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2005 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)

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January, 2007

Dear Colleagues and Friends:

Enclosed is the Department of Mental Retardation Annual Mortality Report for calendar year 2005. 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 2005 for all persons 18 years of age or older who have been determined to be eligible for DMR supports. This is the fifth year in which DMR has commissioned an independent review of all deaths.

This report and a rigorous clinical mortality review process are significant components of the Department's quality management 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 second year, the 2005 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.

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,

Gerald J. Morrissey, Jr.
Commissioner

Table of Contents

List of Tables and Figures

Tables

Figures

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 mortality reviews and reporting. 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 2005.

The Massachusetts DMR served 31,544 individuals, 22,857 of whom were adults with mental retardation over the age of 18-yrs in the middle of calendar year 2005. A decrease of about 1.3%, or 297 people was seen in the mid-year adult client population from June 2004 to June 2005.[1]

For the calendar year of 2005 DMR received death reports for 409 individuals who met the criteria outlined above, representing a crude death rate[2] of 17.9 individuals per thousand.[3] The average age at death of adults in the DMR population during 2005 was 60.8 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 care of 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 one of the smallest residential settings, 29.3% of the deaths in the DMR population are of residents from nursing homes.

Age

Mortality statistics for 2005 show a proportional relationship between rate of mortality and advancing age. As expected, the number of deaths is lowest for the younger age groups, and increases with age.

Gender

For the third year in a row, more men passed away in a calendar year than women. In 2005, the ratio of male deaths to female deaths was the same as the gender ratio in the DMR population (approximately 55% male and 45% female). In 2005 the rate of death between the genders did not vary significantly. Similar to 2004, the age at death was

[1] This change most likely reflects corrections made to the client database over the past few years as new data systems have been introduced.

[2] 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.

[3] 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.

significantly lower in males than in females. The average age at death for females decreased by about 3 years and slightly decreased 0.3 years for males.

Residence

There was a statistically significant difference between average age at death when comparing residential settings in 2005. The lowest average age at death was for individuals living in their own home or with family (47.3 years) and individuals served by DMR living in Non-DMR residences (46.5 years) and highest for those residing in nursing homes (67.7 years).

This year, slightly more deaths occurred in the population living in their own home or with family than in 2004. All other residential settings showed a decrease in the number of deaths in comparison to 2004 figures.

Age-Adjusted Mortality Rates

In a section new to the 2005 Mortality Report, age-adjusted mortality rates were calculated for the DMR population. The overall adjusted death rate is approximately 19.2 per thousand. Because the DMR population has larger proportions in younger age groups, the age-adjusted rate is higher than the crude rate of 17.9 per thousand.

Cause of Death

In 2005, causes of death within the DMR population were more dispersed and the leading causes represented smaller proportions of the annual deaths than in previous years. The mortality rate from Heart Disease was 2.9 per thousand in 2005, which is the lowest rate recorded for this population. Cancer remained as the second leading cause of death. Influenza and Pneumonia was tied with Cardiopulmonary Arrest and Seizure for the third ranked cause of death. These causes replace Aspiration Pneumonia, which dropped to fifth and showed a decrease of 2% of total deaths. While its rank of seventh is unchanged from 2004, the percentage of deaths and the mortality rate for Septicemia have decreased for the third straight year. This cause appears to be trending toward a consistent decline since 2002.

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 2005. Overall, rates for individuals in the DMR population meet many more targets than the general Massachusetts population or the national population.

2005 Mortality Report

As a component of its quality management system, the Massachusetts Department of Mental Retardation (DMR) has an established process for mortality reviews and reporting. Through this process, DMR reviews the causes and circumstances of the deaths of individuals it supports, and uses the findings 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 2005.

Mortality Review in DMR

2005 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 Consumer Registry System (CRS) and who died during the 2005 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.

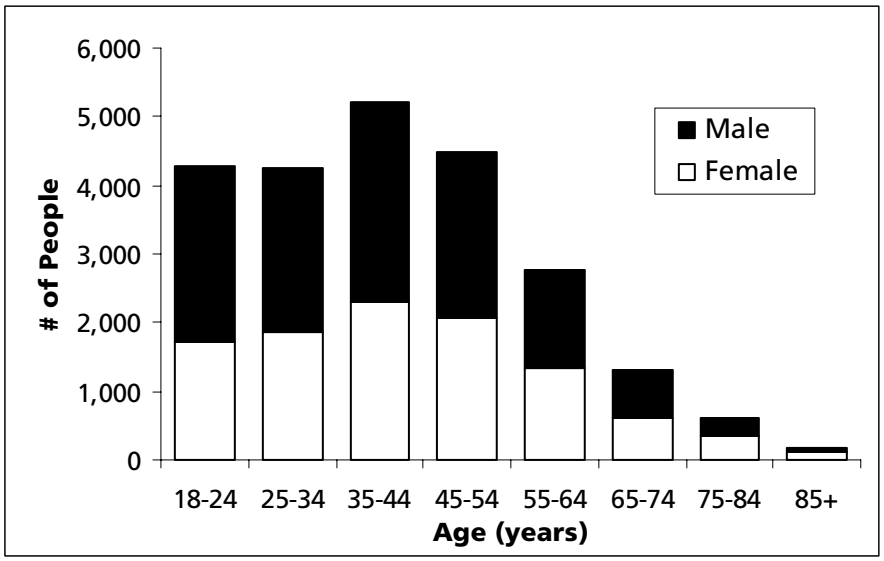
Overview of Population Served by DMR

The Massachusetts DMR served 31,544 individuals, 22,857 of whom were adults with mental retardation over the age of 18-yrs in the middle of calendar year 2005. 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. A decrease of about 1.3%, or 297 people was seen in the mid-year adult client population from June 2004 to June 2005. This change most likely reflects an adjustment to the client database that has occurred over the past few years as new data systems have been introduced.

Age Characteristics

Population and mortality statistics are presented only for adults (age 18 years and older) with mental retardation. Adults comprise the majority of population served by DMR, with most, almost 60%, between the ages of 18-45 years. DMR also serves a significant older population; about 9% of the adult population, or over 2,000 people, are over the age of 65 years. Figure 1 below displays the populations within each age group.

Figure 1
Distribution of the Population Served by DMR by Age and Gender 2005



Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1713	1866	2290	2068	1347	621	341	106	10352
Male	2402	2369	2828	2479	1418	685	274	50	12505
Total	4115	4235	5118	4547	2765	1306	615	156	22857

During 2005, the DMR population experienced a slight decrease of 1.3%, or 297 individuals. This finding is different from the trend seen in previous years of gradual increases in the population served by DMR. In 2005, DMR began the process of a consumer file review in preparation for a migration to a new client data system. A new case status protocol was implemented which resulted in removing individuals who were not receiving services for a period of three years, either because they refused or had moved out of state As a result, the data associated with the DMR population showed population decreases, mostly isolated to the 35-44 and 18-22 year old age groups. The review and updating of DMR data explains the large majority of the decrease in the active client population.

As in previous years, the 45-54 and 55-64 year old age groups saw increases in their population as the "baby boomer" population ages through these groups.[4,5] The increase may also be indicative of an aging phenomenon that exists within the DMR population, and that has also been reported by MR/DD agencies in other northeastern states[6] The 65+ population showed little change from previous years, as about as many people aged into these groups as died.

Table 1
Annual DMR Population Change within Age Group
A Comparison of 2004 and 2005

	Gross Population Fluctuation[7]		
Age Group	**Individuals**	**% Change within Age Group**	**Resulting % Change in Overall DMR Consumer Population**
18-24	-204	-4.7%	-0.9%
25-34	-37	-0.9%	-0.2%
35-44	-128	-2.4%	-0.6%
45-54	+164	+3.7%	+0.7%
55-64	+159	+5.9%	+0.7%
65-74	+88	+6.7%	+0.4%
75-84	+65	+10.3%	+0.3%
85-94	+35	+22.3%	+0.2%
Total	+142	---	+0.6%

Gender Characteristics

Figure 2, below, illustrates how the proportion of men and women served by DMR varies with age. Within younger age groups there are more men than women. However, by about age 55, the ratios become almost even and for individuals in their 70's and above, the trend reverses itself. The change in proportions in the elderly population is consistent with reports from other states[8]. Over the past four years, the elderly population has shown more polarization, with an increasing proportion of the 65+ age groups represented by females. In 2005, the proportion of males to females has become more even in the 55-64 year old age group.

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

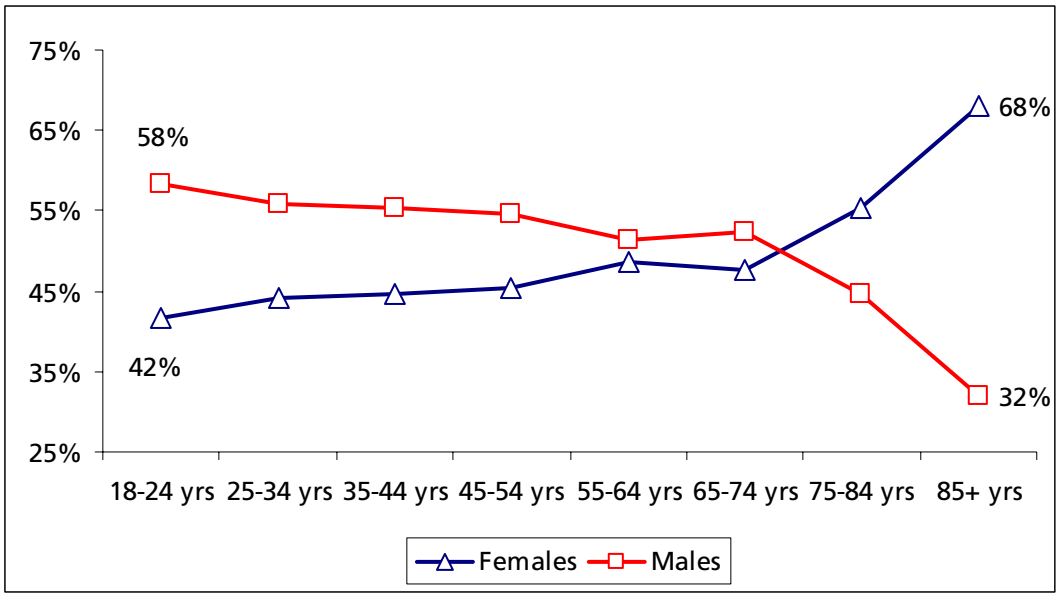
[5] U.S. Census Bureau, Census 2000 Summary file 1; 1990 Census Population, General Population Characteristics, United States (1990 CP-1-1).

