

**Commonwealth of Massachusetts
Department of Mental Retardation**

2003 Mortality Report

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Table of Contents

Executive Summary	2
Overview of DMR	4
Mortality During 2003	8
Age	8
Gender	9
Residence	10
Trends Over Time	15
Cause of Death	18
Mortality Review Process and Committee	22
Investigations	22
Benchmarks	23
Appendices	
A: Methodology for Mortality Review and Analysis	29
B: Residential Codes and Definitions	30
C: Demographic Data	31

Executive Summary

The Massachusetts Department of Mental Retardation (DMR) has established a formal mortality review process as an integral component of its quality management and improvement system. The mortality review process enables DMR to fully analyze the causes and circumstances surrounding the deaths of individuals it supports. The process contributes to organizational learning and efforts to improve the quality of supports to individuals with mental retardation. The University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER) has assisted this effort by preparing annual mortality reports for DMR for the past four years. This *2003 Mortality Report* represents a review of the time period between January and December of 2003.

In calendar year 2003, the Massachusetts DMR served 32,004 individuals, 22,794 of whom were adults over the age of 18.¹ During 2003, 431 deaths were reported for DMR clients, resulting in an average rate of death of 18.9 per thousand adults. This represents an increase of 26 deaths from 2002 when 405 deaths occurred.

A review of mortality data over time shows that death rates have not been evenly distributed throughout the population. The death rate continues to remain lower in younger age groups and in those populations residing in independent and family community settings or in DMR community settings. Rates of death are generally higher and have shown the greatest increase for individuals residing in nursing homes and for older populations (75-84 years), both of which are typically at greater risk for mortality due to age and/or health status.

Age

As expected, mortality rates during 2003 varied by age, with the oldest age group (85+ years old) exhibiting the highest mortality rate (198.7 per thousand) and the youngest group (18-24 years old) showing the lowest rate (2.7 per thousand). These findings and the general mortality trends by age are similar to those found in other state MR/DD systems that report death rates by age.²

Gender

For the first time since 2000, more men than women passed away during 2003, with males representing just over half of all deaths (52.2%). However, since there were substantially more men than women served by DMR during 2003, the death rate for men was slightly lower than that for women (18 deaths per thousand for men and 20 deaths per thousand for women).

¹ DMR population statistics as of June 30, 2003 based on CRS data.

² Based on a comparison of reported mortality rates by the MR/DD state systems in Connecticut and New Mexico for 2002/2003

Residence

As in past years, there continues to be substantial differences in mortality rates by residential setting. The lowest rate occurs for individuals who live independently or at home with their family and the highest rate occurs for those individuals who reside in a nursing home.

Cause of Death

For the fourth year in a row, Heart Disease was the most common cause of death in the DMR client population, representing 22% of all deaths in 2003. However, for the first time, cancer became the second leading cause responsible for 14% of all deaths. Aspiration Pneumonia, ranked second in 2002, was the third leading cause of death in 2003, responsible for 12% of all deaths. Septicemia was the fourth leading cause of death in 2003. The rates of influenza pneumonia and accidents as a cause of death decreased from the rates in prior years.

Benchmarks

Massachusetts DMR mortality data was compared, where possible, with similar information from other state MR/DD systems. This analysis shows no significant differences in the general trends and patterns related to mortality and age, mortality and residential setting and leading causes of death.

Additional Information

The 2003 report includes a number of additional sections that provide a summary of investigations and the methodologies used to analyze data for the report.

2003 Mortality Report

The Massachusetts Department of Mental Retardation (DMR) has established a formal mortality review process as an integral component of its quality management and improvement system. The mortality review process enables DMR to fully analyze the causes and circumstances surrounding the deaths of individuals it supports. The process contributes to organizational learning and efforts to improve the quality of supports to individuals with mental retardation. As part of this quality improvement 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 for the past four years. This report represents a review of the period between January and December of 2003.

Overview of DMR

The Massachusetts DMR served 22,794 adults with mental retardation in June of 2003. Because the population served by DMR tends to increase as the year progresses, using the mid-year population best models the average population across the entire calendar year. The methodology used to calculate the annual client population in 2003 has been adjusted from that used in previous years³. While the client population in 2003 shows an apparent decrease of about 8.2% from the population reported in the 2002 mortality report, this difference is an artifact caused by the way in which the base population was calculated. It is important to note that the actual number of individuals receiving services between 2002 and 2003 has not changed significantly.⁴

MORTALITY REVIEW IN DMR

2003 Mortality Report: The first part of this report includes information and data concerning all adults (persons 18-yrs old and older) served by DMR who were listed in the Consumer Registry System (CRS) and who died during the 2003 calendar year. The data includes persons therefore who do not always meet the specific criteria for formal review by the DMR Mortality Review Committee (see below).

DMR Clinical Mortality Review:

Information regarding clinical mortality reviews is included in the latter part of this report. Such clinical reviews are conducted for deaths of persons served by DMR who:

- are at least 18-yrs of age;
- receive a minimum of 15-hrs 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

³ The client population reported in the 2000-2002 mortality reports includes a group of individuals who were counted twice. This duplication was due to the omission of criteria in the database query that would have counted only current service enrollment for an individual during the time period. In 2003, the criteria were adjusted and this group was not included in the annual client population, thereby eliminating the duplicated count of certain individuals.

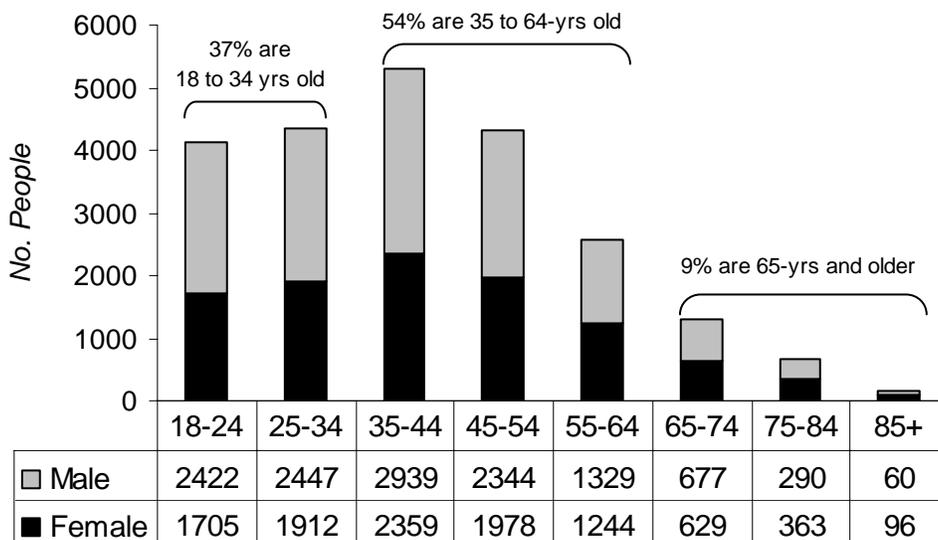
⁴ The reduction in the total number of persons reported by DMR as clients of the agency took place following an update of the data maintained in the CRS during 2004 and as a result of a revision to the data query methodology to improve its accuracy. These changes have not substantially modified the data for clients actively served by DMR and do not reflect any reduction in services or numbers of individuals served. Rather it is a reflection of clarification on how DMR defines individuals who are not actively served.

