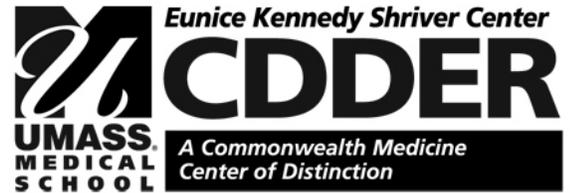


DECEMBER 2007

*(With correction April 2008)*



# 2006 MORTALITY REPORT

COMMONWEALTH OF MASSACHUSETTS  
EXECUTIVE OFFICE OF HEALTH & HUMAN SERVICES  
DEPARTMENT OF MENTAL RETARDATION

PREPARED BY:  
CENTER FOR DEVELOPMENTAL DISABILITIES  
EVALUATION AND RESEARCH (CDDER)







**The Commonwealth of Massachusetts**  
**Executive Office of Health & Human Services**  
**Department of Mental Retardation**  
**500 Harrison Avenue**  
**Boston, MA 02118**

**Deval L. Patrick**  
Governor

**Timothy P. Murray**  
Lieutenant Governor

February, 2008

**JudyAnn Bigby, M.D.**  
Secretary

**Elin M. Howe**  
Commissioner

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

Dear Colleagues and Friends:

Enclosed is the Department of Mental Retardation Annual Mortality Report for calendar year 2006. 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 2006 for all persons 18 years of age or older who have been determined to be eligible for DMR supports. This is the sixth 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 third year, the 2006 report includes a section that allows DMR to benchmark the mortality findings against the health objectives detailed in Healthy People 2010 issued by the U.S. Department of Health and Human Services.

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 of this independent mortality report as a vital and critical component of the Department's quality management and improvement system and an important step in our shared organizational learning process.

Sincerely yours,

A handwritten signature in cursive script that reads "Elin Howe".

Elin Howe  
Commissioner



## TABLE OF CONTENTS

<b>Executive Summary</b> .....	3
<b>Introduction of Integrated Electronic Quality Assurance Data System</b> .....	5
<b>Overview of Population Served by DMR</b> .....	7
<b>Mortality During 2006</b> .....	10
Age.....	10
Gender .....	12
Residence .....	13
<b>Age-adjusted Mortality Rates</b> .....	17
<b>Trends Over Time</b> .....	20
<b>Causes of Death</b> .....	22
Cancer .....	25
Causes of Death for Specific Groups .....	26
<b>Mortality Review Process and Committee</b> .....	29
<b>Investigations</b> .....	30
<b>Benchmarks</b> .....	32
<b>Healthy People 2010 Objectives</b> .....	38
<b>Appendices</b>	
A: Methodology for Mortality Review and Analysis.....	42
B: Residential Codes and Definitions .....	43
C: Demographic Data.....	44
D: Calculations for the Age-adjusted Mortality Rate.....	45
E: ICD-10 Codes Used in this Publication (Sorted by ICD-10 Codes) .....	46
F: ICD-10 Codes Used in this Publication (Sorted by Category).....	47
G: ICD-10 Codes for Selected Healthy People 2010 Mortality Objectives Used in This Publication .....	48

## LIST OF TABLES AND FIGURES

### Tables

Table 1: Annual DMR Population Change within Age Group, a Comparison of 2005 and 2006...	8
Table 2: Distribution of Deaths by Age Group, 2006.....	11
Table 3: No. Deaths, Average Age at Death and Death Rate by Gender, 2006.....	12
Table 4: DMR Mortality Rate by Gender, 2001-2006.....	12
Table 5: Age and Mortality by Type of Residential Setting for Adults Served by DMR, 2006 .....	13
Table 6: Mortality Rate in Nursing Homes, a Comparison of US and MA DMR Populations.....	16
Table 7: Age-adjusted Mortality Rates.....	18
Table 8: Mortality Trends in DMR, 2000-2006.....	20
Table 9: Top 10 Leading Causes of Death.....	23
Table 10: Cause-specific DMR Mortality Rates, 2001-2006 .....	24
Table 11: Top Cancer Causes in the DMR Population, 2006 .....	25
Table 12: Cause of Death by Age Group for DMR, 2006 .....	26
Table 13: Cause of Death by Age Group for Massachusetts Population, 2005.....	27
Table 14: Major Causes of Death for DMR Community .....	28
Table 15: Major Causes of Death for Individuals Served by DMR and Residing in Their Own Home .....	28
Table 16: Major Causes of Death for Individuals Served by DMR in Other Residential Settings .	28
Table 17: Summary of Investigations, 1999 to 2006 .....	30
Table 18: Comparison of the Top 5 Leading Causes of Death As Reported by Four State MR/DD Agencies.....	33
Table 19: Comparison of the Percentage of Deaths by Gender for Three State MRDD Systems.	34
Table 20: Comparison of the Mortality Rate by Age for the Massachusetts DMR and Connecticut DMR.....	35
Table 21: Comparison of the Mortality Rate by Residential Setting for the Massachusetts DMR and Connecticut DMR.....	36
Table 22: Comparison of Crude Mortality Rates for Selected State MRDD Systems .....	37
Table 23: Target Status for Selected Healthy People 2010 Mortality Objectives.....	39

### Figures

Figure 1: Distribution of the Population Served by DMR by Age and Gender 2006 .....	7
Figure 2: Gender Distribution by Age Adults Served by DMR 2006 .....	9
Figure 3: Where People Live.....	9
Figure 4: Mortality Rate by Age Group Adults Served in 2006.....	11
Figure 5: DMR Age at Death by Gender, 2001-2006 .....	13
Figure 6: Relationship between Mortality Rate, Average Age at Death, and Type of Residence, 2006 .....	14
Figure 7: Comparison of MA DMR and U.S. Standard Populations Percentage of Population by Age Group.....	18
Figure 8: Statewide Mortality Rates, 2000-2006 .....	20
Figure 9: Average Age at Death per Year, 2000-2006.....	20
Figure 10: Comparison of Mortality Rate by Age Group over Time, 2002-2006.....	21
Figure 11: Age Distribution of Cancer Deaths .....	25
Figure 12: Connecticut DMR and Massachusetts DMR Mortality Rates by Age .....	35

## EXECUTIVE SUMMARY

The Massachusetts Department of Mental Retardation (DMR) reviews the causes and circumstances of the deaths of individuals it supports through an established process for death reporting and mortality reviews. Findings are used to inform quality improvement efforts for the supports provided by 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 and December of 2006.

The Massachusetts DMR served 31,663 individuals, 23,053 of whom were adults with intellectual disabilities<sup>1</sup> over the age of 18 years, in the middle of calendar year 2006. An increase of about 0.9%, or 196 people was seen in the mid-year adult client population from June 2005 to June 2006.

For the calendar year of 2006 DMR received death reports for 383 individuals who met the criteria outlined above, representing a crude adult death rate<sup>2</sup> of 16.6 individuals per thousand. The average age at death of adults in the DMR population during 2006 was 61.6 years of age.

Mortality rates vary in the DMR population and are related to a number of key factors. Age is one of the strongest predictors, with the lowest death rates seen in the younger age groups and the highest death rates in the elderly populations. Residential settings also show distinct differences in mortality statistics. Those 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, one-quarter (25.6%) of the deaths in the DMR population are of nursing homes residents.

### Age

In 2006 all age groups, except for the 65-74 age group, experienced a decline in mortality rate since 2005.

### Gender

For the fourth year in a row, the number of deaths of males was greater than of females. Because there are fewer women than men in the DMR population, the female death rate is higher than the male rate despite the fact that fewer women than men

---

<sup>1</sup> The term "intellectual disability" is the preferred term in current literature and will be 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.

<sup>2</sup> The crude death rate is a measure of how many people out of every thousand served by DMR 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 DMR during the same year. See Appendix A for more detail.

died during the year. The mortality rate for both genders decreased in 2006; with a larger decrease for males than for females. The average age at death for males increased in 2006, and a significant difference in average age at death no longer exists between genders

## **Residence**

Generally, the average age at death for each residential setting is reflective of the relative age of the population that reside in each setting. Individuals residing in nursing homes experienced the highest rate of death. All residential settings, except Non-DMR settings and the DMR facilities, showed a decrease in rate of death from 2005 rates. Individuals served by DMR living in their own home or with family had the lowest mortality rate in 2006, similar to previous years.

## **Age-Adjusted Mortality Rates**

The overall adjusted death rate<sup>3</sup> for adults served by DMR approximately 17.7 per thousand. Because the DMR population has larger proportions in younger age groups, the age-adjusted rate is higher than the crude rate of 16.6 per thousand.

## **Cause of Death**

Heart disease, consistent with previous years, was the leading cause of death. For the first time, Alzheimer's Disease was the second leading cause due to a sharp increase in the cause-specific rate of death in 2006. Cancer dropped to the third leading cause of death due to a decrease in mortality rate for the third straight year. Mortality rates for influenza and pneumonia fell substantially in 2006 from 1.9 per thousand in 2005 to 0.7 per thousand in 2006, causing it to drop from third to a rank of ninth as a leading cause of death.

## **Benchmarks**

Comparative data drawn from a variety of sources suggests that the patterns and trends of mortality for individuals served by DMR are not unusual and mimic patterns from other state MRDD systems with regard to the major causes of death, age distribution, residential setting and gender. Variations in populations studied, and methods of organizing information most likely account for most if not all of the observed differences.

## **Healthy People 2010**

The health objectives in Healthy People 2010 (HP2010) issued by the U.S. Department of Health and Human Services in 2000 were utilized as a method to benchmark the Massachusetts DMR mortality findings for 2006. Overall, rates for individuals in the DMR population meet many more targets than the general Massachusetts population or the national population.

---

<sup>3</sup> 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.

## 2006 Mortality Report

The Massachusetts Department of Mental Retardation (DMR) has utilized a formal process for reviewing and reporting of instances of mortality since 1999. Through this process, an integral component of the Department's robust quality management and improvement system, DMR 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 2006.

### Mortality Review in DMR

#### 2006 Mortality Report

This report includes information and data concerning all adults (individuals 18 years old and older) served by DMR who were listed in the Meditech Consumer System and who died during the 2006 calendar year. The data includes individuals therefore who do not always meet the specific criteria for formal review by the DMR Mortality Review Committee (see below).

#### DMR Clinical Mortality Review:

Clinical reviews are conducted by the DMR Mortality Review Committee for deaths of individuals served by DMR 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 DMR;
- Died in a day support program funded or certified by DMR;
- Died in a day habilitation program; or
- Died during transportation funded or arranged by DMR.

Not all of the individuals served by DMR who die meet the criteria for a clinical mortality review. This report includes both individuals whose death was reviewed, and those who were not. See page 29 for a more detailed description of the mortality review process.

## INTRODUCTION OF INTEGRATED ELECTRONIC QUALITY ASSURANCE DATA SYSTEM

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

In 2002, DMR started the development of its DMR Information System (DMRIS). The initial phase was the development of the Meditech system, which is an internal system to DMR. Meditech is the system of record for all individuals eligible for DMR services.

Components include the eligibility process, individual demographic information, notes, assessments, services and programs, risk management, contract information, and the individual service planning process. An important component of an effective quality management system is an incident management system. Such a system assures the prompt identification and reporting of an incident and the taking of appropriate action to assure the health and safety of an individual.<sup>4</sup> The final phase of the development process focused on the Home and Community Services Information System (HCSIS), a web-based individual information system to be used by both DMR and providers of services to capture important events and health care information for individuals served by DMR. HCSIS was originally developed for the Pennsylvania Office of Mental Retardation and has been tailored to meet the needs of the Massachusetts DMR. In 2006, DMR completed the transition of its incident management system to a centralized electronic system within HCSIS. The incident management system tracks incidents that occur while individuals are receiving DMR services across five modules, one of which is death reporting. Information from incident reports is now required to be entered electronically into HCSIS.