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

[7] Gross population change reflects the migration of living individuals between age groups. The figures take into account the individuals that must have entered the age group to compensate for death over the course of the year.

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

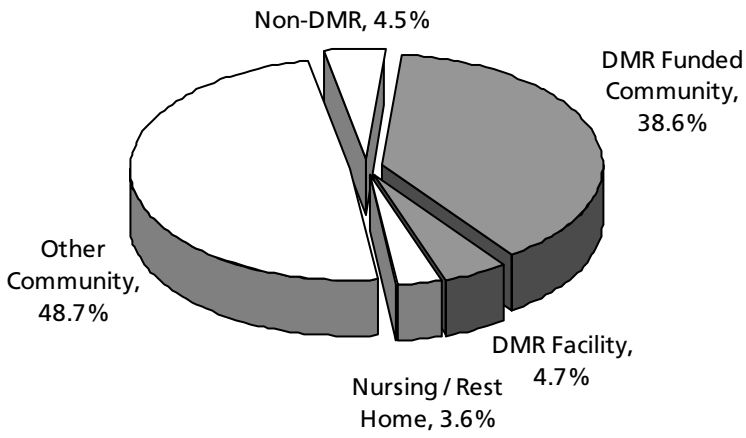
Figure 2
Gender Distribution by Age
Adults Served by DMR 2005



Residential Setting Characteristics

DMR provides services to adults who reside in a variety of different settings. Individuals served by DMR may live independently or with their family, or they may receive residential supports directly from DMR or from another state agency. Each residential setting utilized by individuals served by DMR are grouped into one of five 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.

Figure 3
Where People Live



In 2005, there was a significant change in the population distribution among residential settings since 2004.[9] Population increases were seen in both DMR-Funded Community residences and in "Non-DMR" residences. In these settings the largest increases were seen in the 35-45 age groups. The population living in "Other Community", those living in their own home independently or with

[9] Chi-Squared, Goodness of fit test. χ^2= 38.64, α=0.005, df=4

family, saw the most significant decrease. The decline in the population living in "Other Community" is thought to be related to the file review exercises of the Department as they migrate to a new consumer information system. Those individuals who had not received services or refused services were moved from an "active" client status to an "inactive" client status and were, therefore, no longer counted in the active population totals. The majority of individuals that were moved to "inactive" status were between the ages of 18-24.

The number of individuals served by DMR residing in DMR Facilities and Nursing Homes saw slight decreases. The populations living in these two settings also showed increases in the percent of individuals over the age of 65.

Similar to previous years, almost half of individuals served by DMR receive residential support from DMR. Of the portion of the adult population that did not receive direct residential support from DMR, most lived either independently or with family (and are included in the category "Other Community"). (See Appendix B for a more detailed description of the categories of residential settings.)

Mortality During 2005

The following section provides information on the deaths of individuals with mental retardation 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 2005. 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 2005 DMR received death reports for **409 individuals** who met the criteria outlined above, representing a crude death rate[10] of **17.9 individuals per thousand**.[11] The average age at death of adults in the DMR population during 2005 was **60.8 years of age**.

Age

Table 2 displays mortality statistics for the adult population served by age group, including the number of individuals who died, the relative percentage of deaths across DMR, and the mortality rate. Consistent with previous years, the mortality statistics for 2005 show a proportional relationship between rate of mortality and advancing age. The highest mortality rates are seen in the oldest age groups, with the mortality rate showing some decrease in the younger age groups.

[10] 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.

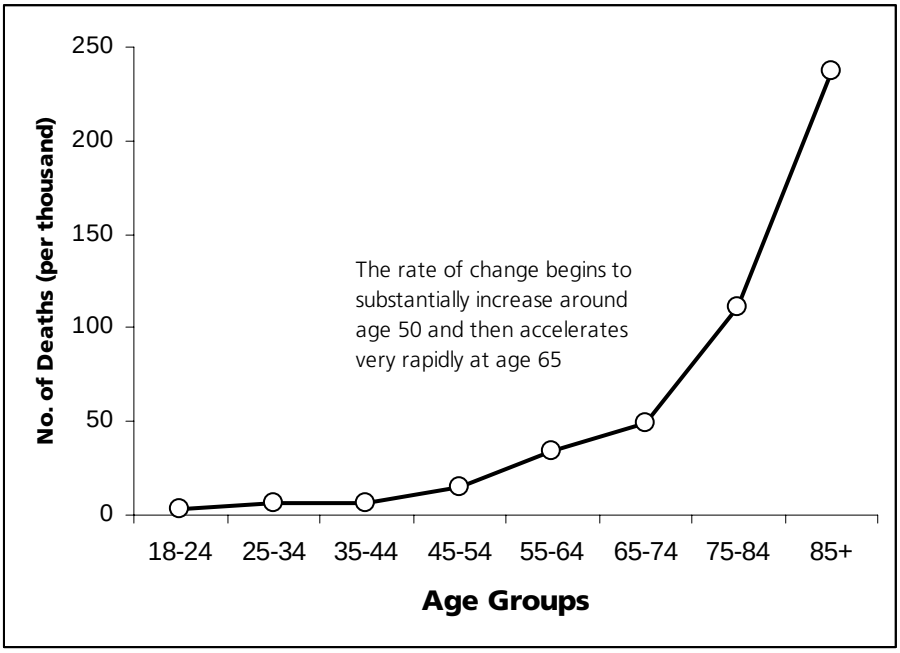
[11] Standard recommended by the U.S. Centers for Disease Control and Prevention, National Vital Statistics Report, *Age Standardization of Death Rates: Implementation of the Year 2000 Standard*, Vol 47, No. 3, 1998.

Table 2
Distribution of Deaths by Age Group, 2005

Age Range	No. Deaths	Percentage	Death Rate (No. per 1000)
18-24 yrs	15	4%	3.6
25-34 yrs	29	7%	6.8
35-44 yrs	34	8%	6.6
45-54 yrs	68	17%	15.0
55-64 yrs	94	23%	34.0
65-74 yrs	64	16%	49.0
75-84 yrs	68	17%	110.6
85 yrs & older	37	9%	237.2
Total	**409**	**100%**	**17.9**

Figure 4 displays the relationship between age and rate of death for adults served by DMR. The mortality rate (deaths per thousand individuals) controls for size differences between age groups. The line in Figure 4 illustrates how mortality rates increase with age. In the elderly age groups (age 65+) mortality rates increase more sharply, reflecting the increased risk of mortality in adults of advanced age.

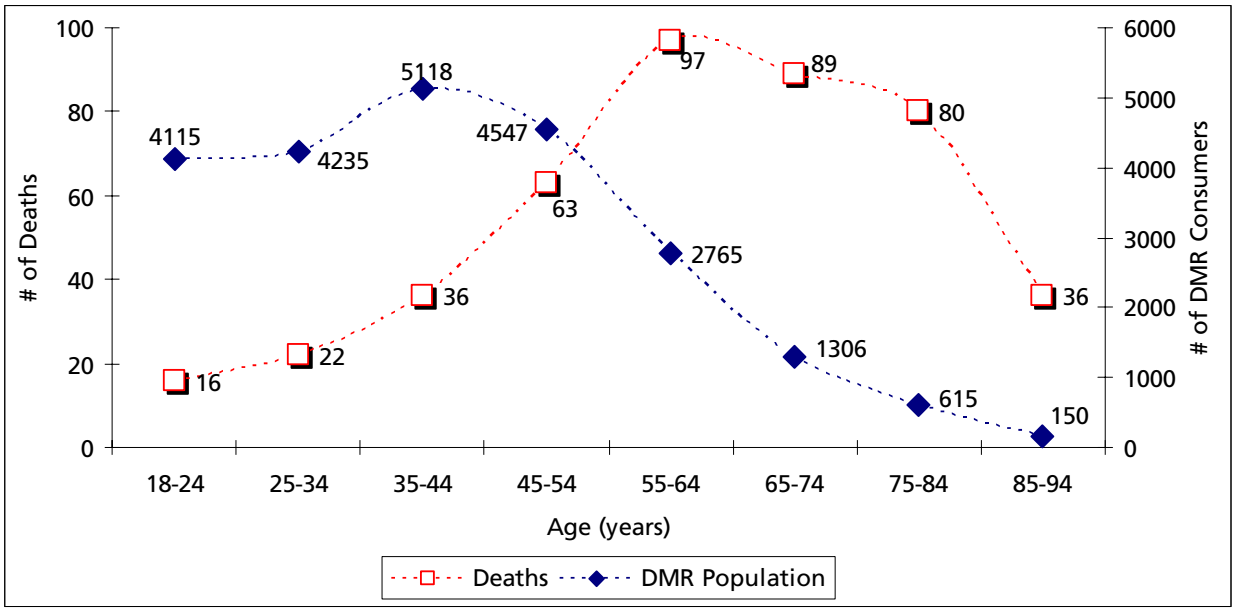
Figure 4
Mortality Rate by Age Group
Adults Served in 2005



The relationship between the size of the DMR population by age group and the corresponding number of deaths for those age groups is displayed in Figure 5 below. In 2005, as with previous years, there is a generally inverse relationship between the size of the population in each age group and the number of deaths. With increasing age, the risk of mortality also increases. As expected, the number of deaths is lowest for the younger age groups, and increases with age. Due to the decreasing size of the population age groups at age 65 and over, the number of deaths also decreases. This trend is similar to the patterns found in the general adult population in the U.S.[12]

In 2005, there was an increase in the number of deaths in the 55-64 age group, however, the rate of death actually decreased in this age group due to an increase in the group's population. This effect is most likely due to the aging 'baby-boom' population. In contrast, the opposite was seen in the 45-54 age group. Here, the number of deaths decreased, but the rate of death increased slightly from 2004 due to a decline in the population in this age group.

Figure 5
DMR Population and Deaths by Age Group
2005



Gender

The population served by DMR displays different gender proportions across age groups, as first described in the 'Overview of the DMR Population' section. While many of the gender differences are similar to state and national populations, the population served by DMR does show a difference from the Massachusetts population in the larger percentage of males in most age groups.