The resulting decrease in the annual client population resulting from this change in methodology affects the ability to directly compare the 2003 mortality rates with previous years. Consequently, in this report comparative data that relies on the overall DMR population will utilize 'adjusted' mortality rates for previous years.⁵

Age Characteristics. DMR serves primarily adults (age 18-yr and older) who have mental retardation. More than half (53%) of all Massachusetts DMR adult consumers are between the ages of 35 and 64 years old. However, and as can be seen in Figure 1 below, DMR also serves a relatively large number of senior citizens, with 9%, or over 2,000 people, aged 65-yrs and older.

Figure 1

**No. Adults Served by DMR during 2003
by Age Range and Gender**



During 2003, the Massachusetts DMR continued to experience a gradual shift in the aging of the adult population it serves. This age shift has also been reported in MR/DD agencies in other northeastern states⁶. Interestingly, this trend is opposite that of the general population in Massachusetts where the proportion of elderly individuals actually decreased from 2000 to 2003⁷. While the proportion of elderly individuals in the DMR population continues to grow, the rate of increase has been reduced from that evident in previous years. This “aging” trend within the population served by DMR may be an important factor influencing mortality trends over time as age significantly increases risk of mortality.

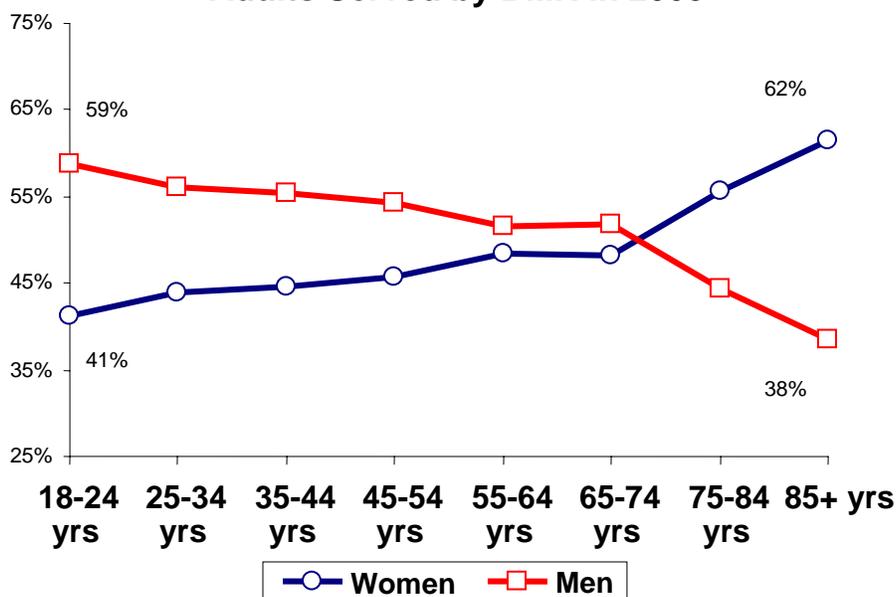
⁵ Rates for prior years have been adjusted by using the current 2003 methodology to calculate the overall client population (denominator for calculating rates). The number of deaths was unchanged (numerator). These adjusted rates are provided to increase the validity of analyses that compare mortality rates from prior years with the data presented for 2003. It is important to note that the methodology used to calculate the actual number of annual deaths has not changed.

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

⁷ Comparison of Massachusetts Fact Sheets 2000 and 2003, US Census Bureau

Figure 2

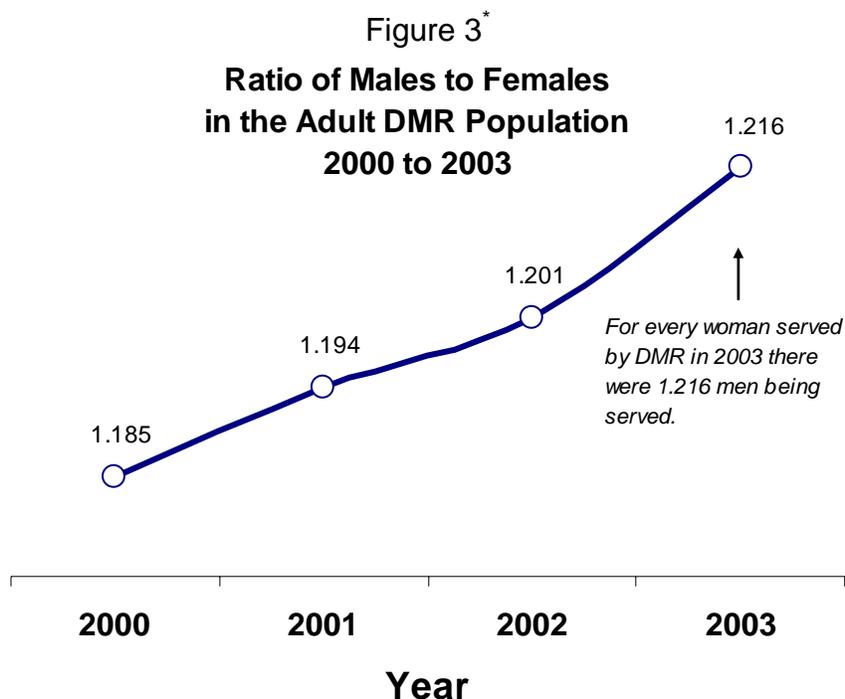
**Gender Distribution by Age
Adults Served by DMR in 2003**



Gender Characteristics. The proportion of men and women served by DMR varies by age (see Figure 2 above). Within younger age groups there are more men than women. However, by about age 65-74 yrs this trend reverses itself, with the oldest age group comprised of a higher proportion of women than men, a finding consistent with reported research from other states⁸.

While the gender gap in the elderly population has been consistent throughout recent years, there is a possible trend toward an increasing proportion of men in the younger age groups. Figure 3 shows the proportion of males to females in the DMR population over the past 4 years. As can be seen, data suggest a relatively consistent increase in the relative number of males in the DMR adult population.