The goal of the DMRIS 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. HCSIS assists in automating the collection and storage of information related to individuals served through DMR so data can be reviewed through a variety of filters and scopes to better plan and support individuals. The system allows for the identification and remediation of individual events, the analysis of patterns and trends, and the identification of service improvement activities.

### **Impact of the system upgrades**

Before the implementation of HCSIS, the DMR mortality reporting system relied on a stand-alone database where information was entered and tracked electronically. This database was not linked to other quality management components. Starting in June 2006, all deaths are reported through the HCSIS system by the DMR Area Office.

The implementation of the HCSIS system added a number of improvements into the death reporting process. The electronic death report now has required fields, which help to ensure completeness across records. In addition, the electronic routing process now has additional levels of review to help ensure the integrity of data reported. Previously, service coordinators or facility nurses completed the death report by paper and submitted them directly to the central office DMR, investigations unit. Now, a DMR area office designee must review and approve the initial reports before they are sent to the DMR Central Office. The DMR Central Office then reviews the report and finalizes it. Additionally, the cause of death is confirmed and finalized by the DMR Director of Health Services, after a DMR clinical mortality review if applicable. The entire review process for death reports is now an internet-based, transparent process to area and regional clinical staff; area nurses can now view and track all of the stages of review for a record, something that was not easily accessible in the paper system.

---

<sup>4</sup> Information on the DMRIS and HCSIS taken from the following document: HCSIS guidelines v. 2-14-07

The information in this mortality report spans the transition year between reporting systems. Therefore, a portion of deaths (152 people) were reported through the paper reporting method utilized in previous years, and all other deaths (231 people) were reported through HCSIS as the new system became available to each administrative region. As in previous years, data was also gathered from death certificates accessed through the Department of Public Health Vital Statistics to confirm, and in some cases clarify, information about individual deaths. Confirmatory checks were also performed between the older system and the new system to ensure all relevant data was included in the final mortality data set.

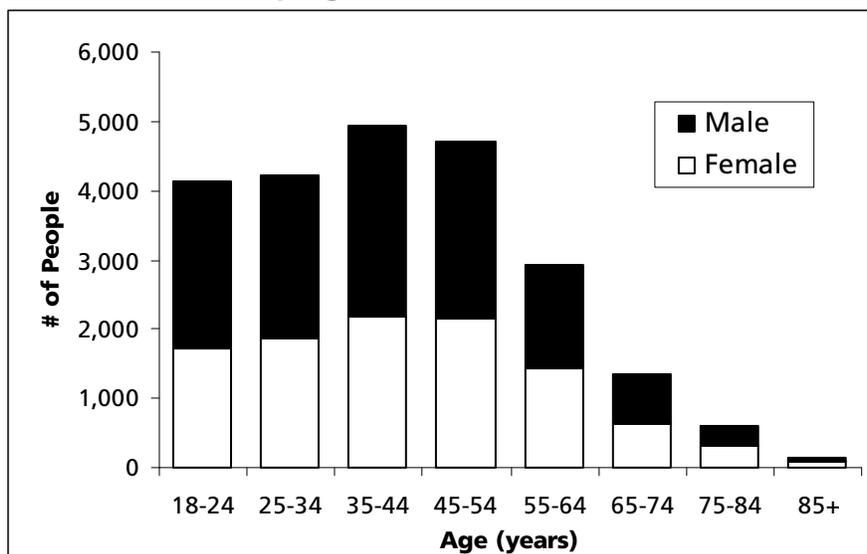
## OVERVIEW OF POPULATION SERVED BY DMR

In the middle of calendar year 2006, the Massachusetts DMR served 31,663 individuals, 23,053 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 DMR tends to increase as the year progresses. An increase of about 0.9%, or 196 people was seen in the mid-year adult client population from June 2005 to June 2006. In this report, population and mortality statistics are presented only for those individuals age 18 years and older who were eligible for services from DMR.

### Age Characteristics

About three quarters (72.5%) of the total population served by the Massachusetts DMR are adults over the age of 18. The majority of adults within this population are between the ages of 18 and 54 years of age. DMR serves a smaller proportion of adults over 65 than exist than in the Commonwealth of Massachusetts. However, this portion of the population is still significant: accounting for 9% of the adult population, or over 2,000 people. Figure 1 below displays the populations within each age group.

Figure 1  
Distribution of the Population Served by DMR  
by Age and Gender, 2006



**2006 DMR Population (Figure 1, continued)**

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
<b>Female</b>	1717	1878	2176	2150	1424	645	324	98	<b>10412</b>
<b>Male</b>	2420	2347	2770	2568	1516	696	278	46	<b>12641</b>
<b>Total</b>	<b>4137</b>	<b>4225</b>	<b>4946</b>	<b>4718</b>	<b>2940</b>	<b>1341</b>	<b>602</b>	<b>144</b>	<b>23053</b>

The 2006 adult DMR population showed a small increase of 0.9%, or 196 individuals since 2005. Table 1 shows the gross population change within each age group. Deaths in each age group are taken into account when calculating annual change.<sup>5</sup> Relative to the 2005 population, age groups of 55 years and older showed the largest increases (about 10% on average). In contrast, the 35-44 age group showed a slight decrease and only very small increases were shown in the age groups under 35 years of age. This annual change is in line with the trend of the population in past years. The population as a whole continues to age, driven by the relative increase of the “baby-boomer” population through the 45-54 and 55-64 age groups.<sup>6,7</sup> Similar aging trends have been cited by other MR/DD agencies in the northeastern states.<sup>8</sup>

Table 1  
Annual DMR Population Change within Age Group  
A Comparison of 2005 and 2006

Age Group	Gross Population Fluctuation <sup>9</sup>		
	Individuals	% Change within Age Group	Resulting % Change in Overall DMR Consumer Population from 2005
<b>18-24</b>	37	0.9%	0.2%
<b>25-34</b>	19	0.4%	0.1%
<b>35-44</b>	-138	-2.7%	-0.6%
<b>45-54</b>	239	5.3%	1.0%
<b>55-64</b>	269	9.7%	1.2%
<b>65-74</b>	99	7.6%	0.4%
<b>75-84</b>	55	8.9%	0.2%
<b>85-94</b>	31	19.9%	0.1%
<b>Total</b>	<b>+605</b>	<b>---</b>	<b>+2.6%</b>

<sup>5</sup> The net increase in the DMR population was 196 individuals in 2006, while the gross population increase was 605 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.

<sup>6</sup> Before the Boom: Trends in Long-Term Supportive Services for Older Americans with Disabilities, October 2002, Public Policy Institute, AARP

<sup>7</sup> U.S. Census Bureau, Census 2000 Summary file 1; 1990 Census Population, General Population Characteristics, United States (1990 CP-1-1).

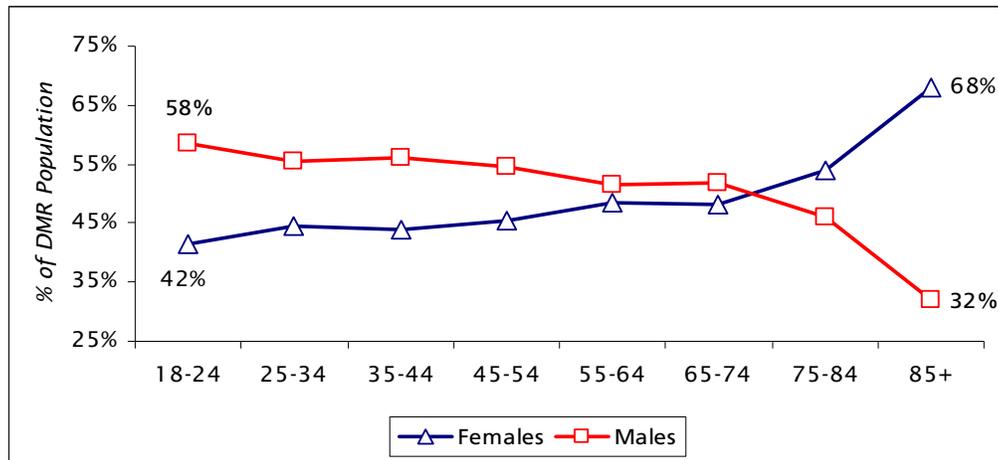
<sup>8</sup> State of Connecticut Department of Mental Retardation. *Aging Focus Team Report and Recommendations*, October 2003.

<sup>9</sup> 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 2006 adult DMR population is very similar to 2005 and previous years. As Figure 2 shows below, the proportion of men and women served by DMR varies with age. Younger age groups have a majority of men. The gender difference begins to equalize by age 55 and steeply moves toward a female majority starting at age 75. The shift in gender distributions in the elderly population is consistent with reports from other states<sup>10</sup>.

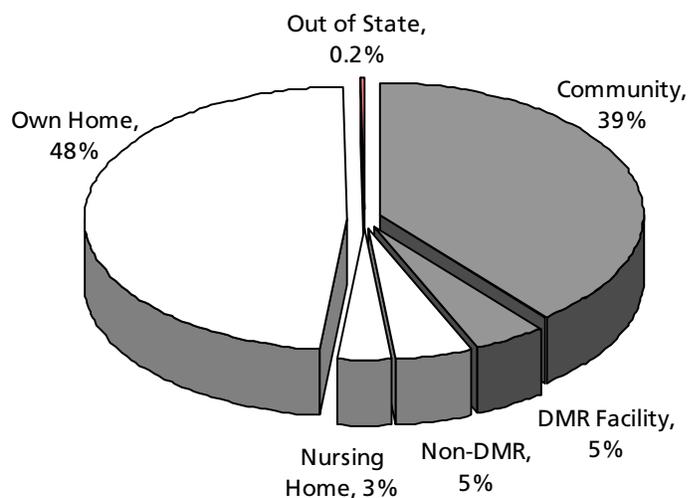
Figure 2  
Gender Distribution by Age, Adults Served by DMR 2006



## Residential Setting Characteristics

Adults receiving services from DMR reside in a variety of different residential settings. Many individuals live independently or with their family, while others may receive residential supports directly from DMR or from another state agency. In this report the various DMR residential settings are grouped into one of six residential categories. The percent of people served by DMR living in each residential category is presented in Figure 3. Residential programs operated, licensed/ certified or funded by DMR are shown in the shaded sections, and provide residential services to almost half of the individuals served by DMR. Individuals counted in the “out of state” category

Figure 3  
Where People Live



<sup>10</sup> Gruman, C. and Fenster, J. *A Report to the Department of Mental Retardation: 1996 through 2002 Data Overview*, April 2002.

are class members in the Ricci V. Okin (1972) lawsuit living outside of the state of Massachusetts. Class members include anyone who was part of the original Class Identification List as of April 30, 1993, or who lived at a state facility for more than thirty consecutive days or for more than 60 days during any twelve-month period after this date. Class members are eligible for DMR 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 DMR population.

The proportional distribution of the population across residential settings has not changed significantly since 2005. (See Appendix B for a more detailed description of the categories of residential settings.)

## MORTALITY DURING 2006

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 DMR services and supports during calendar year 2006. 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 2006 DMR received death reports for **383 individuals** who met the criteria outlined above, representing a crude adult mortality rate<sup>11</sup> of **16.6 individuals per thousand**.<sup>12</sup> The average age at death of adults in the DMR population during 2006 was **61.6 years of age**. Mortality statistics have shown a decline since 2005 in both the number of individuals who died, and the rate of death for the population.

Two deaths reported via the HCSIS were removed from the final data set. The deaths were of consumers who were aging into the adult DMR system and going through the process of a determination of eligibility for adult services at the time of their death. Deaths of individuals within the eligibility process must be reported upon as if they are eligible until they are determined otherwise. Because it was determined that these individuals would not have been eligible for DMR adult services, and were not actively receiving services from DMR at the time of their death, they were removed from this analysis.