[12] Deaths: Final data for 2002, National Vital Statistics Report, 53(5), Oct 2004, National Center for Health Statistics

The relationship between gender and mortality is complex and influenced by both gender proportions and the differences in age distribution that exist between the two groups. For the third year in a row, more men died in a calendar year than women. The first few mortality reports for 2000-2002 showed more deaths in females than in males. Since 2000, the proportion of male deaths has been increasing as the proportion of males has increased in the overall DMR population. In 2005, the ratio of male deaths to female deaths was the same as the gender ratio in the DMR population (approximately 55% male and 45% female).

Table 3
No. Deaths, Average Age at Death and Death Rate by Gender
2005

Gender	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
F	187	45.7%	62.7 yrs	18.1
M	222	54.3%	59.2 yrs	17.8

It might be anticipated that there would be a higher female mortality rate due to the difference in age distribution between the genders. However, in 2005 the rate of death between the genders did not vary significantly. This suggests that other factors may contribute to higher mortality risks in the population of males served by DMR, exclusive of age.

Table 4
DMR Mortality Rate by Gender
2001-2005

	Mortality Rate	
Calendar Year[13]	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

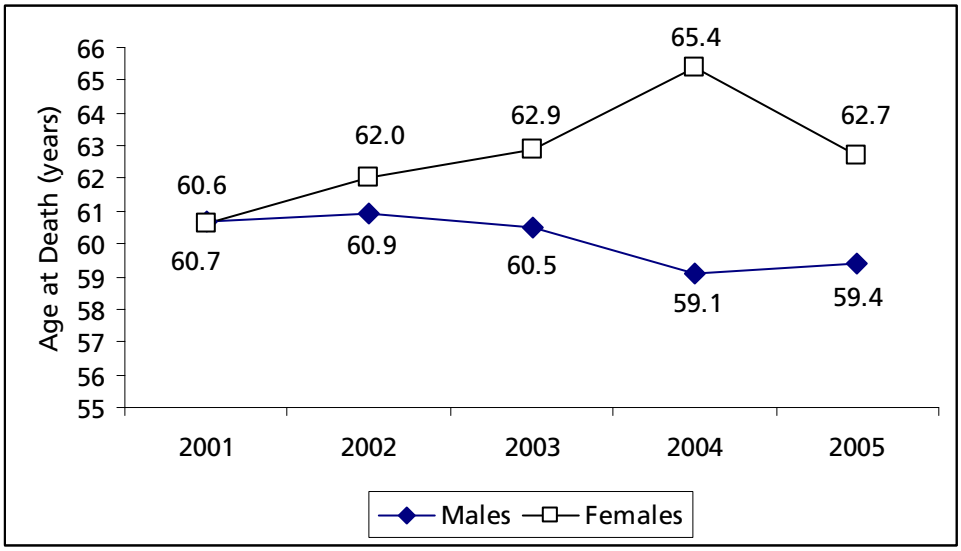
The average age at death also differs between genders in the DMR population. In both 2004 and 2005, the age at death was significantly lower in males than in females (p=.024 in 2005)[14]. The average age at death for females decreased from 65.4 years in 2004 to 62.7 years in 2005. In males, the average age of death decreased slightly from 59.4 years in 2004 to 59.1 years in 2005.

Figure 6 displays recent trends in average age at death by gender. The decrease in average age at death for males in recent years has resulted in significant differences

[13] Revised mortality information is presented for 2001 and 2002
[14] One-tailed t-test with equal variance and hypothesized mean difference of zero. (T=1.98, df=407 p=0.024)

between genders. The higher female to male average age at death is consistent with trends found in the general population both nationally and statewide.

Figure 6
DMR Age at Death by Gender
2001-2005



Residence

People served by DMR 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. Specific definitions, including residential codes, are contained in Appendix B. Mortality statistics for these residential categories are displayed in Table 5 and Figure 7.

Age and Residence

Consistent with findings from previous years, the average age at death was significantly different across residential settings in 2005.[15] Average age at death was lowest for individuals living in their own home or with family (47.3 years) and individuals living in Non-DMR residences (46.5 years) and highest for those residing in Nursing Homes (67.7 years).

Overall the age at death within each residential setting is reflective of the relative age of the population that resided in each setting. The rate of death was higher in residential settings with higher average age at death, an expected finding since age is highly correlated with risk of mortality. This year, slightly more deaths occurred in the population living in their own home or with family than in 2004. All other residential settings showed a decrease in the number of deaths in comparison to 2004 figures.

[15] Analysis of Variance (ANOVA) F=15.6, df=4, p=<0.0001

Table 5
Age and Mortality by Type of Residential Setting
For Adults Served by DMR
2005

Residential Setting	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	11,141	3.8%	66	16.1%	49.4	**5.9**
DMR Community	8,815	9.8%	167	40.8%	60.2	**18.9**
Non-DMR	1,019	11.6%	14	3.4%	46.6	**13.7**
DMR Facility	1,067	25.1%	42	10.3%	65.8	**39.4**
Nursing Home	815	48.7%	120	29.3%	67.7	**147.2**
Total (Statewide)	22,857	9.1%	409	100%		
Average					60.8	**17.9**

Similar to previous years, individuals served by DMR in nursing homes experienced the highest rate of death and accounted for about one-third of all deaths, although they represent the smallest population by residential setting. The relationship between type of residence and mortality are consistent with expectations and with trends present in other state mental retardation systems[16] since average population age tends to vary by type of residential setting.[17] The relationship between age, mortality and type of residential setting is further illustrated in Figure 7.

Own Home

Individuals served by DMR living in their own home or with family had the lowest mortality rate in 2005, consistent with expectations. The rate of death for this residential group was 5.9 per thousand, which is significantly lower than both the crude mortality rate of 8.5 per thousand and the age-adjusted rate of 7.4 per thousand for the general population in Massachusetts.[18] (See the 'Age-adjusted Mortality Rates' section for the age-adjusted mortality rate for the MA DMR.)

People in this residential subgroup are by far the youngest residential subgroup and have 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.

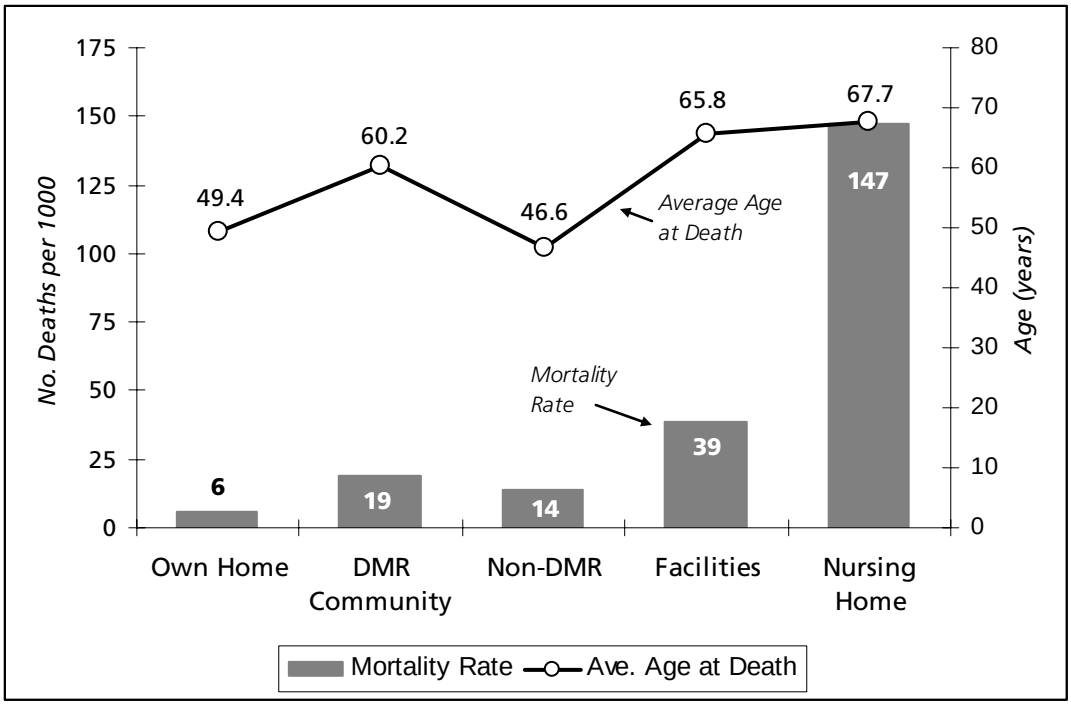
[16] State of Connecticut Department of Mental Retardation. *Health and Mortality Report*, November 2002 and October 2003.
[17] The population that lives at home or with family is substantially younger than the population that lives in nursing homes. The population that lives in community settings and facilities falls in the middle in terms of average age.
[18] *Massachusetts Deaths 2004.* Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, July 2006.

DMR Community

Of all the residential settings, the DMR Community is the most mixed population in terms of both age and level of service need. While the 35-54 year old population represents the largest age group within this type of residential setting, a steadily increasing elderly population appears to be present within this residential category.

The mortality rate for individuals served by DMR living in the DMR Community dropped slightly in 2005 to 18.9 per thousand from a rate of 19.9 per thousand in 2004. This residential setting supports the second-largest residential subpopulation of DMR consumers in Massachusetts (after the group of individuals living at home). 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. A review of individual deaths shows that in 2005 many of the deaths (57 individuals), or 34% of deaths in this setting, occurred in the population of more elderly individuals.

Figure 7
Relationship between Mortality Rate, Average Age at Death, and Type of Residence 2005



Other Residential Settings

The number of people living in the Non-DMR, DMR Facility and Nursing Home settings in total represents less than 13% of the total 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 population living in Non-DMR residences tends to display a wide range of ages. Over one-third of the residents are between the ages of 18-24, while the remainder falls within older age groups. Fourteen (14) individuals served by DMR living in Non-DMR

residences died in 2005. The mortality rates for this population have fluctuated over past reports due to the small population size. In 2005, the rate of 13.7 per thousand fell in between rates for previous years. The average age at death was lower in 2005 than in previous years.

DMR Facilities. In 2005, DMR facilities served an older population, with the majority of residents over the age of 45-yrs. Because the risk of death increases with age, the age composition of the population in this residential setting may cause it to experience a higher rate of death than other settings. In 2005, the mortality rate for individuals living in DMR facilities was 39.4 per thousand, which was between the rates seen in 2003 and 2004. The average age at death for individuals residing in DMR facilities decreased about 3 years in 2005 to 65.8 years.