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

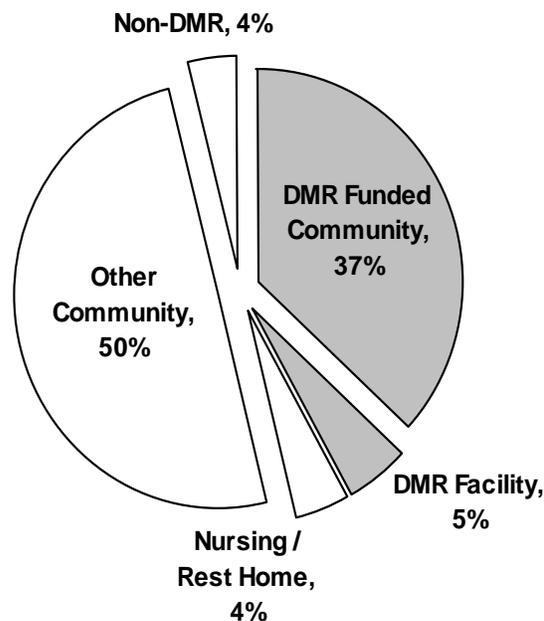


*Gender ratios displayed for 2000-2002 have been adjusted using the 2003 population methodologies

Figure 4
Where People Live

Residential Setting Characteristics.

DMR adult consumers live in a variety of residential settings. Figure 4 shows the number of DMR consumers relative to the type of residential program operated, certified or funded by DMR (shown in the shaded area). 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”). About 4% of the population lived in non-DMR settings or in nursing homes or rest homes. In 2003 a larger portion of individuals (50%) lived in their own homes, either independently or with family than in previous years.



Mortality During 2003

This section of the report provides information on the deaths of persons with mental retardation who were 18 years of age or older and who were determined to be eligible for DMR services and supports during calendar year 2003. Appendix A contains a detailed description of the methodology used to collect and analyze the information and data contained in this section.

During 2003 DMR received death reports for **431** individuals who met the criteria outlined above. This represents a crude death rate⁹ of **18.9** persons per thousand.¹⁰

Age

In previous years, the number of reported deaths according to age was based on 20-year age band cohorts. Beginning with the 2003 report, ten-year age bands are used for all age groups over 24 years¹¹. This reporting methodology is consistent with mortality reports published by the Center for Disease Control (CDC). Use of the ten-year age band will allow more valid comparisons with the CDC national report, state reports and reports from other MR/DD agencies. This new age grouping also allows for an enhanced analysis of those in the 25-64 year age group that represents the overwhelming majority of DMR consumers.

Table 1
Distribution of Deaths by Age Group, 2003

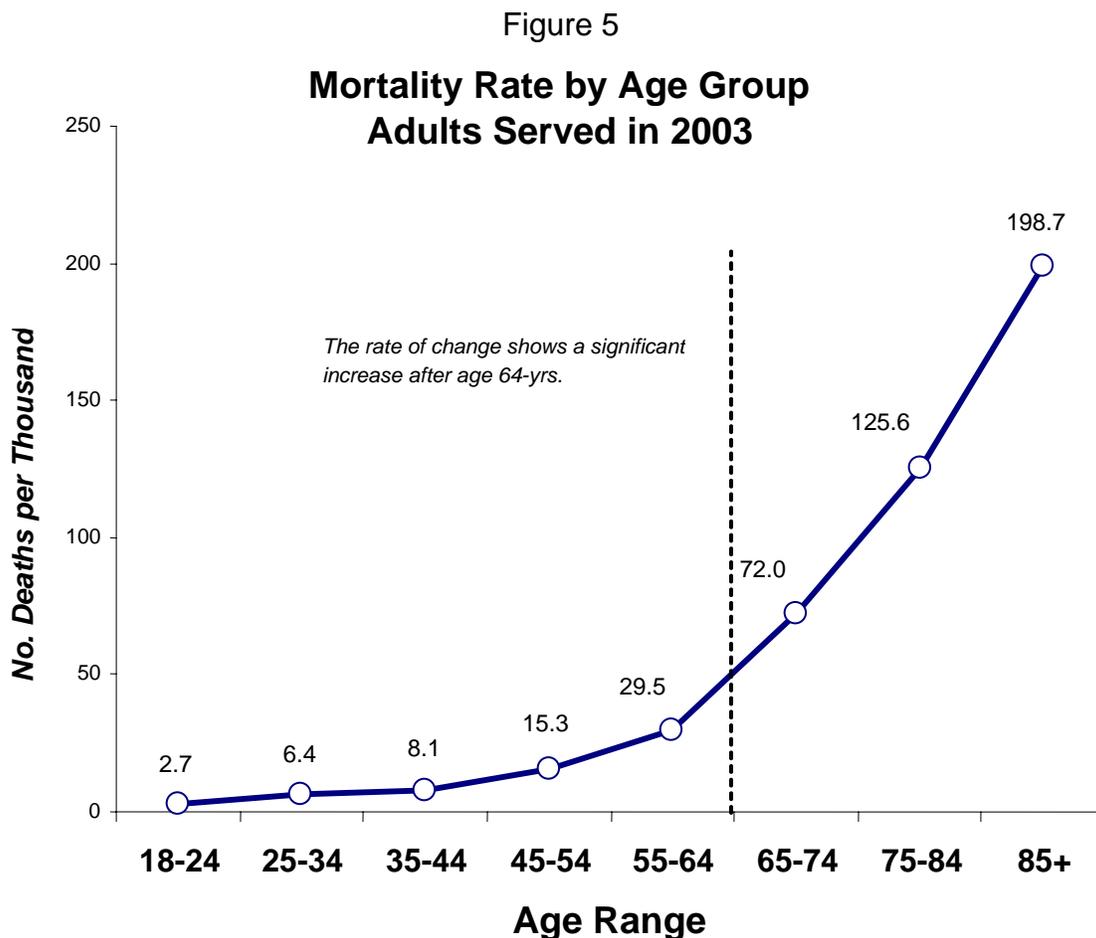
Age Range	No. Deaths	Percentage	Death Rate (No. per 1000)
18-24 yrs	11	3%	2.7
25-34 yrs	28	6%	6.4
35-44 yrs	43	10%	8.1
45-54 yrs	66	15%	15.3
55-64 yrs	76	18%	29.5
65-74 yrs	94	22%	72.0
75-84 yrs	82	19%	125.6
85 yrs & older	31	7%	198.7
Total	431	100%	18.9

⁹ 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 persons who died during the year times one thousand and dividing this by the total number of persons served by DMR during the same year. See Appendix A for more detail.

¹⁰ 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.