### 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 DMR, and the crude mortality rate. A proportional relationship exists between the crude mortality rate and advancing age. Mortality rates are lowest in the youngest

---

<sup>11</sup> The crude death rate is a measure of how many people out of every thousand served by DMR 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 DMR during the same year. The crude death rate can be useful when comparing deaths across populations of varying sizes. See Appendix A for more detail.

<sup>12</sup> 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.

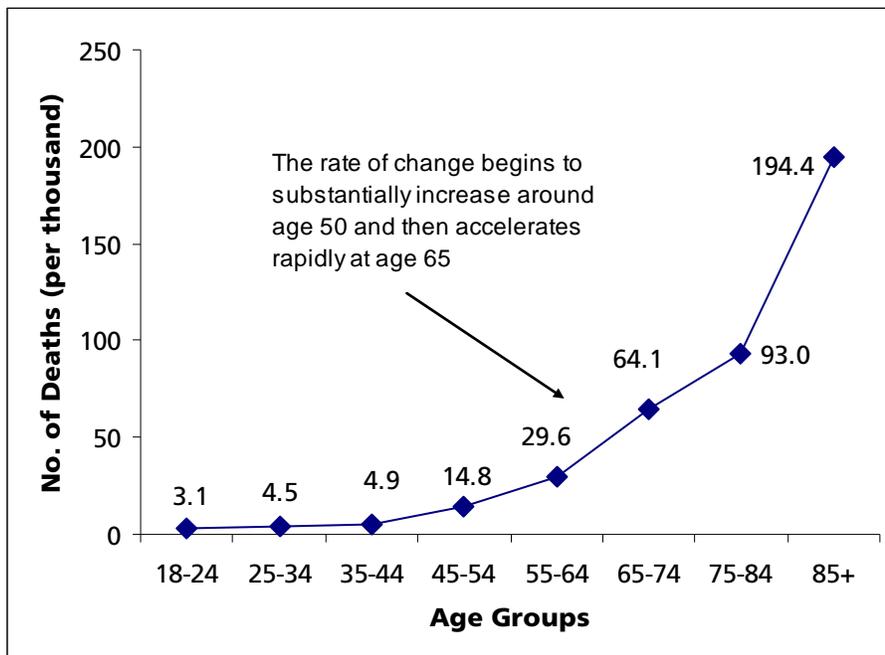
age groups. In 2006 all age groups, except for the 65-74 age group, experienced a decline in mortality rate since 2005.

Table 2  
Distribution of Deaths by Age Group, 2006

Age Range	No. Deaths	Percentage	Death Rate (No. per 1000)
18-24 yrs	13	3.4%	3.1
25-34 yrs	19	5.0%	4.5
35-44 yrs	24	6.3%	4.9
45-54 yrs	70	18.3%	14.8
55-64 yrs	87	22.7%	29.6
65-74 yrs	86	22.5%	64.1
75-84 yrs	56	14.6%	93.0
85 yrs & older	28	7.3%	194.4
<b>Total</b>	<b>383</b>	<b>100%</b>	<b>16.6</b>

The relationship between age and rate of death for adults served by DMR 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 2006



## Gender

Gender proportions vary with age in the population served by DMR, as described in this report's 'Overview of the DMR Population' section. While many of the gender differences are similar to state and national populations, the population served by DMR differs from the general Massachusetts population in the larger percentage of males in age groups under 54 years.

Table 3  
**No. Deaths, Average Age at Death and Death Rate by Gender, 2006**

Gender	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	183	47.8%	62.9 yrs	17.6
Male	200	52.2%	60.4 yrs	15.8

A complex relationship between gender and mortality exists, due in part to both gender proportions and the differences in age distribution that exist between the two groups. For the fourth year in a row, the number of deaths of males was greater than of females. Because there are fewer women than men in the DMR population, the female death rate is higher despite the fact that fewer women than men died during the year. Since 2000, the proportion of male deaths has been increasing as the proportion of males increases in the overall DMR population. Table 4 shows the mortality rate by gender from 2001 to 2006 in the population served by DMR. The mortality rate for both genders decreased in 2006. The decrease in mortality rate was more pronounced for males than for females.

The DMR population also shows differences in average age at death between genders. In 2004 and 2005, the age at death was significantly lower in males than in females. However, in 2006, the average age at death for males has increased, and a significant difference in average age at death no longer exists between genders.<sup>14</sup> 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.

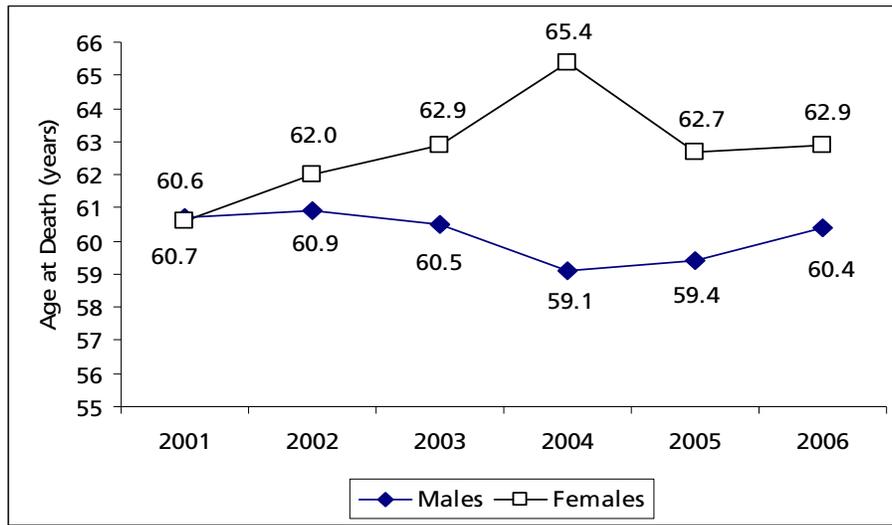
Table 4  
**DMR Mortality Rate by Gender 2001-2006**

Calendar Year <sup>10</sup>	Mortality Rate (per thousand)	
	Males	Females
2001	15.7	17.5
2002	16.1	20.2
2003	18.0	20.0
2004	19.0	18.9
2005	17.8	18.1
2006	15.8	17.6

<sup>13</sup> Revised mortality information is presented for 2001 and 2002

<sup>14</sup> One-tailed t-test with equal variance and hypothesized mean difference of zero. (T=1.46, df=361 p=0.072)

Figure 5  
DMR Age at Death by Gender, 2001-2006



## Residence

Adults eligible for DMR services live in one of five general types of residential settings: their own or family home; community settings operated, funded or certified by DMR; residential programs that are not part of the DMR system; facilities operated by DMR; and nursing homes or other long-term care settings. In addition, a small proportion of the population (0.2%) is made up of Ricci class members residing outside of the Commonwealth of Massachusetts. 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  
For Adults Served by DMR, 2006

Residential Setting	Adult Population (No. People)	Percent of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home	11,116	4.1%	68	17.7%	49.7	6.1
DMR Community	9,024	8.8%	155	40.5%	61.3	17.2
Non-DMR	1,089	19.7%	18	4.7%	62.9	16.5
DMR Facility	1,040	25.5%	44	11.5%	64.9	42.3
Nursing Home	732	47.3%	98	25.6%	68.6	133.9
Out of State	52	15.4%	0	0%	N/A	0.0
<b>Total (Statewide)</b>	23,053	9.1%	383	100%		
<b>Average</b>					61.6	16.6

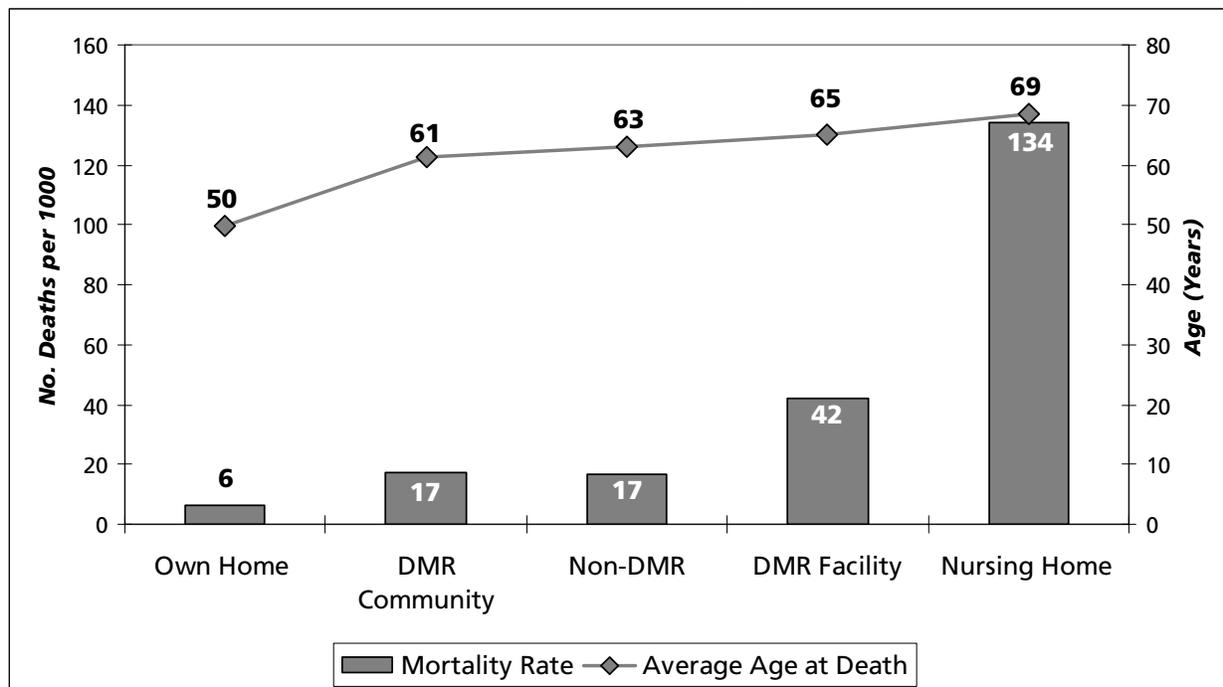
## Age and Residence

The average age at death varies across residential settings. Average age at death was lowest for individuals living in their own home or with family (49.7 years) and highest for those residing in nursing homes (68.6 years).

Generally, the average age at death for each residential setting is reflective of the relative age of the population that reside in each setting. Historically in the DMR population, the rate of death is higher in residential settings with higher average age at death, an expected finding since age is highly correlated with risk of mortality. Mortality statistics in 2006 continued to follow this pattern. In addition, all residential settings, except Non-DMR settings and the DMR facilities, showed a decrease in rate of death from 2005 rates. The population in these two settings is small, and the number of deaths and age at death tends to fluctuate across years.

Individuals residing in nursing homes experienced the highest rate of death in 2006, 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 mental retardation systems<sup>15</sup> since average population age tends to vary by type of residential setting.<sup>16</sup> 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, 2006



<sup>15</sup> State of Connecticut. *Mortality Annual Report*, July 2007.

<sup>16</sup> 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

Individuals served by DMR living in their own home or with family had the lowest mortality rate in 2006, similar to previous years. The crude rate of death for this residential group was 6.1 per thousand, which is a non-significant<sup>17</sup> increase from the 2005 rate of 5.9 per thousand. However, the mortality rate for people living independently or with family is still significantly lower than both the crude mortality rate of 8.5 per thousand and the age-adjusted rate of 7.2 per thousand for the general population in Massachusetts.<sup>18</sup> (See the 'Age-adjusted Mortality Rates' section of this report for the age-adjusted mortality rate for the MA DMR.)

This residential subgroup 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.