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

Age Group	Rate of Death (per thousand)	
	US 2002[19] (estimated)	DMR 2005
under 65	194.6	114.8
65-74	230.8	130.4
75-84	308.4	166.7
85+	544.2	354.8

Nursing Homes. The population of individuals served by DMR living in nursing homes is the oldest of all the residential subpopulations. Almost 60% of these individuals fall between the ages of 55 and 84 years. The rate of death increased moderately for people in this setting to 147.2 per thousand from 136.9 per thousand in 2004. Consistent with previous years, the rate of death in nursing homes was the highest among residential categories. It should be noted that this rate continues to be lower than the general population rate of death (352.6 per thousand) in Massachusetts nursing homes as reported in 2003[20]. As shown in Table 6, Massachusetts DMR mortality rates in nursing homes were also 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. The rate of death decreased in 2005 for the elderly

[19] US Nursing Home Mortality Rate Estimates are based upon 2002 mortality information from: Worktable 309. Deaths by place of death, age, race and sex: United States, 2002, 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. 1995 population figures were adjusted with 4% decline reported to have occurred in nursing home populations by 2002, as reported in: *Across the States: Profiles of Long Term Care, Sixth Edition, 2004,* Public Policy Institute, AARP.

[20] 2001 Rate of Death in Massachusetts Nursing Homes calculated from a population in 2003 of 46,993 living in MA Nursing Homes (from *Across the States: Profiles of Long Term Care: Massachusetts, 2004,* Public Policy Institute, AARP) and a total number of 17,232 deaths in MA Nursing Homes from (*Massachusetts Deaths 2003,* Bureau of Health Statistics, Research and Evaluation Massachusetts Department of Public Health).

residing in nursing homes supported by DMR, and increased for nursing home residents under 65 years of age. Similarly, the average age at death decreased from 71.3 years to 67.7 years in 2005.

Age-Adjusted Mortality Rates

There are a variety of factors that can influence 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 (2005 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).

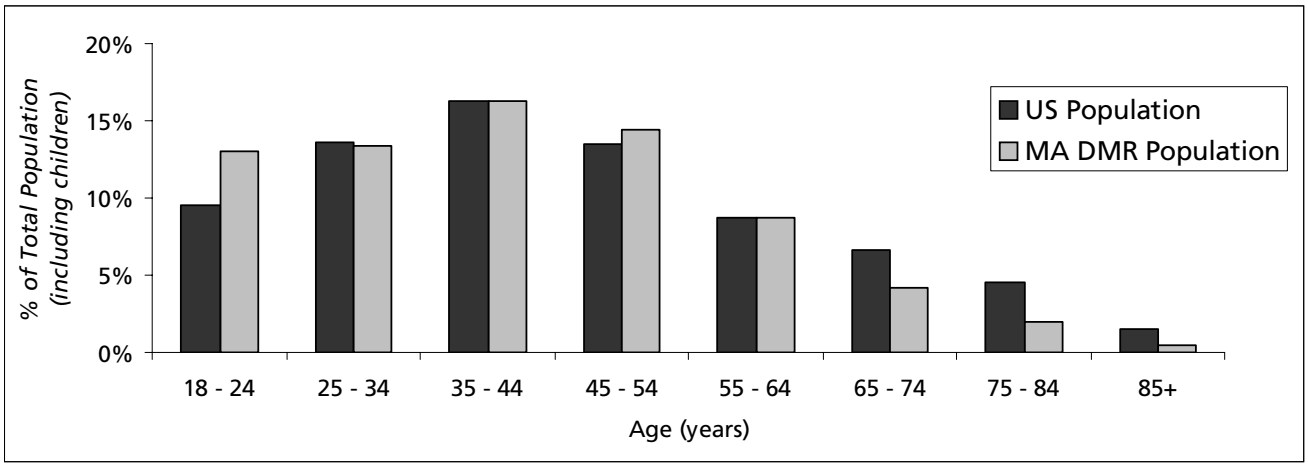
As a standard practice, federal and state mortality reports typically perform age-adjustment using an estimate of the 2000 U.S. population called the “U.S. Standard Population.” This population estimate is also used as the basis for age-adjustment in this section of the report.

Comparison of the MA DMR 2005 Population and the U.S. 2000 Standard Population

Overall, the DMR population tends to be younger than the overall U.S. population. Therefore, it has a greater percentage of individuals within the younger age groups. In the process of age-adjustment, the older age groups 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 effect of weighting them more heavily results in a higher age-adjusted mortality rate than the crude mortality rate for the DMR population.

Figure 8 displays the relative percentage of the U.S. population and the MA DMR population in each age group. As can be seen, higher percentages of younger individuals and smaller percentages of older individuals are present in the DMR population compared to the U.S. Standard Population.

Figure 8
Comparison of MA DMR and U.S. Standard Populations
Percentage of Population by Age Group



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[21] 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 is approximately 19.2 per thousand. Because the DMR population has larger proportions in younger age groups, the age-adjusted rate is higher than the crude rate of 17.9 per thousand. 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 2003[22] age-adjusted U.S. overall mortality rate of 8.01 per thousand and the age-adjusted adult 2004 mortality rate for Massachusetts of 7.31 per thousand[23].

[21] 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.

[22] Insufficient information was provided for the 2004 preliminary US mortality data to calculate the adult age-adjusted mortality rate.

[23] Estimate of age-adjusted rate from populations and number of deaths per age group presented in the Massachusetts Mortality Report. Large age groups are given in the report, so actual age-adjusted rate may vary slightly. Also, "adult" defined as 15 years +, as a 15-24 year old age group is presented in the report.

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 mental retardation.[24]

Table 7
Age-adjusted Mortality Rates

Age Group	% population in age group US	% population in age group DMR	US 2004 Age-Adjusted Rate of Death[25] (per thousand)	DMR 2005 rate of death (per thousand)	Weight	Weighted Rate (per thousand)
18 to 24	9.6%	13.0%	0.8 [26]	3.6	0.096	0.35
25 to 34	13.6%	13.4%	1.0	6.8	0.136	0.93
35 to 44	16.3%	16.2%	1.9	6.6	0.163	1.08
45 to 54	13.5%	14.4%	4.2	15.0	0.135	2.02
55 to 64	8.7%	8.8%	9.1	34.0	0.087	2.97
65 to 74	6.6%	4.1%	21.7	49.0	0.066	3.24
75 to 84	4.5%	1.9%	52.9	110.6	0.045	4.96
85+	1.6%	0.5%	139.0	237.2	0.016	3.68
Adult Total	72.5%	74.2%	8.0	17.9	0.742	**19.2**

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

Age-adjusted Rate[27] = 19.2 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 = 2005 DMR mortality rate for age group * Weight for age group

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

[24] 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.

[25] National Vital Statistics Reports, Vol. 54, No. 19, June 28, 2006. Table 1. Deaths and death rates by age, sex, and race and Hispanic origin, and age-adjusted death rates, by sex and race and Hispanic origin: United States, final 2003 and preliminary 2004.

[26] This rate is for ages 15-24.

[27] 95% Confidence Interval = (19.08, 19.35)

Trends Over Time

Mortality Rate. Both the number of deaths and the rate of death decreased in 2005 in comparison to previous years. As shown in Table 8 and Figure 9, while the mortality rate had previously shown consistent annual increases, this trend was reversed in 2005, with 30 fewer deaths in 2005 than in 2004. This rather substantial reduction in the number of deaths resulted in a decrease in the mortality rate back to levels found in 2002.

Table 8
Mortality Trends in DMR[28]
2000 - 2005

Year	No. Deaths	Mortality Rate[29] (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

Figure 9[30]
Statewide Mortality Rates
(Deaths per 1000)
2000-2005

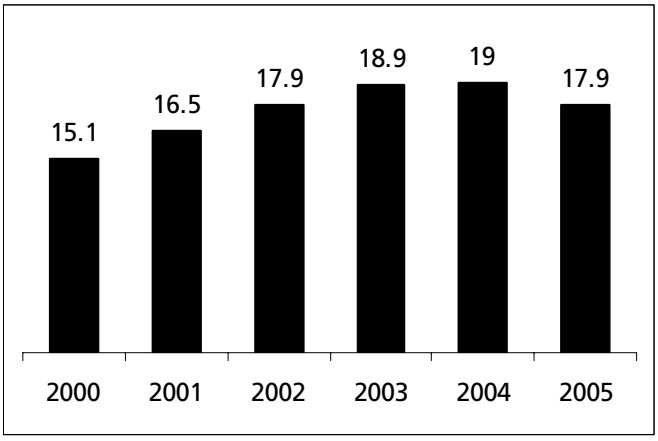
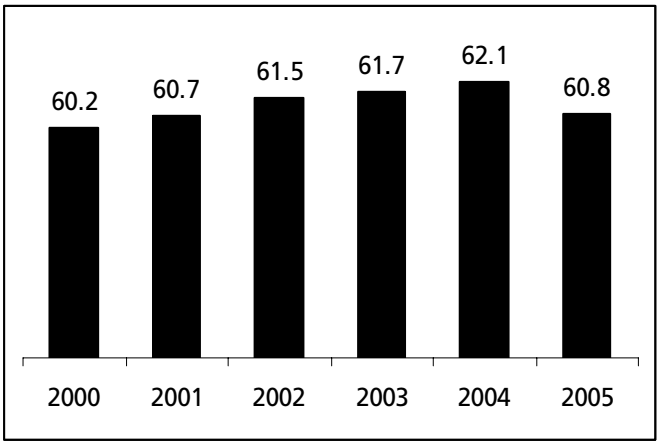


Figure 10
Average Age at Death per Year
2000-2005



[28] 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 changed.

[29] 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.

[30] 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 rates with those from previous years.