¹¹ In this report, adults are defined as individuals over the age of 18. Therefore the youngest age group (18-24) is smaller than the other age groups that use a 10-year age range.

Table 1 presents the number of persons who died, the relative percentage of deaths across DMR and the mortality rate, by age group. These data suggest that mortality rates consistently increase with advancing age, with the oldest age group exhibiting the highest mortality rate and the youngest group showing the lowest rate. Figure 5 below, is a graphic representation of mortality rates according to age.



Gender

The relationship between gender and mortality is complex and influenced by both the proportion of males to females served by DMR and differences in age distribution that exist between the two groups. For example, during 2003 more men passed away than women, representing just over half of all deaths. For the first time since the initial mortality reports in 2000, more men passed away in a calendar year than women. It should be noted however, that the DMR population contains more men than women (55% male, 45% female). And, as shown in figure 3 and noted in the previous section (Gender Characteristics), the last 4 years have shown a steady increase in the relative proportion of men receiving DMR services.

As can be seen in Table 2, while the number of actual deaths was higher for males in 2003, when coupled with the larger male population, their *rate of death* (18 per 1000) was actually lower than the rate for females (20 per 1000). Interestingly, the *average age at death* for females increased almost 1 full year from 62.0 years in 2002 to 62.9 years in 2003. For males it experienced a slight decrease from 60.9 years in 2002 to 60.5 years in 2003.

The higher female to male average age at death is consistent with trends found in the general population both nationally and statewide since in both the DMR population and the general population there are more women than men within the oldest age groups – those at the highest risk of mortality. However, the increasing dominance of younger males in the DMR population is different than that found in the general population and may potentially lead to gender-specific death rates that are not typically seen in the general population of the U.S. or Massachusetts.

Table 2
**No. Deaths, Average Age at Death and Death Rate by Gender
2003**

Gender	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
F	206	47.8%	62.9 yrs	20.0
M	225	52.2%	60.5 yrs	18.0

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.¹² Specific definitions, including residential codes, are contained in Appendix B.

There appears to be substantial differences in mortality rates based upon the type of residential setting using the categories described above. These differences are illustrated in Table 3 and Figure 6 below. As can be seen, the lowest mortality rate occurs for individuals who live independently or at home with their family. The highest rate occurs for those individuals who reside in a nursing or rest home. The relationship between type of residence and mortality is consistent with expectations and with trends

¹² For this report some of the smaller residential groupings were moved from the "non-DMR" residential category to the "DMR Community" residential category to more accurately reflect the level of support provided to individuals residing in these residential settings. The regrouping affects less than 1% of the DMR population.

present in other state mental retardation systems¹³ since average population age tends to vary by type of residential setting.¹⁴

The number of deaths for adults living independently or with family continues to be low. In 2003 the rate of death in this cohort (7.0 per 1000) was lower than the crude mortality rate of 9.0 per 1000 for the general population in Massachusetts.¹⁵

Both the actual number of deaths and the death rate decreased from 2002 levels in the Non-DMR Residence category. However, the number of deaths and the death rate increased from 2002 levels for the DMR Facilities and Nursing Home categories. It should be noted that while the rate of death in Nursing Homes for DMR clients is higher than any of the other residential settings, this rate is actually lower than the general population rate of death (353 per thousand) in Massachusetts Nursing Homes as reported in 2001¹⁶.

Table 3
**Age and Mortality by Type of Residential Setting
For Adults Served by DMR
2003**

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	11,375	3.9%	80	18.6%	51.3	7.0
DMR Community	8,427	9.6%	137	31.8%	58.3	16.3
Non-DMR	890	12.9%	11	2.6%	65.4	12.4
DMR Facility	1,163	24.0%	46	10.7%	60.5	39.6
Nursing Home	939	50.3%	157	36.4%	69.9	167.2
<i>Total (Statewide)</i>	22,794	100%	431	100%		
<i>Average</i>					61.7	18.9

¹³ State of Connecticut Department of Mental Retardation. *Health and Mortality Report*, November 2002 and October 2003.

¹⁴ The population that lives at home or with family is substantially younger than the population that lives in nursing homes. The population that lives in community settings and facilities falls in the middle in terms of average age.

¹⁵ *Massachusetts Deaths 2002*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, June 2004

¹⁶ 2001 Rate of Death in Massachusetts Nursing Homes calculated from a population in 2001 of 48,876 living in MA Nursing Homes (from *Across the States 2002: Profiles of Long Term Care* from the Public Policy Institute, AARP) and a total number of 17,265 deaths in MA Nursing Homes from (*Massachusetts Deaths 2001*, Bureau of Health Statistics, Research and Evaluation Massachusetts Department of Public Health).

The number of deaths in DMR community settings (residential programs operated, certified or funded by DMR) decreased in 2003 (134 deaths) from last year (152 deaths in 2002). The rate of death also decreased significantly in these types of settings when compared with the adjusted 2002 rate, moving from 19.2 per thousand to 16.0 per thousand.

The relationship between type of residential setting, age at death and mortality is presented in Table 3 above. As can be seen, the overall statewide average age at death for the DMR adult population in 2003 was 61.7 years of age. In general, there is a linear relationship between the mortality rate and the proportion of the population that is elderly (age 65+ years). With the exception of deaths in DMR Facilities, data suggest a generally linear relationship between the percentage of the population 65+ years of age and both the average age at death and the mortality rate. These patterns suggest that individuals with the lowest risk due to age have the lowest rate of mortality and those with the highest risk have the highest mortality rate.

As noted earlier, the largest number and percentage of deaths occurred for the population of individuals residing in nursing homes. This group also had the highest mortality rate during 2003. However, it also had the oldest average age at death and the largest percentage of persons 65 years of age and older, once again, the population at highest risk for mortality.

In contrast, the lowest mortality rate and the youngest average age at death occurred for the population of individuals living at home (own home or family home). This group also has the smallest percentage of persons aged 65 years and older.

The relationship between age, mortality and type of residential setting is further illustrated in Figures 6 & 7.