## DMR Community

The DMR 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 DMR consumers in Massachusetts, after the group of individuals living in their own home. The mortality rate for individuals served by DMR living in the DMR Community showed a non-significant<sup>19</sup> drop in 2006 to 17.2 per thousand, continuing a 2-year decline from a rate of 19.9 per thousand in 2004. While the DMR Community subgroup experienced the largest number of deaths, it maintains a low rate of death in comparison to other residential groups due to its relative size.

## Other Residential Settings

The remaining three residential settings, Non-DMR settings, DMR Facilities and Nursing Homes, represent in total less than 13% of the entire DMR 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-DMR.** The Non-DMR 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-DMR residences tend to cover a wide range of ages, with over one-third of the residents between the ages of 18-24, while the remainder falls within older age groups. Eighteen (18) individuals served by DMR living in Non-DMR residences died in 2006, resulting in a mortality rate of 16.5 per thousand. Because of the small size and the diverse nature of the population, the crude mortality rates for this population fluctuate each year. Changes in the rate of death and the average age at death in 2006 were not significantly<sup>20</sup> different from 2005 for the Non-DMR setting.

<sup>17</sup> Z-test between proportions of residential-specific deaths and populations,  $z=-0.186$

<sup>18</sup> *Massachusetts Deaths 2005*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, March 2007.

<sup>19</sup> Z-test between proportions of residential-specific deaths and populations,  $z=0.89$

<sup>20</sup> Z-test between proportions of residential-specific deaths and populations,  $z=-0.525$

**DMR Facilities.** DMR facilities serve an aging population, 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. In 2006, the mortality rate for individuals living in DMR facilities was 42.3 per thousand, a non-significant<sup>21</sup> increase since 2005 and similar to previous years. The average age at death for individuals residing in DMR facilities was similar to 2005 at 64.9 years.

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

Age Group	Rate of Death (per thousand)	
	US 2004 <sup>22</sup> (estimated)	DMR 2005
under 65	216.6	95.9
65-74	234.8	179.1
75-84	313.5	167.8
85+	557.7	174.6
<b>Total</b>	<b>363.5</b>	<b>133.9</b>

**Nursing Homes.** The population of individuals served by DMR living in nursing homes is, on average, the oldest of all the residential subpopulations. Almost 60% of individuals from this population in nursing homes fall between the ages of 55 and 84 years. The rate of death showed a non-significant<sup>23</sup> decrease in 2006 for people in this setting to 133.9 per thousand. While this rate of death is lower than 2005, it is similar to the mortality rate of 136.9 per thousand in nursing homes in 2004. 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 rate of death (363.5 per thousand) in Massachusetts nursing homes in 2005<sup>24</sup>. Massachusetts DMR mortality rates in nursing homes were also much lower than the U.S. nursing home mortality rates across all age groups, although it is important to note that this data is not age adjusted to account for possible differences in age distribution within age groupings. Rate of death by age for both the MA DMR and the US population are shown in Table 6. The rate of death

<sup>21</sup> Z-test between proportions of residential-specific deaths and populations,  $z=-0.341$

<sup>22</sup> 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. US Nursing Home populations are taken from: An Overview of Nursing Homes and Their Current Residents: Data From the 1995 National Nursing Home Survey, Advance Data (280), January 23, 1997, Vital and Health Statistics of the Centers for Disease Control and Prevention/National Center for Health Statistics. The 1995 population was adjusted with a 4% decline reported in nursing home populations by 2002, and a 5.7% decline from 2002 to 2005 as reported in: *Across the States: Profiles of Long Term Care, Seventh Edition, 2006*, Public Policy Institute, AARP.

<sup>23</sup> Z-test between proportions of residential-specific deaths and populations,  $z=0.756$

<sup>24</sup> 2005 Rate of Death in Massachusetts Nursing Homes calculated from a population in 2005 of 45,974 living in MA Nursing Homes (from *Across the States: Profiles of Long Term Care: Massachusetts, 2006*, Public Policy Institute, AARP) and a total number of 16,446 deaths in MA Nursing Homes from (*Massachusetts Deaths 2005*, Bureau of Health Statistics, Research and Evaluation Massachusetts Department of Public Health).

decreased in 2006 for those under the age of 65 and those over the age of 85 living in nursing homes. It increased for those aged 65-75. Because the population of nursing home residents in the DMR population is small, these rates are subject to fluctuation and should be compared with caution.

## **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 DMR 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 when conducting any direct comparisons. 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 for when comparing the DMR population to the U.S. population. Therefore, this report (2006 DMR Mortality Report) includes an *age-adjusted rate of death* to allow for more direct comparisons of the DMR consumer population to the U.S. 2000 population. This adjusted mortality rate represents the *relative* rate of death for the DMR 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 DMR 2006 & U.S. 2000 Standard Populations**

Overall, the DMR 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, the older age groups, which are smaller in comparison, become more heavily "weighted" when establishing the age-adjusted rate to the DMR population (i.e., to statistically model the DMR population after the U.S. population). Because older age groups have the highest mortality rate, the weighting results in an age-adjusted mortality rate that is higher than the crude mortality rate for the DMR population.

Figure 7 displays the relative percentage of the U.S. population and the MA DMR population in each age group. Higher percentages of younger individuals and smaller percentages of older individuals are present in the DMR population compared to the U.S. Standard Population. In 2006, the DMR population experienced a slight shift toward older age groups; the 35-44 age group decreased slightly relative to the US standard population, while the 45-54 and 55-64 age groups increased relatively.

Figure 7  
**Comparison of MA DMR and U.S. Standard Populations  
 Percentage of Population by Age Group**

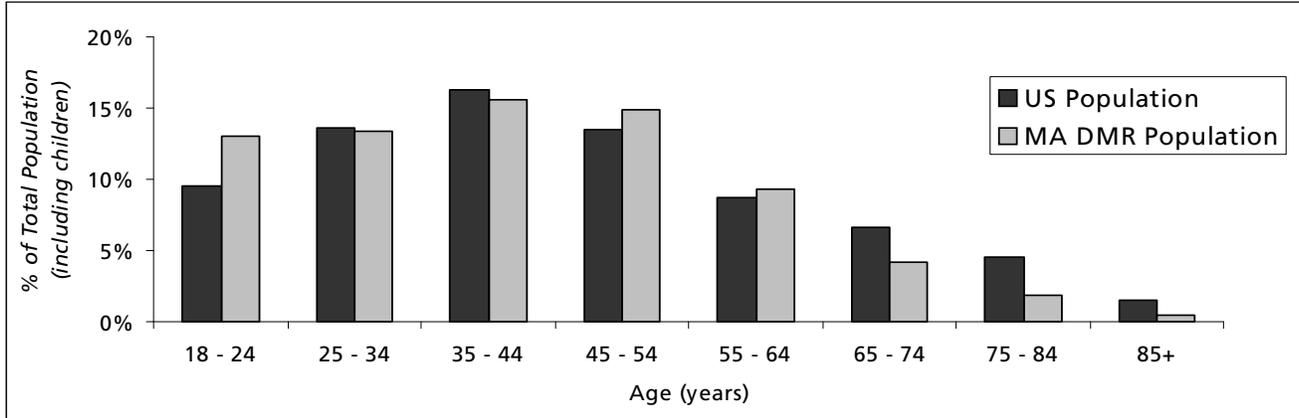


Table 7  
**Age-adjusted Mortality Rates**

Age Group	% population in age group		US 2004	DMR 2006	Weight	Weighted Rate (per thousand)
	US	DMR	Age-Adjusted Rate of Death <sup>25</sup> (per thousand)	rate of death (per thousand)		
18 to 24	9.6%	13.1%	0.9 <sup>26</sup>	3.1	0.096	0.30
25 to 34	13.6%	13.3%	1.0	4.5	0.136	0.61
35 to 44	16.3%	15.6%	1.9	4.9	0.163	0.79
45 to 54	13.5%	14.9%	4.3	14.8	0.135	2.00
55 to 64	8.7%	9.3%	9.1	29.6	0.087	2.58
65 to 74	6.6%	4.2%	21.6	64.1	0.066	4.24
75 to 84	4.5%	1.9%	52.8	93.0	0.045	4.17
85+	1.6%	0.5%	138.2	194.4	0.016	3.02
<b>Adult Total</b>	<b>74.2%</b>	<b>72.8%</b>	<b>8.0</b>	<b>16.6</b>	<b>0.742</b>	<b>17.7</b>

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

**Age-adjusted Rate<sup>27</sup> = 17.7 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 Mortality Rate = 2006 DMR mortality rate for age group \* Weight for age group

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

<sup>25</sup> National Vital Statistics Reports, Vol. 55, No. 19, August 21, 2007, October 10, 2007 Revision. Table 9. Death rates by age, and age-adjusted death rates for the 15 leading causes of death in 2004: United States, 1999–2004.

<sup>26</sup> This rate is for ages 20-24.

<sup>27</sup> 95% Confidence Interval = (17.57, 17.83)

## **Age-adjustment of the MA DMR 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<sup>28</sup> 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 DMR mortality rate “might be” if DMR had similar age structures to the general population. These results are presented in Table 7. See Appendix D for more information on the calculations involved in the direct method of age-adjustment.

The overall adjusted death rate for the DMR population is approximately 17.7 per thousand. The age-adjusted rate is higher than the crude mortality rate of 16.6 per thousand due to the larger proportions of the population in younger age groups. If the DMR 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.

This age-adjusted mortality rate for the DMR population is higher than the 2004 age-adjusted U.S. overall mortality rate of 8.0 per thousand<sup>29</sup> and the age-adjusted adult 2005 mortality rate for Massachusetts of 7.1 per thousand<sup>30</sup>. The findings in the DMR client population are consistent with the nationwide consensus for populations of this type. In general, the average age at death and the lifespan both tend to be lower in individuals with intellectual disabilities.<sup>31</sup>

---

<sup>28</sup> 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 DMR population.

<sup>29</sup> National Vital Statistics Reports, Vol. 55, No. 19, August 21, 2007, October 10, 2007 Revision. Table C. Deaths: Final Data for 2004. Insufficient information was provided for the 2004 preliminary US mortality data to calculate the adult age-adjusted mortality rate.

<sup>30</sup> Estimate of adult age-adjusted rate from populations and number of deaths per age group presented in the 2005 Massachusetts Mortality Report. Also, “adult” defined as 15 years +, as a 15-24 year old age group is presented in the report.

<sup>31</sup> Eyman RK, Grossman HJ, Chaney RH, Call TL. The life expectancy of profoundly handicapped people with mental retardation. N Engl J Med. 1990 Aug 30;323(9):584-9.

## TRENDS OVER TIME

### Mortality Rate

In 2006, both the number of deaths and the adult rate of death decreased in comparison to previous years. From 2000-2004, the adult mortality rate had shown consistent annual increases, as displayed in Table 8 and Figure 8. The decrease in 2006 continues a reversal in the directional change in mortality rate noted in 2005. This rather substantial reduction in the number of deaths resulted in a decrease in the mortality rate similar to levels reported for 2001.