However, and as can be seen in both Table 8 and Figure 10, this reduction in the mortality rate is also accompanied by a change in the average age at death. During 2005 the average age decreased to 60.8 years from a high of 62.1 found during 2004. The range for the average age at death over the 2000-2005 time period is similar to the average age at death reported in Connecticut for adults served by DMR.[31]

Figure 11[29]
Comparison of Mortality Rate by Age Group Over Time
2000-2005

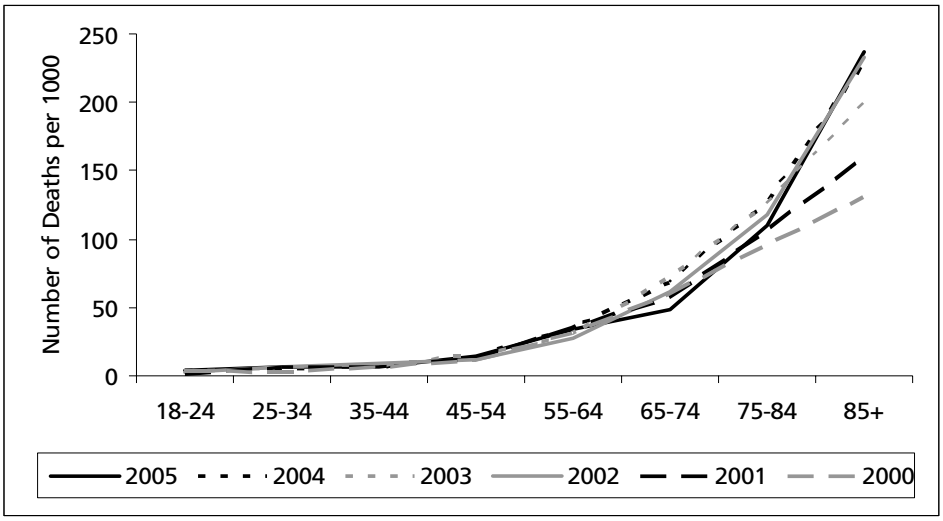


Figure 11 illustrates mortality rates over time by age group. The largest amount of annual variability appears to take place within the older age groups (65+). It is important to note that these older age groups have relatively small populations and are typically at a higher risk of mortality. As a result, annual fluctuations in these groups can be expected. Rates of death in the 65-75 age group were slightly lower in 2005 than in previous years, but the rate of death for the 85+ age group was slightly higher. In contrast, the mortality rates for the younger age groups have remained consistent over time.

The crude mortality rate increases with age across the five-year time period illustrated in Figure 11, a finding that is consistent with expectations.

[31] *Health and Mortality Annual Report*, State of Connecticut Department of Mental Retardation, October 2003.

Causes of Death

The following section presents information about the causes of death for adults served by the Massachusetts DMR during 2005. The World Health Organization's International Classification System for Diseases (ICD-10) is the basis by which diseases and conditions in this report are assigned and 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 and in some cases the Death Certificate. In the case of individuals subject to clinical mortality review, the cause was confirmed by the Mortality Review Committee.[32] [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 selects 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."*[33]

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 2005 are compared with data from five previous years and with state and national data in Table 9. The top two causes of death, Heart Disease and Cancer, have remained constant over the last three years for the DMR population in Massachusetts.

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[32] In some cases, additional reports were available to confirm the cause of death, such as toxicology or medical examiner reports. For all of the deaths in 2003, information gathered by and supplied to DMR was sufficient to assign a cause of death for all individuals, resulting in no "unknown" cases.

[33] 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[34]	MA 2004[35]	DMR 2000[36]	DMR 2001[37]	DMR 2002	DMR 2003	DMR 2004	DMR 2005
1	Heart Disease *27.3%*	Heart Disease *25.3%*	Heart Disease	Heart Disease *21.2%*	Heart Disease *21.2%*	Heart Disease *22.3%*	Heart Disease *18.5%*	Heart Disease *16.4%*
2	Cancer *22.9%*	Cancer *24.5%*	Pneumonia	Aspiration Pneumonia *12.3%*	Aspiration Pneumonia *12.3%*	Cancer *13.5%*	Cancer *12.5%*	Cancer *12.0%*
3	Stroke *6.3%*	Stroke *6.0%*	CLRD	Cancer *12.7%*	Cancer & Septicemia[38] *10.1%*	Aspiration Pneumonia *12.3%*	Aspiration Pneumonia *11.2%*	Influenza and Pneumonia *10.8%* C-P Arrest/ Seizure *10.8%*
4	CLRD *5.2%*	CLRD *4.7%*	Cancer	Septicemia *7.4%*	C-P Arrest/ Seizure[39] *9.4%*	Septicemia *9.0%*	Influenza and Pneumonia *10.9%*	
5	Accidents *4.5%*	Influenza and Pneumonia *3.6%*	Septicemia	Alzheimer's *6.9%*	Alzheimer's *7.2%*	C-P Arrest/ Seizure[39] *7.2%*	Alzheimer's *7.5%*	Aspiration Pneumonia *9.3%*
6	Diabetes *3.0%*	Alzheimer's Disease *3.1%*	Nephritis	Influenza and Pneumonia *6.1%*	CLRD *6.2%*	CLRD *6.0%*	C-P Arrest/ Seizure[39] *6.8%*	Alzheimer's Disease *8.6%*
7	Alzheimer's *2.7%*	Unintentional Injuries *2.5%*	C-P Arrest/ Seizure[39]	CLRD *4.1%*	Influenza and Pneumonia *4.7%*	Alzheimer's Disease *5.3%*	Septicemia *6.6%*	Septicemia *5.9%*
8	Influenza and Pneumonia *2.6%*	Diabetes *2.4%*	Alzheimer's	C-P Arrest/ Seizure[39] *3.3%* Accidents *3.3%*	Nephritis *4.0%*	Influenza and Pneumonia *4.6%*	CLRD *5.7%*	CLRD *4.6%*
9	Nephritis *1.8%*	Nephritis *2.3%*	Stroke		Stroke *3.5%*	Stroke *4.2%*	Nephritis *3.6%* Stroke *3.6%*	Stroke *4.2%*
10	Septicemia *1.4%*	Septicemia *1.8%*	Gastro-intestinal	Stroke *3.0%*	Congenital Defects *2.5%*	Nephritis *2.6%*		Unintentional Injuries *3.4%*

**CLRD = Chronic Lower Respiratory Disease

[34] Table B. Deaths and death rates for 2004 and age-adjusted death rates and percentage changes in age-adjusted rates from 2003 to 2004 for the 15 leading causes of death in 2004: United States, final 2003 and preliminary 2004. National Vital Statistics Reports, Vol. 54, No. 19, June 28, 2006

[35] Top Ten Leading Underlying Causes of Death by Age, Massachusetts 2004, *Massachusetts Deaths 2004.* Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, June 2006. (Most recent data available)

[36] The percent of deaths represented by each cause was unavailable for 2000.

[37] 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.

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

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

The primary causes of death within the DMR population during 2005 were more variable than in previous years. In addition, the top 10 leading causes represented a smaller proportion of the total annual deaths than in previous years. Interestingly, this pattern was also present for both the Massachusetts state and the national populations.

Table 10 displays cause-specific mortality rates for the major causes of death in the DMR population for the five year time period between 2001-2005[40,41]. As can be seen, the mortality rates for 2005 for six out of the top 10 causes fell from previous levels.

The mortality rate in 2005 associated with Heart Disease was 2.9 per thousand. This represents the lowest rate recorded for this population since 2001. Mortality rates for Cancer and Influenza and Pneumonia also fell, although the reduction was not as pronounced as for heart disease. Cancer remained the second leading cause of death. Influenza and Pneumonia were tied with Cardiopulmonary Arrest and Seizure for the third highest ranked cause of death. Rates for Cardiopulmonary Arrest and Seizure increased slightly in 2005; although, and as can be seen in Table 10, the mortality rate for this category tends to vary rather dramatically over time. Aspiration Pneumonia fell to fifth place.

Table 10
Cause-specific DMR Mortality Rates
2001-2005

2005 Rank	Previous Ranking	Cause of Death	DMR Rates of Death (per thousand)				
			2001	2002	2003	2004	**2005**
1	(1)	Heart Disease	4.4	3.8	4.2	3.5	**2.9**
2	(2)	Cancer	2.1	1.8	2.5	2.4	**2.1**
3 & 4	(4)	Influenza and Pneumonia	1.0	0.8	0.9	2.1	**1.9**
	(6)	CP Arrest/ Seizure[39]	0.6	1.7	1.4	1.3	**1.9**
5	(3)	Aspiration Pneumonia	2.4	2.2	2.3	2.1	**1.7**
6	(5)	Alzheimer's Disease	1.1	1.3	1.0	1.4	**1.5**
7	(7)	Septicemia	1.2	1.8	1.7	1.3	**1.1**
8	(8)	Chronic Respiratory Disease	0.7	1.1	1.1	1.1	**0.8**
9	(9/10)	Stroke	0.5	0.6	0.8	0.7	**0.7**
10	(11)	Accidental Injury[42]	0.5	0.4	0.7	0.6	**0.6**

Alzheimer's Disease was the sixth leading cause of death in 2005, dropping from fifth place in 2004; however, the death rate associated with Alzheimer's Disease did increase slightly. In both the U.S. and MA general population rankings, Alzheimer's Disease has increased since the last reported year (2003 for U.S., 2004 for MA) and represents a larger proportion of deaths for both population groups.

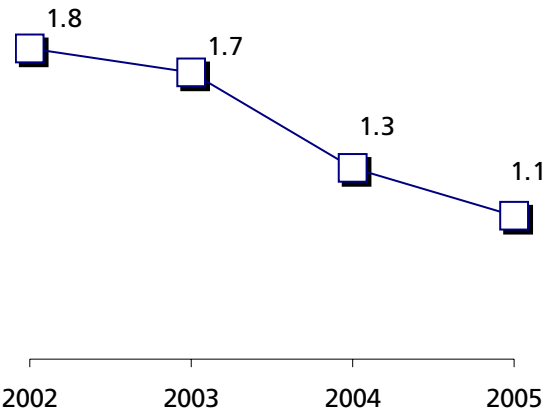
[40] Cause-specific mortality rates are unavailable for 2000.

[41] 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.

[42] 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.

While its rank of seventh is unchanged from 2004, the percentage of deaths and the mortality rate for Septicemia have decreased for the third straight year. This cause of death within the DMR population appears to be consistently declining since 2002 (see Figure 12).

Figure 12
Decreasing trend in Mortality Rates for Septicemia, 2002-2005
(rates per thousand)



Unintentional Injuries entered the top 10 for the first time since 2000. However, its presence in the top 10 is not due to an increase in the actual mortality rate for this cause. Instead, Nephritis, which had historically ranked higher, became less prevalent in 2005. Most deaths from Unintentional Injuries were due to choking and aspiration (10 of 14 deaths)[43]; three deaths were caused by motor vehicle accidents. As shown in Table 10, the rate of accidents did not change from 2004. Deaths from injuries continue to occur at a much lower rate than in the Massachusetts state population. It is important to note, however, that absent more comprehensive statistical analysis it is not known whether or not these fluctuations are a function of actual changes or simply the result of random variation.