Figure 6

**Comparison of Mortality Rate and Average Age at Death by Type of Residential Setting
2003**

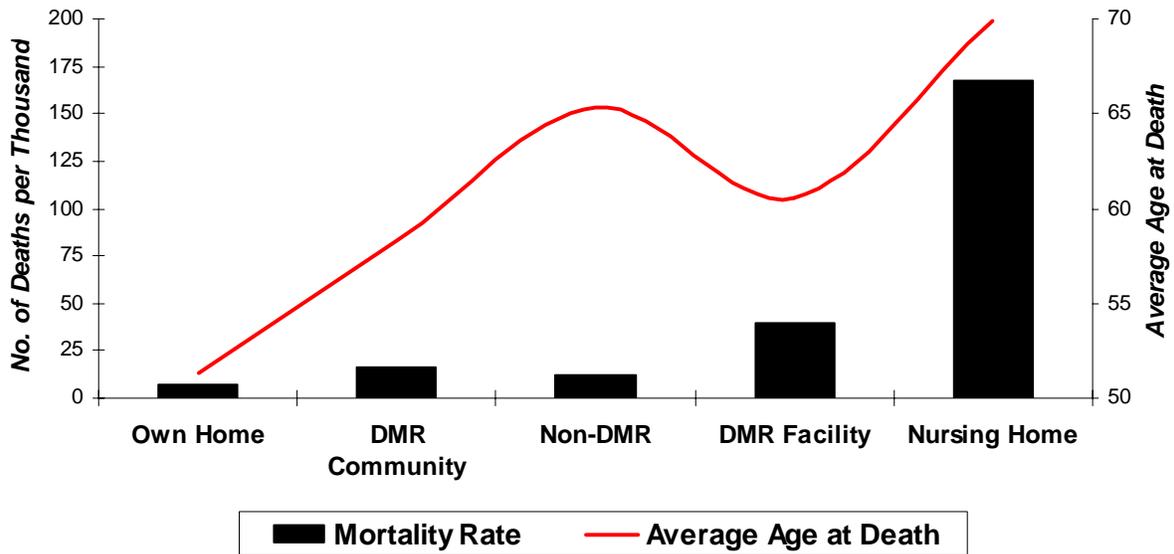


Figure 7

**Comparison of Mortality Rate and Percent of Population 65+ Years of Age by Residential Setting
2003**

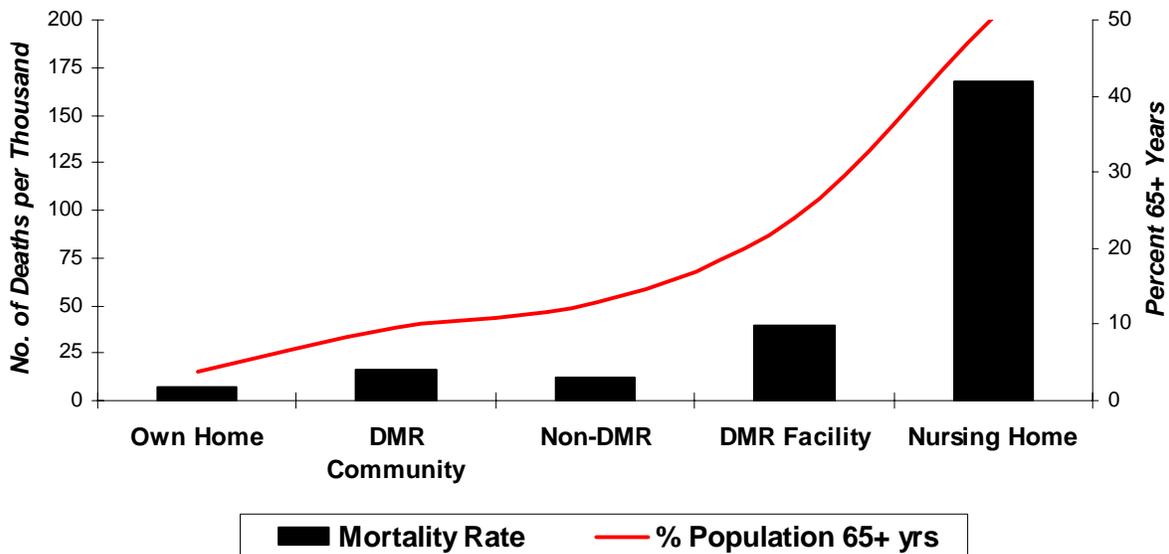


Table 4 below compares the relative proportion of persons residing in nursing homes by age and the number of deaths and the percentage of deaths in nursing homes in the same age groups. As can be seen in Table 4 and Figure 8, in every age group, a larger proportion of deaths occur in nursing homes than the relative proportion of each age group who reside in that type of residential setting. For example, while only 1% of the population in the 18-24 age group resides in a nursing or rest home, 18% of deaths within this age group were represented by nursing home residents. Even within the most elderly age group (85+ years old) a substantially higher percentage of deaths occurred for persons in nursing homes than the relative percentage of the DMR population who resided there. This relationship is seen consistently across age groups. Since 2000, data also suggest a steady increase in both the death rate and the number of deaths of nursing home residents.¹⁷

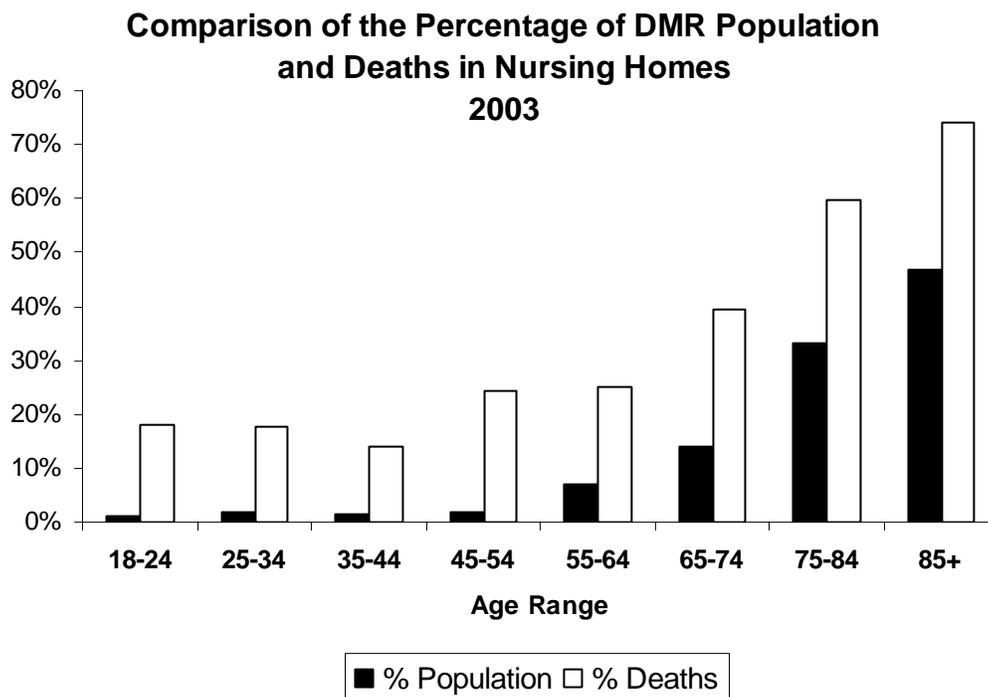
Table 4
Distribution of DMR Population and Deaths
in Nursing Homes for Major Age Groups
2003

Age Range	% Population	No. Deaths	% Deaths
18-24	1%	2	18%
25-34	2%	5	18%
35-44	1%	6	14%
45-54	2%	16	24%
55-64	7%	19	25%
65-74	14%	37	39%
75-84	33%	49	60%
85+	47%	23	74%
Total	4%	157	36%

Consumers living in their own homes, independently or with family, show a very different trend. In every age group, DMR consumers living in their own home represent a far smaller percentage of annual deaths than their relative percentage of the overall population.