Table 8  
Mortality Trends in DMR<sup>32</sup>, 2000 - 2006

Year	No. Deaths	Mortality Rate <sup>33</sup> (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

Figure 8<sup>34</sup>  
Statewide Mortality Rates, 2000-2006  
(Deaths per 1000)

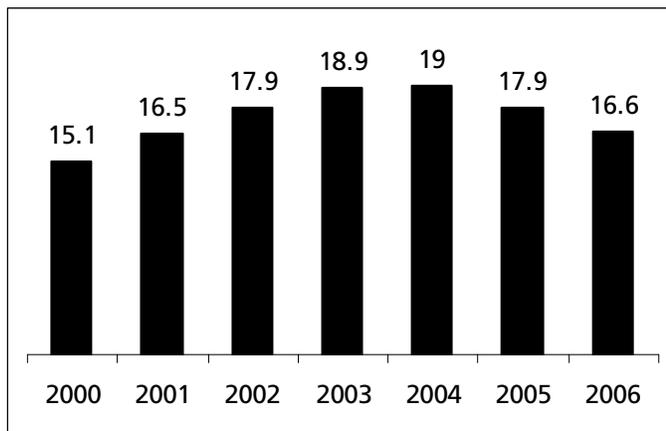
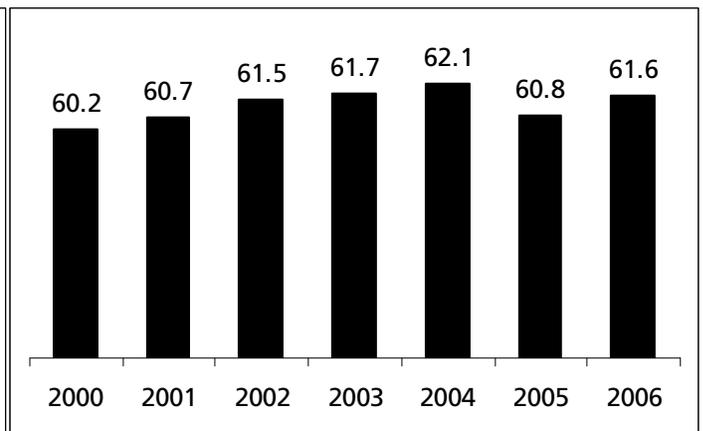


Figure 9  
Average Age at Death per Year  
2000-2006



<sup>32</sup> 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.

<sup>33</sup> The mortality rates for 2000, 2001 and 2002 are calculated with a revised client population that uses the methodology employed in 2003. This adjustment is made to make the rates comparable to 2003 data.

<sup>34</sup> 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 2003 and future rates with those from previous years.

Compared to 2005, the average age at death in 2006 increased slightly to 61.6 years. The range for the average age at death over the 2000-2006 time period is similar to the average age at death reported for adults served by the Connecticut DMR.<sup>35</sup>

Figure 10<sup>33</sup>  
Comparison of Mortality Rate by Age Group Over Time, 2002-2006

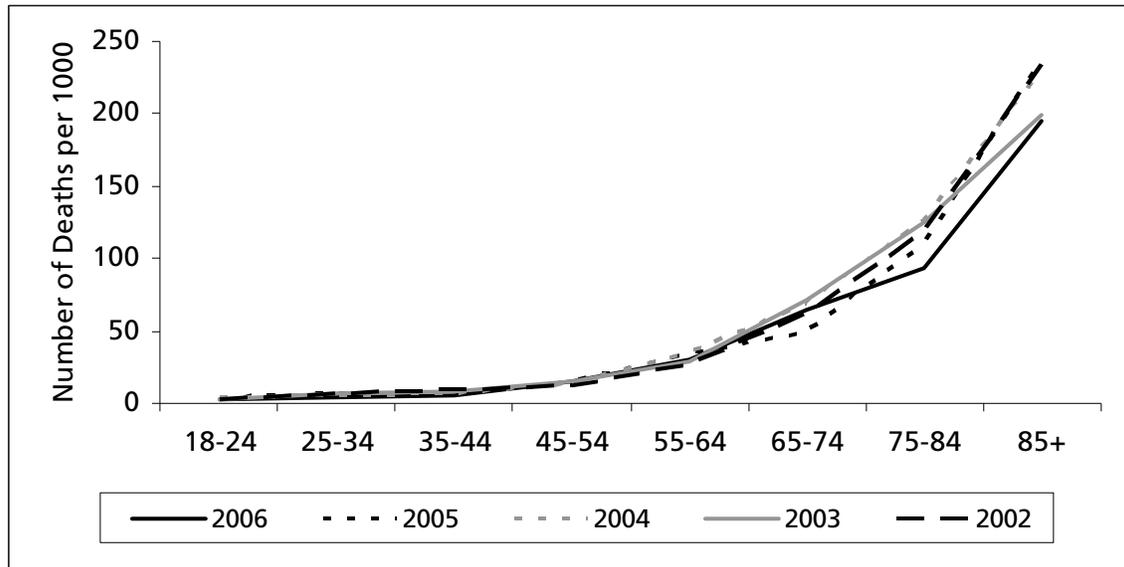


Figure 10 compares mortality rates over time by age group. The crude mortality rate increases with age, as expected. The older age groups (65+) show the largest amount of annual variability. It is important to note that these older age groups have relatively small populations and are typically at a higher risk of mortality. As a result, annual fluctuations in these groups can be expected. Rates of death in the 75-84 age group were slightly lower in 2006 than in previous years. The mortality rates for the younger age groups have remained consistent over time.

<sup>35</sup> CT DMR Mortality Report, 2006, published July 2007

## CAUSES OF DEATH

The following section presents information about the causes of death for adults served by the Massachusetts DMR during 2006. 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 DMR 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 DMR Mortality Review Committee.<sup>36</sup> [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 DMR 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."<sup>37</sup>*

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 DMR client population for 2006 are compared with data from five previous years and with state and national data in Table 9. Heart disease is the leading cause of death in 2006, consistent with data from previous years and with data from the Massachusetts and U.S. general populations.

For the first time, Alzheimer's Disease is the second ranked cause of the death. There was a sharp increase in the rate of death attributed to Alzheimer's Disease in 2006, rising to 2.4 per thousand. Nationally, the rate of Alzheimer's Disease has been

---

<sup>36</sup> In some cases, additional reports were available to confirm the cause of death, such as toxicology or medical examiner reports.

<sup>37</sup> 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.

Table 9  
Top 10 Leading Causes of Death

Rank	U.S. 2004 <sup>38</sup>	MA 2005 <sup>39</sup>	DMR 2001 <sup>40</sup>	DMR 2002	DMR 2003	DMR 2004	DMR 2005	DMR 2006
1	Heart Disease 27.2%	Heart Disease 24.6%	Heart Disease 21.2%	Heart Disease 21.2%	Heart Disease 22.3%	Heart Disease 18.5%	Heart Disease 16.4%	Heart Disease 21.9%
2	Cancer 23.1%	Cancer 24.5%	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 12.3%	Cancer 13.5%	Cancer 12.5%	Cancer 12.0%	Alzheimer's Disease 14.4%
3	Stroke 6.3%	Stroke 5.5%	Cancer 12.7%	Cancer & Septicemia <sup>41</sup> 10.1%	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 11.2%	Influenza and Pneumonia 10.8%	Cancer 9.9%
4	CLRD 5.1%	CLRD 4.9%	Septicemia 7.4%	C-P Arrest/ Seizure <sup>42</sup> 9.4%	Septicemia 9.0%	Influenza and Pneumonia 10.9%	C-P Arrest/ Seizure 10.8%	Aspiration Pneumonia 8.4%
5	Unintentional Injuries 4.75%	Influenza and Pneumonia 3.6%	Alzheimer's Disease 6.9%	Alzheimer's Disease 7.2%	C-P Arrest/ Seizure <sup>42</sup> 7.2%	Alzheimer's 7.5%	Aspiration Pneumonia 9.3%	CLRD 5.7%
6	Diabetes 3.1%	Unintentional Injuries 3.5%	Influenza and Pneumonia 6.1%	CLRD 6.2%	CLRD 6.0%	C-P Arrest/ Seizure <sup>42</sup> 6.8%	Alzheimer's Disease 8.6%	C-P Arrest/ Seizure <sup>42</sup> 5.5%
7	Alzheimer's Disease 2.8%	Alzheimer's Disease 3.0%	CLRD 4.1%	Influenza and Pneumonia 4.7%	Alzheimer's Disease 5.3%	Septicemia 6.6%	Septicemia 5.9%	Stroke 5.2%
8	Influenza and Pneumonia 2.5%	Nephritis 2.6%	C-P Arrest/ Seizure <sup>42</sup> 3.3%	Nephritis 4.0%	Influenza and Pneumonia 4.6%	CLRD 5.7%	CLRD 4.6%	Septicemia 5.2%
9	Nephritis 1.8%	Diabetes 2.4%		Accidents 3.3%	Stroke 3.5%	Stroke 4.2%	Nephritis 3.6%	Stroke 4.2%
10	Septicemia 1.4%	Septicemia 1.8%	Stroke 3.0%	Congenital Defects 2.5%	Nephritis 2.6%	Stroke 3.6%	Unintentional Injuries 3.4%	Influenza and Pneumonia 3.9%
								Unintentional Injuries 3.7%

\*\*CLRD = Chronic Lower Respiratory Disease

<sup>38</sup> 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;

<sup>39</sup> 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)

<sup>40</sup> Causes of death in 2001 were assigned by clinicians based on the Death Report, Mortality Review and in 25% of cases confirmed by Death Certificates.

<sup>41</sup> Septicemia and Cancer were tied for 3<sup>rd</sup> leading cause of death among DMR clients in 2002.

<sup>42</sup> Includes sudden deaths reported as cardio-pulmonary arrest whether or not seizure was present.

increasing with this rate projected to rise by 38% between 2000 and 2025.<sup>43</sup> The Commonwealth of Massachusetts is projected to experience a 17% increase in adults with Alzheimer's Disease during the same time period.<sup>43</sup> In addition, the shift in death reporting to use the underlying causes of death has increased the reporting of this disease as the final cause of death. Many of the deaths related to Alzheimer's Disease are in individuals with Down Syndrome, who experience an increased risk of early-onset Alzheimer's Disease. Almost 90% of the deaths from Alzheimer's Disease in individuals between the ages of 44 and 64 were in individuals with Down Syndrome.

Table 10  
Cause-specific DMR Mortality Rates, 2001-2006

2006 Rank	Previous Ranking	Cause of Death	DMR Rates of Death (per thousand)					
			2001	2002	2003	2004	2005	2006
1	1	Heart Disease	4.4	3.8	4.2	3.5	2.9	<b>3.6</b>
2	6	Alzheimer's Disease	1.1	1.3	1.0	1.4	1.5	<b>2.4</b>
3	2	Cancer	2.1	1.8	2.5	2.4	2.1	<b>1.6</b>
4	5	Aspiration Pneumonia	2.4	2.2	2.3	2.1	1.7	<b>1.4</b>
5	8	Chronic Respiratory Disease	0.7	1.1	1.1	1.1	0.8	<b>1.0</b>
6	3/4	CP Arrest/ Seizure <sup>42</sup>	0.6	1.7	1.4	1.3	1.9	<b>0.9</b>
7	9	Stroke	0.5	0.6	0.8	0.7	0.7	<b>0.9</b>
8	7	Septicemia	1.2	1.8	1.7	1.3	1.1	<b>0.9</b>
9	3/4	Influenza and Pneumonia	1.0	0.8	0.9	2.1	1.9	<b>0.7</b>
10	10	Unintentional Injury <sup>44</sup>	0.5	0.4	0.7	0.6	0.6	<b>0.6</b>

Table 10 displays cause-specific mortality rates for the major causes of death in the DMR population for the six year time period between 2001-2006<sup>45,46</sup>. In 2006, the mortality rate associated with heart disease was 3.6 per thousand, an increase over 2005, but similar to the rates reported for 2004 and previous years.

Mortality rates for cancer fell for the third straight year to 1.6 per thousand. Cancer dropped to the third leading cause of death. Mortality rates for influenza and pneumonia fell substantially in 2006 from 1.9 per thousand in 2005 to 0.7 per thousand in 2006, lowering it from third to a rank of ninth as a leading cause of death. Rates of death from aspiration pneumonia have continued to decline over the past 3 years, to the lowest reported rate (1.4 per thousand) since 2000. Rates of death from cardiopulmonary arrest and seizure decreased in 2006. Rates of death from septicemia also declined, continuing a trend noted for the past four years.