Cancer

The mortality rate for Cancer has continued to decline in 2005, equaling 2.1 per thousand. Cancer remains the second leading cause of death for the DMR Population.

In 2005, the types of cancer causing death were more widely distributed than in some previous years. For example, the top cancer (colorectal) in 2004 caused ten deaths, whereas esophageal and stomach cancers tied for first in 2005, with five deaths each. In contrast, there were only two deaths from colorectal cancer in 2005.

Interestingly, two of the four deaths from breast cancer, ranked third in the DMR population, occurred in males, even though breast cancer is less common in males than in females in the general population.[44]

Table 11
Top Cancer Causes in the DMR Population, 2005

Primary Site	Number of Deaths	Average Age at Death
Esophagus	5	56.2
Stomach	5	62.3
Breast	4	55.7
Colon, Rectum and/or Anus	4	64.3
Lung	4	59.5

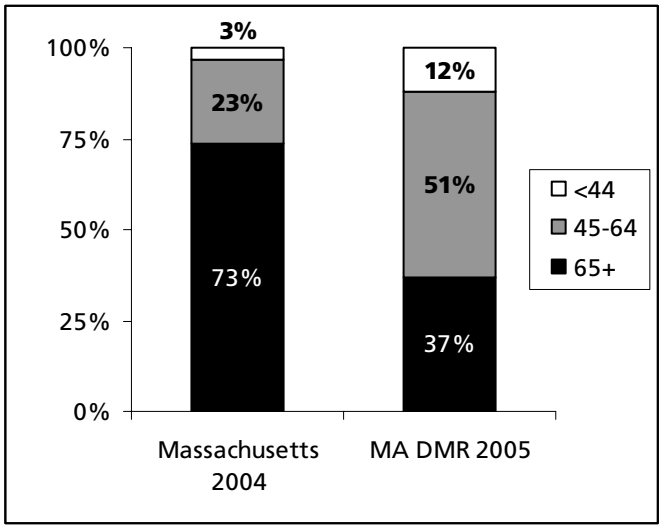
[43] Deaths within the MRDD population due to choking and aspiration are experiencing increased attention nationally as evidenced by special notations in mortality reports within other states (e.g., State of Tennessee Division of Mental Retardation Services Annual Report FY 2005, Arizona Division of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

[44] American Cancer Society: Cancer Facts and Figures 2006. Atlanta, Ga: American Cancer Society, 2006. http://www.cancer.org/downloads/STT/CAFF2006PWSecured.pdf

Stomach cancer was ranked second in 2005 and has held similar rankings in previous years. Deaths from stomach cancer appear at a higher rate in this population than in the general population. This finding is consistent with results of studies in other states, Europe and in the Netherlands, which show higher rates of stomach cancer in individuals with mental retardation when compared to the general population.[45,46,47] Stomach cancer has been found to be more prevalent in males with intellectual disabilities,[48,56] and in individuals with moderate to profound mental retardation.[56] It has been reported that about half of individuals with moderate to profound levels of retardation have swallowing disorders, which may contribute to the risk of stomach cancer in this population.[56] In 2005, three of the deaths from stomach cancer were in males, two were in females in the DMR population.

Gender and cancer mortality do not appear to be independent in the DMR population. Females are significantly more likely to die from cancer than are males in this population.[49] The rate of death from cancer for females in 2005 was 4.7 per thousand, for males it was 1.7 per thousand. This finding is in contrast to the general Massachusetts population, where males are significantly more likely to die from cancer than females. However, this finding is in accordance with other populations of individuals with intellectual disabilities that have shown higher rates of cancer in females.[50,51]

Figure 13[47]
Age Distribution of Cancer Deaths



The age distribution of deaths from cancer differs between the Massachusetts DMR and the Massachusetts general population, as shown in Figure 13. In Massachusetts, over two-thirds of deaths from cancer occur in the elderly. 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[53,54,55,56] (e.g. leukemia,

[45] Cooke LB. Cancer and learning disability. *Journal of Intellectual Disability Research* 1997. 41, 312–6.
[46] Jancar J. Cancer and mental handicap – a further study (1976–1985). *British Journal of Psychiatry* 1990. 156, 531-3.
[47] Jancar MP & Jancar J. Cancer and mental retardation (a forty year review). *Bristol Medico-Chirurgical Journal.* 1997. 92, 3–7.
[48] Sullivan SG, Hussain R, Threlfall T & Bittles AH. The incidence of cancer in people with intellectual disabilities. *Cancer Causes and Control* 15: 1021–1025, 2004.
[49] Chi-squared, Test for Independence. χ^2= 17.2, α=0.005, df=1
[50] Janicki MP, Davidson PW, Henderson CM, McCallion P, Taets JD, Force LT, Sulkes SB, Frangenberg E & Ladrigan PM. Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research* 46, 287-298.
[51] Duff M, Scheepers M, Cooper M, Hoghton M & Baddeley P. Helicobacter pylori: Has the killer escaped from the institution? A possible cause of increased stomach cancer in a population with intellectual disability. *Journal of Intellectual Disability Research* 2001 Jun 45(3):219-225.
[52] 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.
[53] Lucci-Cordisco E, Zollino M, Baglioni S, et al. A novel microdeletion syndrome with loss of the MSH2 locus and hereditary non-polyposis colorectal cancer. *Clin Genet.* 2005 Feb;67(2):178-82.

colorectal, oropharygeneal, thyroid, testicular, gastrointestinal) and the appearance of cancers at significantly younger ages (e.g. colorectal cancer around age 35[57]) in individuals with mental retardation of certain etiologies. In 2005, the DMR population showed an increase in deaths from cancer in the 45-64 year old age group, but a decrease in the number of cancer deaths in the under 44 and over 65 age groups.

The incidence of cancer in individuals with mental retardation 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. Similar to past years, the rate of death from cancer in the DMR population (2.1 per thousand) was slightly higher than the national (1.9 per thousand) and statewide (1.8 per thousand) general population rates[58]. In recent years, the mortality rate for cancer within the DMR population has gradually approached the state and national rates.

While there is a predisposition to certain cancers, not all types of cancer have been reported in the literature at elevated rates in individuals with mental retardation. Lower mortality rates have been reported for some types of cancers in individuals with mental retardation, including prostate, urinary tract and lung cancers.[56] These cancers had lower mortality rates in the DMR population as well.

Cause of Death by Age Group

Tables 12 and 13 compare age-specific causes of death for the 2005 DMR population and the 2004 Massachusetts population.[59] Consistent with data from 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. 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 or aspiration/choking.

In older age groups in the general population, deaths from Heart Disease and Cancer are most common; however, these causes of death appear to become prevalent at younger ages in the DMR population. Alzheimer's Disease is the leading cause of death in the 55-64 year old group in the DMR population, but this cause does not make the leading three causes at any age in the general population. Many of the deaths related to Alzheimer's Disease are in individuals with Down Syndrome, which can contribute to early-onset

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[54] 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.

[55] 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.

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

[57] 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.

[58] National and Massachusetts cancer rates from *Massachusetts Deaths 2004.* Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, July 2006.

[59] The most current data available for the Massachusetts general population was for the year 2003.

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.

Influenza & Pneumonia appears as a more prominent cause of death in the elderly in the DMR population than in the general population. Consistent with previous years, Aspiration Pneumonia continues to be more prevalent in the DMR community than in the general population; however, the number of deaths from this cause has decreased in 2005.

Table 12
Cause of Death by Age Group for DMR
2005
(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	CP Arrest/ Seizure [39]	Heart Disease	Cancer	Alzheimer's	Heart Disease	Influenza & Pneumonia	Heart Disease	Heart Disease
2		Influenza & Pneumonia, Heart Disease	CP Arrest/ Seizure	Alzheimer's, CP Arrest/ Seizure	Cancer	Influenza & Pneumonia	Cancer	CLRD	Cancer
3			Influenza & Pneumonia, Aspiration Pneumonia		Heart Disease, CP Arrest/ Seizure[39]	Aspiration Pneumonia	CP Arrest/ Seizure[39]	Cancer, Influenza & Pneumonia, Septicemia	Influenza & Pneumonia

* CLRD = Chronic Lower Respiratory Disease

Table 13
Cause of Death by Age Group for Massachusetts Population
2004[60]

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

* CLRD = Chronic Lower Respiratory Disease

[60] Top Ten Leading Underlying Causes of Death* by Age, Massachusetts 2004, *Massachusetts Deaths 2004.* Center for Health Information, Statistics, Research & Evaluation, Massachusetts Department of Public Health, June 2006. Mortality information from 2004 was the most recent available from the state of Massachusetts.

Cause of Death by Residence

The populations of individuals served by DMR living in different residential settings tend to have different age and health characteristics. This appears to influence the associated causes of death. In 2005, a large decrease in the number of deaths and the death rate from Heart Disease in the DMR Community took place. While there were 42 deaths from heart disease in 2004, only 22 deaths were from Heart Disease in 2005. Within community residential settings, Alzheimer's Disease moved up to the third leading cause, replacing Aspiration Pneumonia. This change is due to both an increase in the rate of death from Alzheimer's Disease and fewer deaths from Aspiration Pneumonia. Deaths from Septicemia in the DMR Community also declined. The rate of deaths from Cancer for persons residing in community residential settings showed a small increase from 2004.

Table 14
Major Causes of Death for DMR Community[61]

Rank	Cause of Death	Number of Deaths	Rate of Death
1	Heart Disease	22	2.50
2	Cancer	20	2.27
3	Alzheimer's Disease	19	2.16
4	C-P Arrest/ Seizure[39]	18	2.04
5	Influenza and Pneumonia	17	1.93

In general, the top causes of death for individuals residing in their own home or with family were similar to the most frequent causes for the general population in Massachusetts. During 2005, Influenza and Pneumonia continued to fall within the top five causes of death for this group of individuals.

Table 15
Major Causes of Death for Individuals Served by DMR and Residing in Their Own Home[62]

Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)
1	Heart Disease	11	0.99
	Cancer	11	0.99
3	C/P Arrest/ Seizure[39]	9	0.81
4	Influenza & Pneumonia	8	0.72
5	Stroke	6	0.54

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

[62] 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 in 2005 was small, (about 800 individuals or 3.6% of the DMR population), almost thirty percent of all DMR deaths occurred in this type of residential setting. As in past years, individuals served by DMR in Nursing Homes consistently experienced higher mortality rates from Heart Disease, Influenza and Pneumonia and Aspiration Pneumonia.