¹⁷Initiatives over the past few years by DMR to transition DMR consumers from Nursing Homes to community supports and services may have resulted in an ever increasing proportion of individuals still living in Nursing Homes who have more complex health issues and medical needs, and who are therefore at a higher risk of mortality. Such redistribution could account, at least in part, for the escalating mortality rate within the DMR Nursing Home population.

Figure 8



DMR Regions

During 2003 the Massachusetts Department of Mental Retardation reconfigured its administrative regions. Because there have not been any significant differences in regional rates of death or age at death in past years, and due to the substantial changes in the geographic areas of responsibility for the regions, an analysis of mortality by DMR Region is not included in this report.

Trends Over Time

Mortality Rate. The number of deaths reported within DMR increased in 2003 from the prior year and continues the trend of increasing deaths noted in last year's report and as illustrated in Table 5 and Figure 9 below. It should be noted that the change in the actual number of deaths between 2002 and 2003 is the smallest annual increase since 2001.

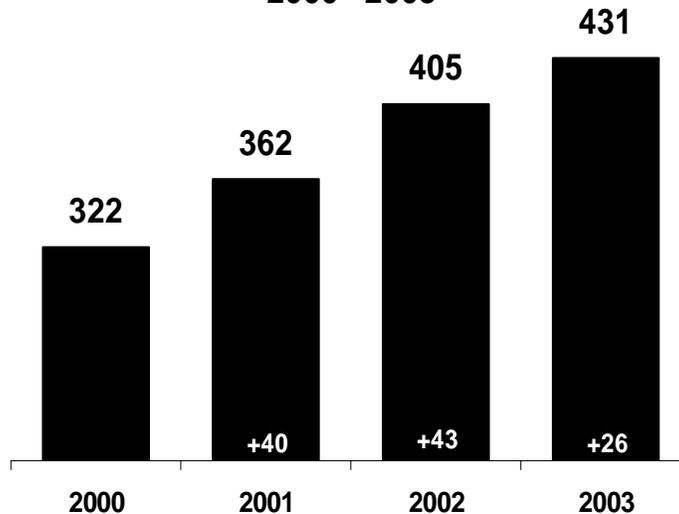
Table 5
Mortality Trends in DMR
2000 - 2003

Year	No. Deaths	Mortality Rate* ¹⁸ (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

As can be seen in Table 5, the average age at death has gradually increased over the four year time period between 2000 and 2003, suggesting that DMR consumers may be experiencing a longer life expectancy over time. The average age at death has steadily increased since 2000, with a relatively small increase of 0.2 years taking place between 2002 and 2003.

Figure 9

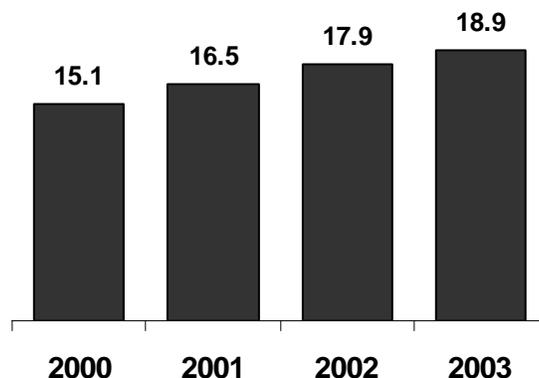
Number of Deaths by Year
2000 - 2003



Figures 9 and 10 show gradual increases in both the number of deaths and the rate of death each year.

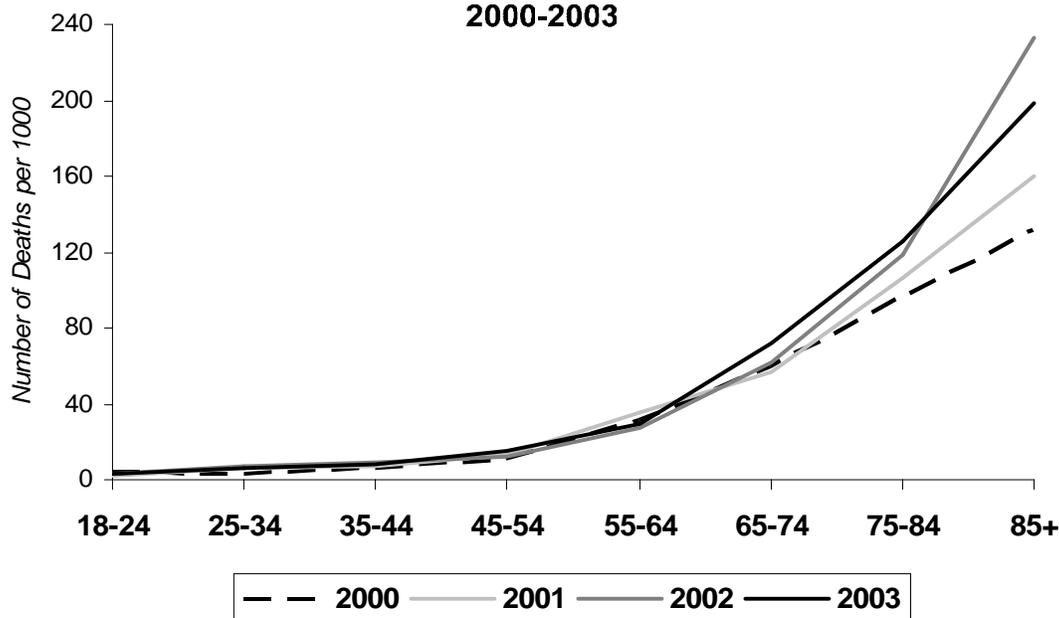
¹⁸ The mortality rates for 2000, 2001 and 2002 are calculated with a revised client population that uses the methodology employed in 2003. This adjustment is made to make the rates comparable to 2003 data.

Figure 10¹⁹
Statewide Mortality Rate
 (Deaths per 1000)
 2000-2003



The rate of death has not increased uniformly across all age groups over the past four years. Figure 13 displays the adjusted rates of death by age group for 2000-2003. As expected, the annual rate of death for adults varies little among the younger age groups. However, the rate of death for individuals over 65 varies more noticeably between years, showing a trend of increasing death rates in this elderly population. The increase in death rate is most noticeable for individuals 85 years or older, with the rates of death in 2002 and 2003 much higher than those in 2000 and 2001. This age group is the smallest served by DMR, and also has the highest mortality risk.