Unintentional injuries was again ranked tenth, with the rate of death for this cause remaining unchanged since 2004. Most deaths from unintentional injuries were due to

<sup>43</sup> *Across the States: Profiles of Long Term Care: Massachusetts, 2006*, Public Policy Institute, AARP, Pg W-14

<sup>44</sup> 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.

<sup>45</sup> Cause-specific mortality rates are unavailable for 2000.

<sup>46</sup> 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.

choking and aspiration (5 of 14 deaths)<sup>47</sup> or motor vehicle accidents (5 of 14 deaths). In past years, many of the deaths from unintentional injuries were due to falls. However in 2006, no fall-related deaths were reported. The number of deaths from choking and aspiration was half what it was in 2005. Deaths from injuries continue to occur at a much lower rate than in the Massachusetts state population.

## Cancer

The adult mortality rate for cancer declined substantially in 2006 to 1.6 per thousand. This is the lowest cancer rate since mortality reporting for this population began in 2000. Cancer fell among the leading cause of deaths to third for the DMR Population.

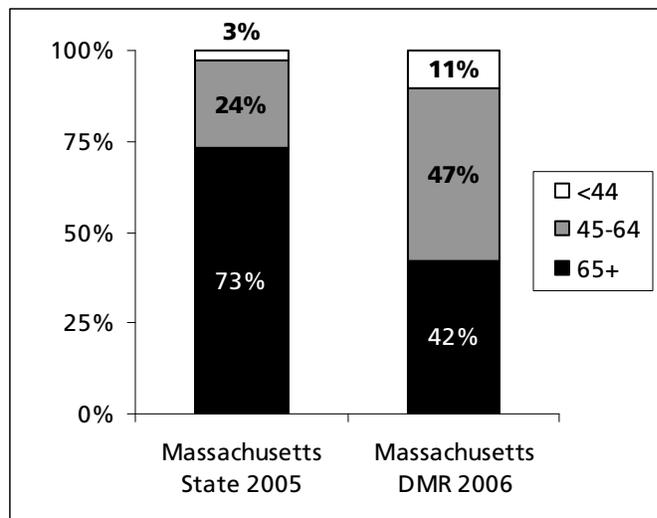
Cancer of the colon, rectum or anus was the most common primary site (7 deaths). The next three most common sites of cancer resulted in 5 deaths each: female breast cancer; cancer of the trachea, bronchus and lungs; and cancer of the meninges, brain and the central nervous system. The mortality rate due to stomach and esophageal cancers, which both ranked highly in 2005, has dropped in 2006. Some variation exists across years with the primary sites of cancers resulting in death in this small population.

The age distribution of deaths from cancer differs between the Massachusetts DMR and the Massachusetts general population, as shown in Figure 11. In Massachusetts, almost two-thirds of deaths from cancer occur in adults over the age of 65. The population served by the Massachusetts DMR 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<sup>49,50,51,52</sup> (e.g. leukemia, colorectal,

Table 11  
Top Cancer Causes  
in the DMR Population, 2006

Primary Site	Number of Deaths	Average Age at Death
Colon, Rectum and/or Anus	7	55.6
Female Breast	5	69.4
Trachea, Bronchus and Lungs	5	67.2
Meninges, Brain and other parts of Central Nervous System	5	55.3

Figure 11<sup>43</sup>  
Age Distribution of Cancer Deaths



<sup>47</sup> 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)

<sup>48</sup> In Figure 22 in the state report, Massachusetts data includes ages 1-44 in the "<44" group, whereas MA DMR includes ages "18-44" in this group.

<sup>49</sup> 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.

oropharyngeal, thyroid, testicular, gastrointestinal) and the appearance of cancers at significantly younger ages (e.g. colorectal cancer around age 35<sup>49</sup>) in individuals with intellectual disabilities of certain etiologies.

In 2006, the rate of death from cancer in the DMR population (1.6 per thousand) was lower than the 2004 national (1.8 per thousand) and 2005 statewide (1.8 per thousand) general population rates.<sup>53</sup> 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**

Tables 12 and 13 compare age-specific causes of death for the 2006 DMR population and the 2005 Massachusetts population.<sup>54</sup> Similar to previous years, the causes of death in the younger DMR age group vary from statewide general population findings. In younger individuals served by DMR, the primary causes of death are related to medical conditions. In the general population accidents and 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 DMR population and no deaths occurred from accidents (unintentional injuries) in the 18-24 year old group for the DMR population. Findings over the past five years suggest deaths from accidents in the DMR population are most likely to occur for individuals over the age of 55 and are most often related to falls, aspiration/choking or motor vehicle accidents.

Table 12  
**Cause of Death by Age Group for DMR, 2006**  
*(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	Not enough data to rank	Not enough data to rank	CP Arrest/Seizure <sup>42</sup>	Heart Disease, Alzheimer's Disease	Alzheimer's Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease
2			Nephritis and Other Renal Disease		Heart Disease	Alzheimer's Disease	Aspiration Pneumonia	Influenza & Pneumonia, Aspiration Pneumonia, Cancer	Alzheimer's Disease
3			Multiple Causes	Cancer	Cancer	Cancer	Stroke (Cerebrovascular Disease)	Cancer	

<sup>50</sup> 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.

<sup>51</sup> 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.

<sup>52</sup> Patja K, Eero P & Livanainen M. Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research*. 2001 Aug 45(4):300-307.

<sup>53</sup> National and Massachusetts cancer rates from *Massachusetts Deaths 2005*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, March 2007.

<sup>54</sup> The most current data available for the Massachusetts general population was for the year 2005.

Table 13  
Cause of Death by Age Group for Massachusetts Population, 2005<sup>55</sup>

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*	CLRD*	Stroke	Stroke

\* CLRD = Chronic Lower Respiratory Disease

In 2006, Alzheimer's Disease was a leading cause of death starting in the 45-54 year old age group for the MA DMR population. However, Alzheimer's Disease does not rank as a leading cause at any age in the general population. Many of the deaths related to Alzheimer's Disease are in individuals with Down Syndrome, who experience an increased risk of early-onset Alzheimer's Disease.

More of the deaths from cancer were in older age groups than in previous years. The percent of cancer deaths in the under 44 and 45-64 age groups decreased in 2006.

Interestingly, chronic lower respiratory disease (CLRD) moved to third for the 75-84 year old population in Massachusetts. The Massachusetts DMR population experienced a slight increase in the mortality rate from CLRD, although it was not one of the leading causes of death for any age group.

### **Cause of Death by Residence**

Average age and health characteristics tend to vary across the DMR subpopulations living in different residential settings. These differences may appear to influence the associated causes of death.

In DMR Community residential settings, heart disease remained the leading cause of death in 2006, with the crude mortality rate for this cause increasing from 2.5 in 2005 to 3.9 in 2006. Cancer dropped from the second leading cause to the fourth due to a decrease in the rate of death from 2005. The rate of death from Alzheimer's Disease increased in this group to 2.9 per thousand, moving it up to the second leading cause of death. The rate of death from aspiration pneumonia dropped slightly from 1.5 per thousand in 2005 to 1.4 per thousand in 2006. However, its relative rank increased to third because of a drop in the rate of death of other common causes of mortality. Rates of septicemia and influenza pneumonia related deaths decreased in 2006 in DMR Community residential settings.

<sup>55</sup> 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)

Table 14  
Major Causes of Death for DMR Community<sup>56</sup>

Rank	Cause of Death	Number of Deaths	Rate of Death
1	Heart Disease	35	3.88
2	Alzheimer's Disease	26	2.88
3 & 4	Aspiration pneumonia	13	1.44
	Cancer	13	1.44
5	Stroke (Cerebrovascular disease)	10	1.11

Table 15  
Major Causes of Death for Individuals  
Served by DMR and Residing in Their Own Home<sup>57</sup>

Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)
1	Heart Disease	12	1.17
2	Cancer	10	0.90
3	C/P Arrest/ Seizure <sup>42</sup>	8	0.72
4	Congenital Anomalies	6	0.54
5	Nephritis and other Renal	5	0.45

As shown in Table 15, 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. However, in 2006 congenital anomalies increased to the fourth leading cause of death. Rates of influenza and pneumonia declined in this group in 2006.

Table 16\*  
Major Causes of Death for Individuals  
Served by DMR in Other Residential Settings

Rank	Nursing Home	Non-DMR	DMR Facility
1	Heart Disease	Aspiration Pneumonia, CLRD	Aspiration Pneumonia
2	Alzheimer's Disease		Heart Disease
3	Cancer	Alzheimer's Disease, Heart Disease	Cancer

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

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

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

Although the population of individuals served by DMR in Nursing Homes is small (732 individuals or 3.2% of the DMR population), about one-quarter of all DMR deaths occurred in this type of residential setting. Both the population size of people served by DMR in nursing homes and the proportion of overall deaths in nursing homes declined in 2006. As in past years, individuals served by DMR in nursing homes consistently experienced higher mortality rates from heart disease and cancer. In 2006, there was a substantial increase in deaths from Alzheimer's Disease, making it the second leading cause of death for nursing home residents. The rate of deaths from cancer in this group dropped in 2006. Heart disease and aspiration pneumonia are common top causes for this residential setting in previous years. The top causes of death for individuals residing in DMR facilities are similar to previous years.

## **MORTALITY REVIEW PROCESS AND COMMITTEE**

Clinical mortality reviews are completed by DMR 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 DMR, or
3. died in a day support program funded or certified by DMR, or
4. died while participating in a day habilitation program, or
5. died during transportation funded or arranged by DMR.

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 DMR policy were completed, resulting in 100% compliance. A total of 197 mortality reviews were completed for 2006 deaths, 192 of these reviews were required by DMR policy.

### **Mortality Review Procedure**

A clinical Mortality Review is conducted by the DMR 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 DMR Director of Health Services, DMR Director of Risk Management, DMR Director of Investigations, at least one representative from each of the Regional Mortality Review Committees, 2 physicians (one DMR and one a community practitioner), a representative each from the Department of Public Health and the Disabled Person’s Protection Commission, a clinical pharmacist, 2 DMR nurse practitioners, one from a facility and one from an area office, and a DMR 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 DMR are reported to the DMR 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 DMR 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.<sup>58</sup>

Table 17  
Summary of Investigations, 1999 to 2006

Type of Activity	1999	2000	2001	2002	2003	2004	2005	2006
DMR Investigation	7	5	5	14	9	5	10	2
DPPC Investigation	5	1	2	2	4	6	5	3
DPH Investigation	2	1	8	10	10	9	4	2
District Attorney/Law Enforcement Investigation	0	3	1	3	2	4	4	2
Other/dismisssed <sup>59</sup>	5	3	5	4	2	1	2	3
Total Number of Deaths Investigated	19	13	21	33	27	20	19	9
No. Substantiations	0	0	1	2	2	1	4	2
Pending								3

<sup>58</sup> “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.”

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

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 DMR may conduct an investigation of issues in a DMR funded or licensed setting and DPH may conduct a separate, non-duplicative investigation of the care of the individual received while in an acute care hospital.

During 2006 there were nine (9) deaths investigated by one or more of the agencies identified above, two of which also involved law enforcement investigation. Investigations about four of the deaths were found to be unsubstantiated. Three investigations by agencies other than DMR are still pending. DMR conducted two investigations on 2006 deaths, both of which were found to be unsubstantiated. A total of three investigations were conducted by DPPC. Two of those cases were found to be unsubstantiated and one case is still pending. Two investigations were conducted by DPH; one case was found to be unsubstantiated and one case is still pending. Two cases were investigated by the District Attorney/Law Enforcement, one of which was substantiated and one that is pending criminal action. The cases listed as "other/dismissed" were referred to DMR regional directors. Of the 2 cases that were substantiated, 1 involved a bowel obstruction due to Pica and was referred to the Board of Nursing Home Administrators. The other case involved a choking episode that occurred on a van. It was referred to the District Attorney. As can be seen in Table 17, the number of investigations in 2006 was much smaller than in previous years.