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	Heart Disease	Aspiration Pneumonia
2	Influenza & Pneumonia	C-P Arrest/ Seizure[39], Aspiration Pneumonia	Heart Disease
3	Cancer, Aspiration Pneumonia		Cancer, Influenza & Pneumonia

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

Deaths in the Non-DMR setting were distributed among a variety of causes. Heart Disease, the leading cause of death in this type of setting, accounted for three deaths. Within the DMR Facilities, Aspiration Pneumonia accounted for 9 deaths, Heart Disease for 8 deaths and Cancer for 4 deaths. The leading causes of death in DMR facilities were similar to previous years, although 2005 experienced a decrease in deaths from Septicemia.

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. During 2005, 210 required reviews were completed and analyzed by the Regional and/or Central Mortality Review Committee. All reviews required by DMR policy were completed, resulting in 100% compliance.

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 mental retardation 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.[63]

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 2005 there were nineteen (19) deaths investigated by one or more of the agencies identified above, four (4) of which also involved law enforcement investigation. There were twenty-one (21) complaints regarding deaths generated in calendar year 2005, nineteen (19) of which resulted in civil investigation. One case handled by DMR Investigations was dismissed; another was resolved without investigation. Of the fifteen (15) complaints assigned to DPPC and DMR, thirteen (13) are complete. Of the complete investigations, nine (9) were unsubstantiated and four (4) were substantiated. As can be seen in Table 17, the number of investigations in 2005 is similar the number in 2004. However, in 2005 there were more substantiated investigations than in previous years.

Table 17
Summary of Investigations
1999 to 2005

Type of Activity	1999	2000	2001	2002	2003	2004	2005
DMR Investigation	7	5	5	14	9	5	10
DPPC Investigation	5	1	2	2	4	6	5
DPH Investigation	2	1	8	10	10	9	4
District Attorney/Law Enforcement Investigation	0	3	1	3	2	4	4
Other/dismissed[64]	5	3	5	4	2	1	2
Total Number of Deaths Investigated	19	13	21	33	27	20	19
No. Substantiations	0	0	1	2	2	1	4

[63] "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."

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

Benchmarks

As in past reports, the 2005 DMR Mortality Report incorporates a variety of comparative benchmarks that can be used to better understand the analytic 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 mental retardation and/or developmental disability.

Individuals with mental retardation, such as those supported by the Massachusetts DMR very frequently present with a variety of often complex co-morbidities (secondary health and behavioral conditions) that can elevate their relative mortality risk compared to the general population. Therefore, reliance on comparative benchmarks from the general population can be misleading. While age-adjustment is used to correct for varying mortality risk as a result of differences in age distribution, such an approach does not correct for other factors that can strongly influence mortality findings (e.g., higher prevalence of health-related issues present in persons with significant disability). Therefore, it is potentially more useful to examine mortality statistics in adult populations with mental retardation/developmental disability 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 MRDD agencies 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 2005 Massachusetts findings. Direct comparisons of specific data should NOT be made.

Cause of Death Benchmarks. Comparisons of the top five leading causes of death as reported by the MR/DD state agencies in Connecticut[65], New Mexico[66], Ohio[67] and Vermont[68] are presented below in Table 18. Rank order is a very general indicator and is extremely sensitive to small changes in the number of deaths present within each category due to 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 the top three causes of death for three out of the four benchmark state systems. Interestingly, septicemia (infection) falls within the top five rankings for three state MR/DD systems while, as mentioned previously, its relative rank in Massachusetts has been declining since 2002, now ranking as the seventh leading cause of death within DMR.

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[65] *Health and Mortality Review: 2005 Annual Report*. Connecticut Department of Mental Retardation, 2006.

[66] Personal Communication, New Mexico Department of Health, Mortality Review Data, DD Waiver, LTSD Steering Committee, February 1, 2005.

[67] Cause of Death Annual 2005, Ohio MRDD, at http://odmrdd.state.oh.us/health/report.htm

[68] *Mortality among People Receiving Developmental Services in Vermont FY 2004*, Vermont Division of Developmental Services, 2005.

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

Rank	MA DMR 2005	CT DMR 2005	OH OMRDD 2005	NM DH 2004	VT DDS 2004
1	Heart Disease	Heart Disease	Heart Disease	Respiratory & Aspiration Pneumonia	Respiratory/ Pneumonia & Alzheimer's
2	Cancer	Respiratory Disease	Pneumonia	Cancer	Heart Disease & Seizure
3	Influenza & Pneumonia, CP-Arrest/ Seizure[39]	Pneumonia & Aspiration Pneumonia	Cancer	Heart Disease	Cancer & Genetic
4		Cancer	Aspiration Pneumonia	Sepsis	GI & Other Neurological
5	Aspiration Pneumonia	Septicemia	Infection (Septicemia)	CP Arrest	Misc. Other

Mortality and Gender Benchmarks. Published mortality data from both Connecticut and Ohio are used for comparative purposes for reviewing the distribution of deaths by gender. These data are presented below in Table 19 and suggest that an almost identical ratio of male to female deaths is present in all three 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 rates in Massachusetts.

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

Gender	Measure	MA DMR 2005	CT DMR 2005	OH DMRDD 2005
Male	Percentage of Deaths	54%	53%	54%
	Death Rate	17.8	12.4	NA
Female	Percentage of Deaths	46%	47%	46%
	Death Rate	18.1	14.4	NA

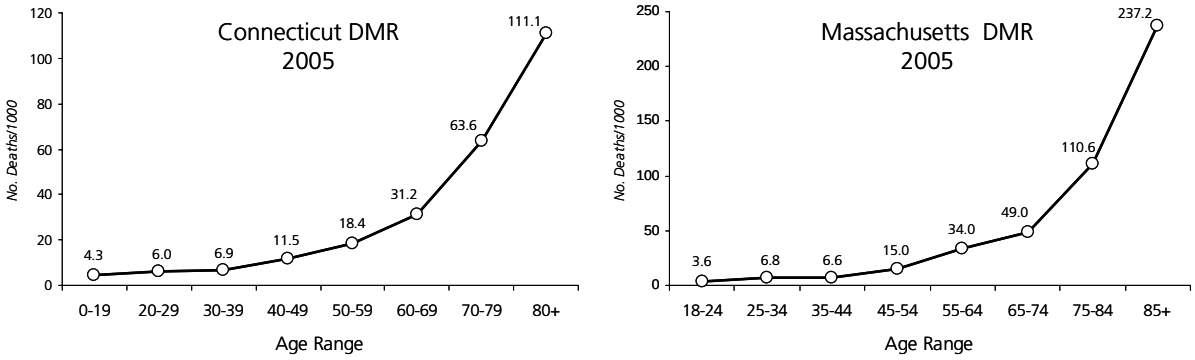
Note: Death Rate for CT includes children. MA only includes adults.

Mortality and Age Benchmarks. Both Connecticut and Massachusetts provide crude mortality rates by age range. However, the ages included in each grouping 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 CT and MA, with death rates showing a sharp increase after age 60-65 years. Differences in the age ranges utilized for the analyses conducted by these state systems makes it is difficult to draw direct comparisons, particularly in the more elderly age groups where each year of age begins to substantially increase risk of mortality (i.e., Massachusetts ranges are about 5 years older than Connecticut's resulting in an older age cohort, a factor that can be significant in the 60-yr plus groupings).

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

Crude Mortality Rate by Age (Not Age Adjusted)			
CT DMR (2005)		**MA DMR (2005)**	
Age Range	Mortality Rate	Age Range	Mortality Rate
0-19	4.3	18-24	3.6
20-29	6.0	25-34	6.8
30-39	6.9	35-44	6.6
40-49	11.5	45-54	15.0
50-59	18.4	55-64	34.0
60-69	31.2	65-74	49.0
70-79	63.6	75-84	110.6
80+	111.1	85+	237.2

Figure 14
Graphic Illustration of the Mortality Rate by Age
For the Connecticut DMR and Massachusetts DMR



Mortality and Residence Benchmarks. As noted in previous reports, there are significant differences in the populations served and residential groupings utilized by different state MRDD agencies that make direct comparisons of mortality by residential setting difficult.[69] Of special concern are the differences in population characteristics, e.g., the Connecticut DMR provides some residential services to children with mental retardation who are included in the base for computing mortality rates. The influence of this age difference on

[69] For example, in addition to Massachusetts, only five other states have a specific MRDD agency dedicated to serving only persons with mental retardation. Most state systems serve a broader DD population. In addition, available data on mortality is very limited, especially with regard to analyses that look at death rates by where people live. 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.

resultant mortality rates is not known, but should be taken into consideration when comparing the mortality rates by residence for these benchmark state systems.

Table 21 below provides crude mortality rates (no. of deaths per 1000 people served) by type of residential setting for the California DDS (2002 data) and the Connecticut and Massachusetts DMR state systems (2005 data). As can be seen, community residence and facility (ICF/MR) mortality rates for the Massachusetts DMR appear to be somewhat higher than for the Connecticut or California systems. However, mortality rates for persons served within nursing facilities appear lower. Differences in population characteristics (e.g., both CT and CA serve 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, California DDS[70] and Connecticut DMR

Type of Residential Setting	Mortality Rate - No./1000		
	MA DMR 2005	CT DMR 2005	CA DDS 2002
At Home/Family	5.9	4.8	6.4
Independent and Supported Living		5.5	6.1
Community Residence	18.9	13.0	10.3
Regional Center	39.4	25.5	19.1
Facility-ICF/MR		25.6	
Nursing Facility	147.2	163.0	156.4

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 mental retardation 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 can be seen in Table 22, the reported crude death rate for the MA DMR appears to be higher than that reported by the other five states included in this

[70] California DDS: Reported in the Biannual Summary for Community-based Mortality for Data January-June 2002, Columbus Organization, October 2003

analysis. However, the Massachusetts data is based on an analysis of an adult population only, whereas the other benchmark states include children served by the agency (often a rather large group that primarily lives at home). Given that age is the single most important risk factor for mortality, the higher rate for Massachusetts is to be expected. For example, when only adults are included in the Connecticut analysis, the mortality rate increases from 13.3 to 16.2 per 1000 people served, a rate closer to that for Massachusetts. Nonetheless, 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** 2005	**CT DMR** 2005	**CT DMR** 2005	**AZ DDD** 2004	**TN DMRS**[71] 2005	**NM DOH** 2004	**CA DDS** 2002
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 (18+ yrs)	children and adults	NA	children and adults	children and adults
No. Deaths	409	201	185	216	89	36	685
Mortality Rate (no./1000)	**17.9**	13.3	**16.2**	9.7	10.0	11.0	9.2

Healthy People 2010 Objectives

The Healthy People 2010 (HP2010) initiative contains a series of health-related goals and objectives for the nation to achieve by the year 2010 promulgated by the U.S. Department of Health and Human Services in November 2000. 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 were not included.