Figure 13
Comparison of Mortality Rate by Age Group
 2000-2003



¹⁹ 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.

Causes of Death

In this report the causes of death and the general categories to which the diseases and conditions are assigned is based on the World Health Organization's International Classification System for Diseases (ICD-10). This 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).

Cause of death was obtained from the DMR Death Report or the Death Certificate. In the case of persons subject to clinical mortality review, the cause was confirmed by the Mortality Review Committee.²⁰

It should be noted that in recent years, national and state mortality reporting regarding cause of death has focused on underlying causes. This approach has been used since the 2001 DMR Mortality Report and is the methodology used in the current report. As with past reports, deaths due to pneumonia are distinguished into two types: pneumonia due to acute infection (Influenza and Pneumonia) and pneumonia due to aspiration of liquids and solids (Aspiration Pneumonia).

Table 6 lists the top ten causes of death in the DMR client population for 2003 and compares these with data from three previous years as well as state and national data. For the fourth consecutive year, Heart Disease was the most common cause of death in the DMR client population, representing 22% of all deaths in 2003. For the first time since 2000, cancer was the second leading cause, responsible for 14% of all deaths. Aspiration pneumonia was the third leading cause, responsible for 12% of deaths. Septicemia (9%) followed as the fourth leading cause and Cardiopulmonary Arrest and Seizure²¹ (7%) were fifth. The relative ranking of these latter causes has been consistent over the past four years; however the percent of deaths represented by each has dropped from 2002.

Table 7 compares the mortality rates by cause for 2000-2003²². Rates of death from influenza pneumonia and from accidents have varied over time. For example, influenza Pneumonia fell from an adjusted rate of 1.00 in 2001 to 0.84 in 2002, but then increased to 0.88 per thousand in 2003. Accidents fell out of the top ten ranking in 2002, decreasing from 0.56 in 2001 to 0.40 in 2002 and increasing slightly to 0.44 per thousand in 2003.²³ In addition, while 2002 experienced an increased rate of sudden deaths from Cardiopulmonary Arrests and Seizures with an adjusted rate of 1.68 per

²⁰ 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.

²¹ Includes sudden deaths reported as cardio-pulmonary arrest whether or not seizure was present.

²² Cause-specific mortality rates are unavailable for 2000.

²³ This analysis is based on relatively small numbers and is therefore subject to fluctuations in rate based on minor changes from year to year in the number of deaths for any given category.

thousand, there was a decrease in rate to 1.36 per thousand in 2003.²⁴ 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 non-significant random variation.

Table 6
Top 10 Leading Causes of Death

Rank	U.S. 2002	MA 2002 ²⁵	DMR 2000 ²⁶	DMR 2001 ²⁷	DMR 2002	DMR 2003
1	Heart Disease 28.5%	Heart Disease 25.8%	Heart Disease	Heart Disease 21.2%	Heart Disease 21.2%	Heart Disease 22.3%
2	Cancer 22.8%	Cancer 24.4%	Pneumonia	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 12.3%	Cancer 13.5%
3	Stroke 6.7%	Stroke 6.3%	Chronic Respiratory Disease	Cancer 12.7%	Cancer & Septicemia ²⁸ 10.1%	Aspiration Pneumonia 12.3%
4	Chronic Respiratory Disease 5.1%	Chronic Respiratory Disease 4.8%	Cancer	Septicemia 7.4%	C-P Arrest/ Seizure ²⁹ 9.4%	Septicemia 9.0%
5	Accidents 4.4%	Influenza and Pneumonia 3.6%	Septicemia	Alzheimer's 6.9%	Alzheimer's 7.2%	CP Arrest/ Seizure ²⁹ 7.2%
6	Diabetes 3.0%	Alzheimer's Disease 2.8%	Nephritis	Influenza and Pneumonia 6.1%	Chronic Respiratory Disease 6.2%	Chronic Respiratory Disease 6.0%
7	Influenza and Pneumonia 2.7%	Diabetes 2.8%	C-P Arrest/ Seizure ²⁹	Chronic Respiratory Disease 4.1%	Influenza and Pneumonia 4.7%	Alzheimer's Disease 5.3%
8	Alzheimer's 2.4%	Unintentional Injuries 2.5%	Alzheimer's	C-P Arrest/ Seizure ²⁹ 3.3%	Nephritis 4.0%	Influenza and Pneumonia 4.6%
9	Nephritis 1.7%	Nephritis 2.3%	Stroke	Accidents 3.3%	Stroke 3.5%	Stroke 4.2%
10	Septicemia 1.4%	Septicemia 1.8%	Gastro-intestinal	Stroke 3.0%	Congenital Defects 2.5%	Nephritis 2.6%

²⁴ 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.

²⁵ Most recent data available from *Massachusetts Deaths 2002*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, June 2004

²⁶ The percent of deaths represented by each cause was unavailable for 2000.

²⁷ 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.

²⁸ Septicemia and Cancer were tied for 3rd leading cause of death among DMR clients in 2002.

²⁹ Includes sudden deaths reported as cardio-pulmonary arrest whether or not seizure was present.

The rate of deaths from Cancer rose to 2.54 per thousand in 2003 from an adjusted rate of 1.81 in 2002. Cancer of the bladder, breast, colon and pancreas all tied for the most common cause of cancer deaths with 6 deaths from each. Two deaths were from cancer of unknown etiology. The rate of death from cancer in the DMR population is now higher than the national rate of 1.9 per thousand and the statewide general population rate of 2.1 per thousand³⁰. In the Massachusetts general population, cancer of the lung and the colon are the top two causes of cancer deaths. Breast cancer is ranked third for females and cancer of the prostate is third for males. In contrast, there were two fatal cases of lung cancer and 3 fatal cases of prostate cancer in the DMR population in 2003.

**Table 7
Cause-specific DMR Mortality Rates
2001-2003**

2003 Rank	Cause of Death	DMR Rates of Death (per thousand)		
		2001	2002	2003
1	Heart Disease	4.4	3.8	4.2
2	Cancer	2.1	1.8	2.5
3	Aspiration Pneumonia	2.4	2.2	2.3
4	Septicemia	1.2	1.8	1.7
5	CP Arrest/ Seizure	0.6	1.7	1.4
6	Chronic Respiratory Disease	0.7	1.1	1.1
7	Alzheimer's Disease	1.1	1.3	1.0
8	Influenza and Pneumonia	1.0	0.8	0.9
9	Stroke	0.5	0.6	0.8
10	Nephritis	0.5	0.7	0.5

Tables 8 and 9 compare causes of death by age-specific groupings for the DMR population in 2003 and the Massachusetts population in 2002.³¹ Consistent with data from previous years, the cause of death in the younger age group varies between the DMR population and statewide data. The primary causes of death for the DMR population in younger individuals are related to medical conditions, whereas in the general population accidents and homicide are the most common causes of death. As mentioned above, the rate of accidents as a cause of death in the DMR population is extremely low across all age groups.