## BENCHMARKS

Each of the annual DMR 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 DMR, 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 DMR 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 DMR 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 DMR 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 DMR.**

### Cause of Death Benchmarks

Comparisons of the top five leading causes of death as reported by the MR/DD state agencies in Connecticut<sup>60</sup>, Ohio<sup>61</sup> and Vermont<sup>62</sup> are presented below in Table 18.

---

<sup>60</sup> *Health and Mortality Review: 2005 Annual Report*. Connecticut Department of Mental Retardation, 2006.

<sup>61</sup> Cause of Death Annual 2005, Ohio MRDD, at <http://odmrdd.state.oh.us/health/report.htm>

<sup>62</sup> *Mortality among People Receiving Developmental Services in Vermont FY 2004*, Vermont Division of Developmental Services, 2005.

**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 DMR 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. 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.

Table 18  
**Comparison of the Top 5 Leading Causes of Death  
 As Reported by Four State MR/DD Agencies**

Rank	MA DMR 2006	CT DMR 2006 <sup>63</sup>	OH OMRDD 2006 <sup>64</sup>	VT DDS 2005 <sup>65</sup>
Method	Underlying	Primary	Unknown	Underlying
1	Heart Disease 21.9%	Heart Disease 25.4%	Heart Disease 18%	Respiratory Disease/ Pneumonia 23%
2	Alzheimer’s Disease 14.4%	Respiratory Disease 18.2%	Pneumonia 13%	Alzheimer’s Disease, Cancer and Heart Disease 12% each
3	Cancer 9.9%	Pneumonia (non- aspiration) 14.4%	Cancer 12%	
4	Aspiration Pneumonia 8.4%	Cancer 11%	Aspiration Pneumonia 11%	
5	Chronic Lower Respiratory Disease 5.7%	Septicemia 7.8%	Accidents and Adverse Actions 9%	Seizure Disorder and Diabetes 8% each

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. Nonetheless, it is interesting to note that there is some similarity 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 represent top causes of death for four state systems. While septicemia was previously within the top five rankings for many benchmark states, it has fallen out of the top 5 for all states except Connecticut. The most common primary sites of cancer resulting in death in Connecticut were tied as: stomach, colorectal, breast and trachea, bronchus and lungs. These primary sites are very similar to those seen in the Massachusetts DMR.<sup>63</sup>

<sup>63</sup> CT DMR Mortality Report, 2006, published July 2007

<sup>64</sup> Ohio, Cause of Death Annual 2006

<sup>65</sup> Mortality Among People in Vermont Receiving Developmental Disability Services (DDS) FY 2005

Alzheimer’s Disease, however, appears to be increasing and is now a leading cause of death for both Vermont and Massachusetts. 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<sup>43</sup>. In 2006, Connecticut reported their causes of death for those with Down Syndrome separately in a section of their report. While the most common primary causes of death for individuals with Down Syndrome were (1) cardiac arrest, (2) aspiration pneumonia and (3) respiratory failure, they also note that seventy-three percent (73%) of people with Down Syndrome who died also had a diagnosis of Alzheimer’s Disease at the time of their death.<sup>63</sup> The average age at death in 2006 for those in Connecticut with both Down Syndrome and Alzheimer’s Disease was 57.3 years.<sup>63</sup>

In their annual mortality report for 2006, the Connecticut DMR reported causes of death separately for those where their department “has direct or oversight responsibility for medical care.” These individuals receive a mortality review by the Connecticut DMR. This subpopulation would be similar to the DMR Community and DMR facilities in the Massachusetts population. In Connecticut this subpopulation includes 145 deaths, and represents 71% of all deaths in the state’s DMR population. The report lists the primary causes of death as: heart disease, ranked first with 29% of deaths and respiratory disease, ranked second with 16.5% of deaths. Cancer was ranked third, and aspiration pneumonia was ranked fourth in Connecticut’s subpopulation. According to their annual report, most of the pneumonia deaths in Connecticut are reported to be due to aspiration pneumonia. This finding is similar to the Massachusetts DMR mortality findings.

**Mortality and Gender Benchmarks**

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 19. 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 be responsible for the higher relative crude mortality rates in Massachusetts.

Table 19  
**Comparison of the Percentage of Deaths by Gender  
 for Two State MRDD Systems**

<b>Gender</b>	<b>Measure</b>	<b>MA DMR 2006</b>	<b>CT DMR 2006</b>
<b>Male</b>	Percentage of Deaths	52%	56%
	Death Rate	15.8	11.9
	Ave. Age of Death	60.4	56.8
<b>Female</b>	Percentage of Deaths	48%	44%
	Death Rate	17.6	15.1
	Ave. Age of Death	62.9	58.3

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

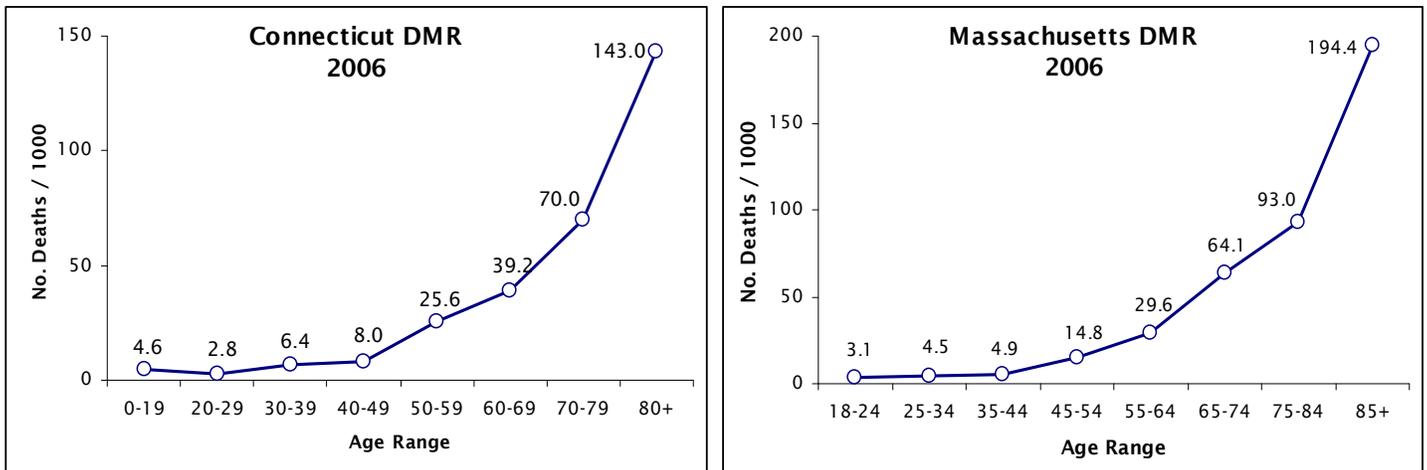
## Mortality and Age Benchmarks

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 20 and Figures 14 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 difficult to draw direct comparisons, particularly in the more elderly age groups where each year of age begins to substantially increase risk of mortality (i.e., Massachusetts ranges are about 5 years older than Connecticut's resulting in an older age cohort, a factor that can be significant in the 60-yr plus groupings).

Table 20  
**Comparison of the Mortality Rate by Age  
 For the Massachusetts DMR and Connecticut DMR**

<b>Crude Mortality Rate by Age (Not Age Adjusted)</b>			
<b>CT DMR (2006)</b>		<b>MA DMR (2006)</b>	
<b>Age Range</b>	<b>Mortality Rate</b>	<b>Age Range</b>	<b>Mortality Rate</b>
0-19	4.6	18-24	3.1
20-29	2.8	25-34	4.5
30-39	6.4	35-44	4.9
40-49	8.0	45-54	14.8
50-59	25.6	55-64	29.6
60-69	39.2	65-74	64.1
70-79	70.0	75-84	93.0
80+	143.0	85+	194.4

Figure 12  
**Connecticut DMR and Massachusetts DMR Mortality Rates by Age**



## 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.<sup>66</sup> 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.

Crude mortality rates (no. of deaths per 1000 people served) by type of residential setting are provided in Table 21 for the Connecticut and Massachusetts DMR state systems (2006 data). The facility (ICF/MR) crude mortality rates for the Massachusetts DMR appear to be somewhat higher than for the Connecticut system. However, mortality rates for persons served within nursing facilities appear to be much lower. Crude mortality rates in the Massachusetts DMR system for community residence has declined in 2006, and is now quite similar to the Connecticut mortality rate for this setting. Differences in population characteristics (e.g., Connecticut serves a small number of children within community residences and facilities) may contribute to such differences in death rate by type of residence. Once again, the absence of age-adjusted rates compromises the ability to make valid and direct comparisons. 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).

Table 21  
Comparison of the Mortality Rate by Residential Setting  
For the Massachusetts DMR and Connecticut DMR

Type of Residential Setting	Mortality Rate (per thousand)	
	MA DMR 2006	CT DMR 2006
At Home/Family	6.1	4.6
Independent & Supported Living		6.3
Community Group Home	17.2	17.1
Community Training Home		4.8
Regional Center	42.3	18.4
Facility-ICF/MR		36.7
Nursing Facility	133.9	176.0

<sup>66</sup> 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 two other states, California and Connecticut that presented mortality data according to this variable. However, both California and Connecticut organize residential data using slightly different categories than does Massachusetts. In addition, these states provide some residential services for children, whereas Massachusetts serves an adult population.

## 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 22, the reported crude death rate for the MA DMR 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, the higher rate for Massachusetts is to be expected since the MA mortality rate is based only on adults whereas some of the other state rates are based on a population 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 22  
Comparison of Crude Mortality Rates for Selected State MRDD Systems

Comparative Mortality Rates	MA DMR 2006	CT DMR 2006	CT DMR 2006	AZ DDD 2004	TN DMRS <sup>67</sup> FY2005	VT FY2005	OH 2006
Population Served	MR only	MR only	MR only	DD	DD	DD	DD
Age Range (for computing rate)**	adults only (18+ yrs)	children and adults	adults only (20+ yrs)	children and adults	N/A	children and adults	children and adults
No. Deaths	383	202	185	216	108	26	746
<b>Mortality Rate (no./1000)</b>	<b>16.6</b>	13.5	<b>16.3</b>	9.7	10	8.4	9.5 <sup>68</sup>

<sup>67</sup> TN rate is approximate, as it was reported as 1 per 100 individuals. Specific population analyzed in the mortality analysis was not included in the narrative. Rate is approximate, as it was reported as 1 per 100 individuals.

<sup>68</sup> Death rate calculated a 2006 population reported in "Reporting Rates for MUIs per 1000 Individuals":  
<http://odmrdd.state.oh.us/health/MUI%20Annual%20Report/2006/Reporting%20Rates%20per%201000%20Individuals.pdf>

## 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 23 below displays data associated with 27 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 DMR 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.

Statistics from 2004 were the most current figures available for the U.S. population. 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 DMR serves a relatively small population (about 23,000 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 DMR 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 (2002-2006). 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 DMR 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.