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.

[71] TN data based on narrative within report (p 25) and did not include specific data tables. Specific population analyzed in the mortality analysis was not included in the narrative.

Statistics from 2003 were used for the U.S. objectives to ensure increased accuracy.[72] 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 (2001-2005). 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. Since it is not possible to have a death rate under 0.8 per 100,000 for DMR over five years due to the small size of the population, these smaller rates are not included.

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, but lower than national rates.[73]

While reviewing the table, it should be kept in mind that the risk of cancer significantly increases with age.[50] 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.

Analysis suggests that mortality rates for colorectal cancer decreased by about 3 deaths per thousand and moved closer to the targeted rate. As mentioned previously, individuals with mental retardation 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, although some improvement is noted from last year for this form of cancer death. Rates of cervical, oropharyngeal and malignant melanoma were 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 4, 5 and 5 cases respectively across the past 5 year time period).

[72] Preliminary U.S. rates for 2004 have been released, however because they have not yet been finalized, 2003 rates are used to ensure accuracy.

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

Table 23

Target Status for Selected Healthy People 2010 Mortality Objectives[74]

Objective Number	HEALTHY PEOPLE 2010 OBJECTIVE *Rates per 100,000 population; MA and US are Age-adjusted*	TARGET 2010[75]	DMR 2001-2005	DMR TARGET STATUS	MA 2004[75]	US 2003[75]
3-1	Overall Cancer death rate	159.9	218.7	●	188.4	190.1
3-2	Lung Cancer	44.9	14.1	✓	52.0	54.1
3-3	Female Breast Cancer (per 100,000 females)	22.3	43.2	●	24.2	25.3
3-4	Cervical (per 100,000 females)	2.0	7.8	●	1.7	2.5
3-5	Colorectal Cancer	13.9	22.0	●	17.7	19.1
3-6	Oropharyngeal Cancer	2.7	4.4	●	2.8	2.6
3-7	Prostate Cancer (per 100,000 males)	28.8	17.7	✓	23.4	26.5
3-8	Malignant Melanoma	2.5	5.3	●	2.7	2.7
5-5	Diabetes-related deaths	46	16.7	✓	61	78
12-7	Stroke deaths	48.0	66.9	●	42.5	53.0
26-3	Drug-induced deaths	1.0	0.0	✓	11.1	9.9
13-14	HIV-infection deaths	0.7	--[76]	✓*	3.1	4.7
24-10	Chronic Obstructive Pulmonary Disease Deaths (age 45+)	62.3	161.4	●	106.0	118.7
	Injuries					
15-3	Firearm-related	4.1	0.0	✓	3.2	10.3
15-8	Poisonings	1.5	--[76]	✓*	11.2	9.9
15-9	Hanging, strangulation or suffocation	3.0	0.0	✓	4.4	4.4
15-13	Unintentional injuries (Accidents)	17.5	30.9	●	19.4	37.3
15-15a	Motor vehicle crashes	9.0	4.4	✓	8.0	14.8
15-29	Drowning	0.9	--[76]	✓*	1.2	1.2
15-25	Residential fire deaths	0.9	0.0	✓	0.4	1.2
15-27	Falls	3.0	11.0	●	4.0	5.9
15-32	Homicide	3.0	--[76]	✓*	2.8	6.0
18-1	Suicide	5.0	--[76]	✓*	6.4	10.8

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

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

[74] 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.

[75] Data 2010 the Healthy People 2010 Database. CDC Wonder website: http://wonder.cdc.gov. Goals revised January 2006. Rates for objective 5-5 (Diabetes-related deaths) and 24-10 (COPD) are from 2004, as they were not available for 2004.

[76] 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.

Mortality rates for diabetes-related deaths showed a slight increase from last year; however, the rate for the DMR population was once again significantly lower than both the rate for the general population in Massachusetts and the Healthy People 2010 target.

The DMR population experienced more stroke deaths on average than the HP2010 target rate and both the national and Massachusetts general population rates.

The objectives for chronic obstructive pulmonary disease focus only on adults over the age of 45. Adult rates of COPD exceeded the HP2010 goal. However, it should be noted that many adults with mental retardation have higher rates of respiratory problems that may help account for this finding.[77,78]

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.

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

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

APPENDICES

Appendix A

Methodology

The 2005 Mortality report analyzes information on all deaths occurring in calendar 2005 for all individuals with mental retardation, 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 2005 Mortality Report includes statistics on all deaths of individuals who died in calendar year 2005 and whose Death Report was received by DMR by the end of January 2006. A total of 409 deaths were reported to have occurred between January 1, 2005 and December 31, 2005.

The data used to calculate death rates per 1000 by age group and type of residence was supplied by the DMR CRS of June 30, 2005.[79] 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 409 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:

$$\text{Crude Death Rate} = \frac{(\text{Number of individuals who died in calendar year 2005} \times 1000)}{(\text{No. Individuals in CRS in June 2005})}$$

[79] CDDER relies on the accuracy of information about the number of individuals eligible for DMR services, their ages, region and type of residential placement. Inaccuracies in the CRS, if any, will be reflected in the numbers used to compute death rates in the DMR population. The number of individuals served by DMR by region and type of residence used in the calculations of death rates were based on data as of June 30, 2005.

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
3151	Residential 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

Appendix C

Demographic Data

Age and Residential Distribution of the 2005 DMR Adult population

SEX	Age	DMR Funded Community	DMR Facility	Nursing / Rest Home	Own Home	Non-DMR	Total
F	18-24 yr	143	1	22	1414	133	1,713
M	18-24 yr	207	3	27	1942	223	2,402
F	25-34 yr	600	4	43	1182	37	1,866
M	25-34 yr	828	15	39	1422	65	2,369
F	35-44 yr	1021	65	39	1080	85	2,290
M	35-44 yr	1409	81	31	1223	84	2,828
F	45-54 yr	1022	138	39	785	84	2,068
M	45-54 yr	1292	211	42	859	75	2,479
F	55-64 yr	671	105	90	419	62	1,347
M	55-64 yr	755	176	46	388	53	1,418
F	65-74 yr	269	81	88	157	26	621
M	65-74 yr	318	99	73	160	35	685
F	75-84 yr	116	29	112	57	27	341
M	75-84 yr	116	35	62	40	21	274
F	85+ yr	33	13	49	4	7	106
M	85+ yr	15	11	13	9	2	50
Total		8,815	1,067	815	11,141	1,019	22,857

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_{Si} = standard population for age group I,
P_{Si} = total U.S. standard population (all ages combined)

Appendix E

ICD-10 Codes Used in this Publication

(Sorted by ICD-10 Codes)

Cause of Death	ICD-10 Code
Infectious and parasitic diseases	A00-B99
Septicemia	A40-A41
Human Immunodeficiency Virus (HIV) disease	B20-B24
Cancer (Malignant Neoplasms)	C00-C97
of esophagus	C15
of stomach	C16
of colon, rectum, rectum and anus	C18-C21
of pancreas	C25
of trachea, bronchus and lung	C33-C34
of female breast	C50
of cervix uteri	C53
of corpus uteri and uterus, part unspecified	C54-C55
of ovary	C56
of prostate	C61
of kidney and renal pelvis	C64-C65
of bladder	C67
of meninges, brain & other parts of central nervous system	C70-C72
Hodgkin's Disease	C81
Non-Hodgkin's lymphoma	C82-C85
Leukemia	C91-C95
Multiple myeloma and immunoproliferative neoplasms	C88, C90
Diabetes Mellitus	E10-E14
Alzheimer's Disease	G30
Heart Disease	I00-I09, I11, I13, I20-I51
Stroke (Cerebrovascular Disease)	I60-I69
Influenza and Pneumonia	J10-J18
Chronic Lower Respiratory Diseases[1]	J40-J47
Chronic Liver Disease and Cirrhosis	K70, K73-K74
Nephritis	N00-N07, N17-N19, N25-N27
Congenital malformations, deformations, and Chromosomal abnormalities	Q00-Q99
External causes of injuries and poisonings (intentional, unintentional and of undetermined intent)	V01-Y89
Accidents (Unintentional Injuries)	V01-X59, Y85-Y86
Suicide	X60-X84, Y87.0
Homicide	X85-Y09, Y87.1
Injuries of undetermined intent	Y10-Y34,Y87.2,Y89.9

Appendix F

ICD-10 Codes Used in this Publication

(Sorted by Category)

Cause of Death	ICD-10 Code
Accidents (Unintentional Injuries)	**V01-X59, Y85-Y86**
Alzheimer's Disease	G30
Aspiration Pneumonia	J69
Cancer (Malignant Neoplasms)	C00-C97
Cardiopulmonary Arrest/ Seizure	G40, R09.2, J96.0
Chronic liver disease and cirrhosis	K70, K73-K74
Chronic Lower Respiratory Diseases[1]	J40-J47
Congenital malformations, deformations, and Chromosomal abnormalities	Q00-Q99
Diabetes Mellitus	E10-E14
Heart Disease	I00-I09, I11, I13, I20-I51
Influenza and Pneumonia	J10-J18
Nephritis	N00-N07, N17-N19, N25-N27
Septicemia	A40-A41
Stroke (Cerebrovascular disease)	I60-I69
Unknown	R96-R99

Appendix G

ICD-10 Codes for Selected Healthy People 2010 Mortality Objectives Used in this Publication

(Sorted by Objective Number)

Objective Number	Cause of Death*	ICD-10 Identifying Codes
3-1	Cancer (all sites)	C00-C97
3-2	Lung cancer	C33-C34
3-3	Female breast cancer	C50
3-4	Uterine Cervix cancer	C53
3-5	Colorectal cancer	C18-C21
3-6	Oropharyngeal cancer	C00-C14
3-7	Prostate cancer	C61
3-8	Malignant melanoma	C43
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 underlying cause-of-death data.

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