74]	✓*	14.9	11.0
15-9	Hanging, strangulation or suffocation	3.3	0.0	✓	4.2	4.6
15-25	Residential fire deaths	0.2	--[74]	✓*	0.4	0.9
15-29	Drownings	0.7	2.6	●	1.1	1.3
15-32	Homicide	2.8	--[74]	✓*	2.9	6.1
18-1	Suicide	4.8	--[74]	✓*	6.5	10.9

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

✓* = Too few deaths from this cause to provide rate

[71] 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.

[72] Data 2010 the Healthy People 2010 Database. CDC Wonder website: http://wonder.cdc.gov. February, 2009 Edition, Accessed 2/25/09.

[73] 2006 MA rate unavailable, so 2005 rate is used from Data 2010 the Healthy People 2010 Database. CDC Wonder website: http://wonder.cdc.gov

[74] Too few deaths occurred to be statistically reliable (i.e. only 1-2 deaths occurred from this cause over the 5 years). Because of the small population size, a rate lower than 0.8 per 100,000 was not possible in the DMR population during this time period.

increases with age.[75] The rates included for the DDS population are only for the adult population, while HP2010 goals and national and state rates are for all ages (except where noted). Therefore it would be expected that the rate for most cancers and the overall cancer rate will be relatively higher for the DDS population since only adults are used for the rate calculations. The averaged crude mortality rate for cancer in the DDS population is above the HP2010 target and state and national rates. Rates of death from cancer in the DDS population have been steadily declined until 2006, and a small increase was seen in 2007.

Rates of death from lung and prostate cancer for the DDS population were well within the Healthy People 2010 targets. Average mortality rates for colorectal cancer were higher than the Healthy People 2010 targets, but were similar to previously reported rates for the DDS population. Individuals with intellectual disabilities may have a predisposition to this type of cancer, so it is not unexpected that the rate would be higher than for the general population.

Mortality rates due to female breast cancer were substantially lower in 2007 in the DDS population. The average rate has declined steadily since 2004, and the rate is closer to state and national rates. Mortality rates due to cervical and oropharyngeal cancer were slightly to moderately higher than the 2010 targets. However, there were a relatively small number of deaths associated with these forms of cancer within the DDS population (i.e., only 2 and 5 cases respectively across the past 5 year time period). Mortality rates due to malignant melanoma are higher than targeted rates, but are very similar to statewide rates.

In general, rates for unintentional injuries (accidents) are higher than the goal, and are substantially higher than state and national rates. In most of the measured subcategories for specific injury categories, the DDS population meets or exceeds the target rate for 2010. The average rate for falls in the MA DDS population is higher than state and national rates.[76]

Mortality rates for diabetes-related deaths continued to be lower for the DDS population than both the rate for the general population in Massachusetts and the Healthy People 2010 target.

The DDS population experiences a higher rate of death from cerebrovascular conditions (stroke) on average than the HP2010 target rate and both the national and Massachusetts general population rates.

The objectives for chronic obstructive pulmonary disease (COPD) focus only on adults over the age of 45. Adult rates of COPD in the DDS population exceeded the HP2010 goal. It should be noted that many adults with intellectual disabilities have higher rates of respiratory problems that may help account for this finding.[77,78]

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[75] Janicki MP, Davidson PW, Henderson CM, McCallion P, Taets JD, Force LT, Sulkes SB, Frangenberg E & Ladrigan PM. Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research* 46, 287-298.

[76] Mobility limitations for some individuals may contribute to the rate of deaths from falls in the DMR population.

[77] Laurvick CL, de Klerk N, Bower C, Christodoulou J, Ravine D, Ellaway C, Williamson S, Leonard H. Rett syndrome in Australia: a review of epidemiology. J Pediatr. 2006 Mar;148(3):347-52.

APPENDICES

[78] Graham RJ. Acute respiratory distress syndrome in children with severe motor and intellectual disabilities. Brain Dev. 2006 Jun;28(5):342. Epub 2006 Feb 14.

Appendix A

Methodology for Mortality Review and Analysis

The 2007 Mortality report analyzes information on all deaths occurring in calendar 2007 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 2007 Mortality Report includes statistics on all deaths of individuals who died in calendar year 2007 and whose Death Report was received by DDS by the end of January 2008. A total of 416 deaths were reported to have occurred between January 1, 2007 and December 31, 2007.