Overall, rates for individuals in the Massachusetts DMR population meet many more HP2010 targets than the general Massachusetts population or the national population. In most injury categories, the DMR population meets or exceeds the target rate for 2010. However, rates for unintentional injuries (accidents) and injuries from falls are higher than the goal. Rates of unintentional injuries are similar to Massachusetts rates

Table 23  
Target Status for Selected Healthy People 2010 Mortality Objectives<sup>69</sup>

<u>Objective Number</u>	<u>HEALTHY PEOPLE 2010</u>		<u>TARGET 2010<sup>70</sup></u>	<u>DMR 2002-2006</u>	<u>DMR TARGET STATUS</u>	<u>MA 2005<sup>71</sup></u>	<u>US 2004<sup>70</sup></u>
	<u>OBJECTIVE</u>	<i>Rates per 100,000 population; MA and US are Age-adjusted</i>					
3-1	Overall Cancer death rate		158.6	210.5	●	185.8	185.8
3-2	Lung Cancer		43.3	16.6	✓	52.4	53.2
3-3	Female Breast Cancer (per 100,000 females)		21.3	36.8	●	23.1	24.4
3-4	Cervical (per 100,000 females)		2.0	5.8	●	1.6	2.4
3-5	Colorectal Cancer		13.7	23.5	●	17.6	18.0
3-6	Oropharyngeal Cancer		2.4	4.4	●	2.1	2.6
3-7	Prostate Cancer (per 100,000 males)		28.2	12.7	✓	21.8	25.4
3-8	Malignant Melanoma		2.3	4.4	●	3.3	2.7
5-5	Diabetes-related deaths		46	22.7	✓	56.0 <sup>72</sup>	76.0
12-7	Stroke deaths		50	74.2	●	38.7	50.0
26-3	Drug-induced deaths		1.2	0.0	✓	12.9	10.4
13-14	HIV-infection deaths		0.7	-- <sup>73</sup>	✓*	2.7	4.5
24-10	Chronic Obstructive Pulmonary Disease Deaths (age 45+)		62.3	182.2	●	96.3 <sup>72</sup>	112.8
	<u>Injuries</u>						
15-3	Firearm-related		3.6	0.0	✓	3.4	10.0
15-8	Poisonings		1.5	0.0	✓	122	10.3
15-9	Hanging, strangulation or suffocation		3.3	0.0	✓	4.9	4.8
15-13	Unintentional injuries (Accidents)		17.1	29.7	●	27.4	37.7
15-15a	Motor vehicle crashes		8.0	7.8	✓	7.2	14.7
15-29	Drowning		0.7	-- <sup>73</sup>	✓*	1.2	1.3
15-25	Residential fire deaths		0.2	-- <sup>73</sup>	✓*	0.6	1.0
15-27	Falls		3.3	8.7	●	3.8	6.3
15-32	Homicide		2.8	-- <sup>73</sup>	✓*	2.8	5.9
18-1	Suicide		4.8	-- <sup>73</sup>	✓*	7.0	10.9

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

<sup>69</sup> 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.

<sup>70</sup> Data 2010 the Healthy People 2010 Database. CDC Wonder website: <http://wonder.cdc.gov>. October, 2007 Edition, Accessed 12/07/07.

<sup>71</sup> Data 2010 the Healthy People 2010 Database. CDC Wonder website: <http://wonder.cdc.gov>.

<sup>72</sup> 2005 rate was unavailable. Rate from 2004 substituted.

<sup>73</sup> Too few deaths occurred to be statistically reliable (i.e. only 1-3 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.

and lower than national rates. The average rate for falls in the MA DMR population is higher than state and national rates.<sup>74</sup>

While reviewing the table, it should be kept in mind that the risk of cancer significantly increases with age.<sup>75</sup> The rates included for the DMR 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 DMR population since only adults are used for the rate calculations.

The averaged crude mortality rate for cancer in the DMR population is above the HP2010 target and state and national rates. However, for the first time since 2000, the 2006 mortality rate from cancer dropped within 25% of the HP2010 target, with a rate of 164.8 per hundred thousand. Rates of death from cancer in the DMR population have been steadily declining since 2003. If this trend continues, the 5-year average for the MA DMR will soon be within 25% of the HP2010 target.

Average mortality rates for colorectal cancer were similar to previously reported rates for the DMR 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. Rates of death from lung and prostate cancer for the DMR population were well within the Healthy People 2010 targets.

Rates of female breast cancer continue to be higher than the 2010 target and both the Massachusetts and national rates. Rates of cervical, oropharyngeal and malignant melanoma were moderately higher than the 2010 targets. However, there were a relatively small number of deaths associated with these forms of cancer within the DMR population (i.e., only 3, 5 and 5 cases respectively across the past 5 year time period). Average rates of cervical cancer dropped in 2002-2006.

Mortality rates for diabetes-related deaths were once again lower for the DMR population than both the rate for the general population in Massachusetts and the Healthy People 2010 target.

The DMR population experienced more deaths 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 DMR population exceeded the HP2010 goal, and increased with the addition of the 2006 data. It should be noted that many adults with intellectual disabilities have higher rates of respiratory problems that may help account for this finding.<sup>76,77</sup>

---

<sup>74</sup> Mobility limitations for some individuals may contribute to the rate of deaths from falls in the DMR population.

<sup>75</sup> Janicki MP, Davidson PW, Henderson CM, McCallion P, Taets JD, Force LT, Sulkes SB, Frangenberg E & Ladriagan 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.

<sup>76</sup> 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.

<sup>77</sup> 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.

## **APPENDICES**

- Appendix A: Methodology for Mortality Review and Analysis
- Appendix B: Residential Codes and Definitions
- Appendix C: Demographic Data
- Appendix D: Calculations for the Age-Adjusted Mortality Rate
- Appendix E: ICD-10 Codes Used in this Publication (Sorted by ICD-10 Codes)
- Appendix F: ICD-10 Codes Used in this Publication (Sorted by Category)
- Appendix G: ICD-10 Codes for Selected Healthy People 2010 Mortality Objectives Used in this Publication

## Appendix A

### **Methodology**

The 2006 Mortality report analyzes information on all deaths occurring in calendar 2006 for all individuals with intellectual disabilities, 18 years of age or older, who have been determined to be eligible for DMR supports.

The source data for this report comes from DMR Death Records that must be completed within 24 hours of an individual's death according to DMR policy. The 2006 Mortality Report includes statistics on all deaths of individuals who died in calendar year 2006 and whose Death Report was received by DMR by the end of January 2007. A total of 383 deaths were reported to have occurred between January 1, 2006 and December 31, 2006.

The data used to calculate death rates per 1000 by age group and type of residence was supplied by the DMR Meditech System of June 30, 2006.<sup>78</sup> The CRS contains information on every person eligible for DMR supports, including those who may not be receiving DMR services currently. In addition DMR made Mortality Review forms and clinical notes available to CDDER for verification of information about the individuals subject to clinical mortality review.

DMR provided the following information for all 383 deaths:

- Name of the individual
- Date of birth
- Date of death
- Social security number
- Cause of death, if known
- Residence type
- DMR 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 DMR 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:

$$\text{Crude Death Rate} = \frac{(\text{Number of individuals who died in calendar year 2006} \times 1000)}{(\text{No. Individuals in CRS in June 2006})}$$

---

<sup>78</sup> 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**

**DMR Community:** *DMR-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	Temporary Residence
4157	DMR State Operated Residential

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

3200	ICF-MR
4000	DMR Nursing Facility

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

3000	Nursing Facility
------	------------------

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

0000	Living at Home with Family
9999	Living at Home-Independently

**Non-DMR:** *A small segment of the DMR population lives in residences and facilities not covered by the above definitions and not funded by DMR, such as special education schools, DMH and MCB group homes, DPH hospitals, adult foster care funded by Medicaid or in temporary residences and respite homes.*

3001	DMH Inpatient
3950	DMA Adult Foster Care
3951	Homeless/Homeless Shelter
3952	Incarceration
3953	DMH Community Residential Program
3977	766 Residential Program
3978	Rehab Hospital (non-DMH)
MCBR	MCB Residential Supports

**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 2006 DMR Adult population

SEX	Age	DMR-Funded Community	DMR Facility	Nursing / Rest Home	Own Home	Non-DMR	Out of State	Total
F	18-24 yr	164	3	14	1415	121	0	1,717
M	18-24 yr	245	3	26	1916	230	0	2,420
F	25-34 yr	597	2	43	1193	43	0	1,878
M	25-34 yr	835	11	33	1412	56	0	2,347
F	35-44 yr	974	52	46	1016	88	0	2,176
M	35-44 yr	1397	72	39	1170	90	2	2,770
F	45-54 yr	1069	134	33	807	99	0	2,142
M	45-54 yr	1358	204	33	864	96	21	2,576
F	55-64 yr	715	108	71	446	78	0	1,418
M	55-64 yr	788	186	48	417	62	21	1,522
F	65-74 yr	281	78	76	175	32	0	642
M	65-74 yr	323	99	58	174	39	6	699
F	75-84 yr	122	29	91	56	26	0	324
M	75-84 yr	115	40	58	44	19	2	278
F	85+ yr	27	9	51	4	7	0	98
M	85+ yr	14	10	12	7	3	0	46
Total		9,024	1,040	732	11,116	1,089	52	23,053

## 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 DMR population.

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

Where

*R'* = age-adjusted rate,

*P<sub>Si</sub>* = standard population for age group *i*,

*P<sub>S</sub>* = total U.S. standard population (all ages combined)

## Appendix E

**ICD-10 Codes Used in this Publication**

(Sorted by ICD-10 Codes)

<b><u>Cause of Death</u></b>	<b><u>ICD-10 Code</u></b>
<b>Infectious and parasitic diseases</b>	A00-B99
Septicemia	A40-A41
Human Immunodeficiency Virus (HIV) disease	B20-B24
<b>Cancer (Malignant Neoplasms)</b>	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
<b>Diabetes Mellitus</b>	E10-E14
<b>Alzheimer's Disease</b>	G30
<b>Heart Disease</b>	I00-I09, I11, I13, I20-I51
<b>Stroke (Cerebrovascular Disease)</b>	I60-I69
<b>Influenza and Pneumonia</b>	J10-J18
<b>Chronic Lower Respiratory Diseases<sup>1</sup></b>	J40-J47
<b>Chronic Liver Disease and Cirrhosis</b>	K70, K73-K74
<b>Nephritis</b>	N00-N07, N17-N19, N25-N27
<b>Congenital malformations, deformations, and Chromosomal abnormalities</b>	Q00-Q99
<b>External causes of injuries and poisonings (intentional, unintentional and of undetermined intent)</b>	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)

---

<b><u>Cause of Death</u></b>	<b><u>ICD-10 Code</u></b>
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 <sup>1</sup>	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

---

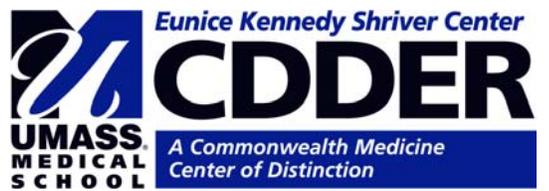
## Appendix G

**ICD-10 Codes for Selected Healthy People 2010**  
**Mortality Objectives**  
**Used in this Publication**  
(Sorted by Objective Number)

<b>Objective Number</b>	<b>Cause of Death*</b>	<b>ICD-10 Identifying Codes</b>
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
12-7	Stroke	I60-I69
13-14	HIV infection	B20-B24
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
15-15	Motor vehicle-related	V02-V04, V09.0, V09.2, V12-V14, V19.0-V19.2, V19.4-V19.6, V20-V79, V80.3-V80.5, V81.0-V81.1, V82.0-V82.1, V83-V86, V87.0-V87.8, V88.0-V88.8, V89.0, V89.2
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
16-1h	Sudden infant death syndrome (SIDS)	R95
18-1	Suicide	X60-X84, Y87.0
24-1	Asthma	J45-J46
26-1	Motor-vehicle crash deaths	V02-V04, V09.0, V09.2, V12-V14, V19.0-V19.2, V19.4-V19.6, V20-V79, V80.3-V80.5, V81.0-V81.1, V82.0-V82.1, V83-V86, V87.0-V87.8, V88.0-V88.8, V89.0, V89.2
26-2	Cirrhosis	K74

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





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