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, 2007.[79] 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 416 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:

$$\text{Crude Death Rate} = \frac{(\text{Number of individuals who died in calendar year 2007} \times 1000)}{(\text{No. Individuals in CRS in June 2007})}$$

[79] CDDER relies on the accuracy of information about the number of individuals eligible for DMR 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 DMR population. The number of individuals served by DMR 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
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
3975 / zTEMPRES	Temporary Residence
4157	DDS State Operated Residential

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

3200 / ICFMR	ICF-MR
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 / zADFOSCARE	Adult Foster Care
3951 / zHOMELESS	Homeless/Homeless Shelter
3952 / zINCAR	Incarceration
3953 / zDMHCOMRES	Community Residential Program
3977 / zDOERES	766 Residential Program
3978 / zREHABHOSP	Rehab Hospital (non-DMH)
MCBR	MCB Residential Supports
/ zDPHFAC	DPH Facility
/ zDSSRES	DSS Residential Program
/ zGRPASSTLV	Group Assisted Living
/ zNONDMHPSY	Non-DMR 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

Age and Residential Distribution of the 2007 DDS Adult population

SEX	Age	DDS-Funded Community	DDS Facility	Nursing / Rest Home	Own Home, Living with Family	Own Home, Living Independently	Non-DDS	Out of State	Total
M	18-24 yr	296	2	35	1,965	9	262	0	2,569
F	18-24 yr	186	3	12	1,427	18	162	0	1,808
M	25-34 yr	860	11	32	1,366	82	73	0	2,424
F	25-34 yr	615	5	40	1,085	101	58	0	1,904
M	35-44 yr	1,377	59	32	975	110	115	1	2,669
F	35-44 yr	973	43	35	822	127	112	1	2,113
M	45-54 yr	1,429	191	26	716	166	125	14	2,667
F	45-54 yr	1,132	131	29	689	148	107	6	2,242
M	55-64 yr	857	188	41	335	92	77	13	1,603
F	55-64 yr	779	100	56	320	114	95	8	1,472
M	65-74 yr	360	94	45	111	68	46	2	726
F	65-74 yr	328	76	68	144	34	40	3	693
M	75-84 yr	133	39	48	33	13	20	2	288
F	75-84 yr	142	25	64	37	17	28	0	313
M	85+ yr	13	10	14	4	2	3	1	47
F	85+ yr	31	7	38	4	1	6	0	87
	Total	9,511	984	615	10,033	1,102	1,329	51	23,625

Appendix D

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_{Si} = total U.S. standard population (all ages combined)

Appendix E

ICD-10 Codes Used in this Publication

(Sorted by ICD-10 Codes)

Cause of Death	ICD-10 Code
Infectious and parasitic diseases	A00-B99
Septicemia	A40-A41
Human Immunodeficiency Virus (HIV) disease	B20-B24
Cancer (Malignant Neoplasms)	C00-C97
of esophagus	C15
of stomach	C16
of colon, rectum, rectum and anus	C18-C21
of pancreas	C25
of trachea, bronchus and lung	C33-C34
of female breast	C50
of cervix uteri	C53
of corpus uteri and uterus, part unspecified	C54-C55
of ovary	C56
of prostate	C61
of kidney and renal pelvis	C64-C65
of bladder	C67
of meninges, brain & other parts of central nervous system	C70-C72
Hodgkin's Disease	C81
Non-Hodgkin's lymphoma	C82-C85
Leukemia	C91-C95
Multiple myeloma and immunoproliferative neoplasms	C88, C90
Diabetes Mellitus	E10-E14
Alzheimer's Disease	G30
Heart Disease	I00-I09, I11, I13, I20-I51
Stroke (Cerebrovascular Disease)	I60-I69
Influenza and Pneumonia	J10-J18
Chronic Lower Respiratory Diseases[1]	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)

Cause of Death	ICD-10 Code
Accidents (Unintentional Injuries)	**V01-X59, Y85-Y86**
Alzheimer's Disease	G30
Aspiration Pneumonia	J69
Cancer (Malignant Neoplasms)	C00-C97
Cardiopulmonary Arrest / Seizure	G40, R09.2, J96.0
Chronic liver disease and cirrhosis	K70, K73-K74
Chronic Lower Respiratory Diseases[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.

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