In the 2003 report, new age groups are used for individuals in the 25-64 age range. Cancer and heart disease, more common causes of death in older populations, are present in the DMR 35-44 group. The 45-54 year old cohort is the only one in which Alzheimer's is one of the top three causes of death.

³⁰ National and Massachusetts cancer rates from *Massachusetts Deaths 2002*. Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, June 2004

³¹ The most current data available for the Massachusetts population was for the year 2002.

The expansion of age groupings in the current analysis suggests the presence of potentially important differences in the middle age population within DMR. Not only does the mortality rate double between the 45-54 and 55-64 group, as discussed above, but there appears to be a shift in the leading causes of death. Heart Disease emerges as the leading cause of death in the 55-64 age group, and deaths within this cohort begin to model the older categories with regard to the leading causes of death. Deaths in the 45-54 age group continue to model the younger age groups, with aspiration pneumonia as the top cause of death and relatively few deaths from heart disease.

Table 8
**Cause of Death by Age Group for DMR
 2003**

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	Congenital defects	Cancer	Aspiration Pneumonia	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease
2		Aspiration Pneumonia, Septicemia, CP Arrest/ Seizure	Aspiration Pneumonia, CLRD*, Heart Disease	Alzheimer's Disease	Cancer	Cancer	Cancer	CLRD*	Cancer
3				Cancer, CP Arrest/ Seizure, Heart Disease	Septicemia	Septicemia	Aspiration Pneumonia	Aspiration Pneumonia, Influenza Pneumonia	Aspiration Pneumonia

* CLRD = Chronic Lower Respiratory Disease

Table 9
**Cause of Death by Age Group for Massachusetts Population
 2002**

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

* CLRD = Chronic Lower Respiratory Disease

The causes of death in the DMR 55-64 age group are more consistent with those found for the 45-64 age group within the general Massachusetts population. In DMR's 55-64 age group, heart disease and cancer rank the highest, similar to the general population. Deaths due to Aspiration Pneumonia appear to be a more prominent cause of death in the DMR population than within the general population. Deaths from septicemia would appear to be a more prominent cause of death within the DMR population than in the general population. Deaths from cancer or stroke assume a lower incidence for DMR than for the general population of Massachusetts.

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,
3. died in a day support program funded or certified by DMR
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 either the Regional or Central Mortality Review Committee for analysis, confirmation of cause of death and follow-up if indicated. During 2003, 168 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. Two additional cases that did not meet the criteria for review were also reviewed at the request of DMR.

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 outlined by the Massachusetts General Law, chapters six and thirty-eight.³²

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 2003 there were 23 deaths investigated by one or more of the agencies identified above, two of which also involved law enforcement investigation. Twenty-seven (27) cases were generated concerning these 23 deaths, of which only two cases were substantiated. Two of the complaints in 2003 were generated as a result of individual deaths occurring in 2002. As can be seen in Table 10, the number of investigations decreased from the 2002 level.

³² "Any death in which the Chief Medical Examiner takes responsibility for determining the cause and manner of death, to include all cases of suspected homicide, suicide, accidental drug overdose, or sudden and unexpected natural deaths."

Table 10
**Summary of Investigations and Autopsy Information
 1999 to 2003**

Type of Activity	1999	2000	2001	2002	2003
DMR Investigation	7	5	5	14	9
DPPC Investigation	5	1	2	2	4
DPH Investigation	2	1	8	10	10
District Attorney/Law Enforcement Investigation	0	3	1	3	2
Other/dismissed	5	3	5	4	2 ³³
Total Investigations	19	13	21	33	27
No. Substantiations	0	0	1	2	2

Of the individuals who received a mortality review by DMR, autopsies were requested for 16 people. Five (5) of these autopsies were performed, and the results were used to confirm the cause of death. Because autopsy status is no longer available for all individuals in the DMR population, a comparison with autopsy data from previous years is not appropriate.

Benchmarks

As noted in the 2002 Mortality Report, the presence of mental retardation and numerous co-morbid conditions within the population of individuals served by DMR significantly compromises the use of general population benchmarks, even when adjusted for age. Therefore, CDDER has focused on comparative mortality data from other state MR/DD agencies, where appropriate. Unfortunately, most state MR/DD systems do not routinely publish mortality data. Those that do, often configure the data using a wide variety of non-standard configurations, making specific comparisons difficult.³⁴

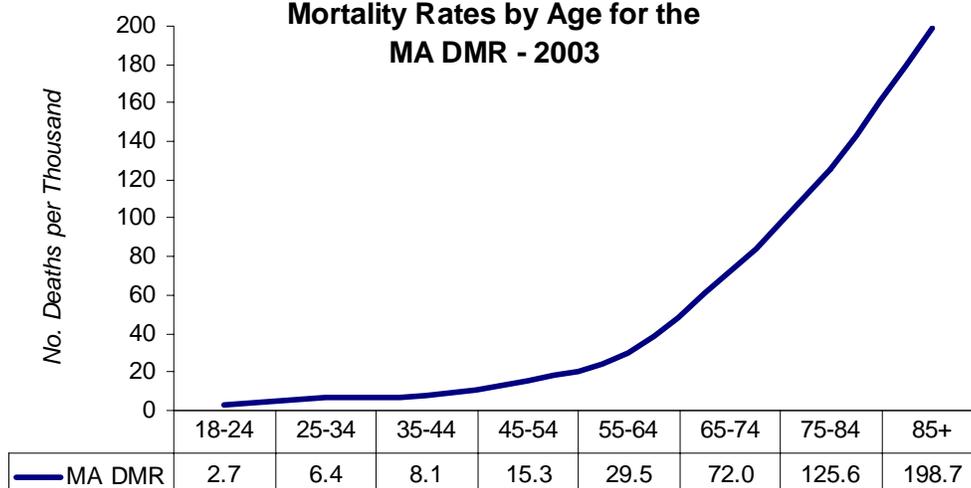
³³ Complaint was Dismissed, Resolved w/o Investigation or Referred to the Regional Office for administrative review.

³⁴ A review of national mortality reports by CDDER re: published by state MR/DD agencies is currently underway. This review, to date, has identified numerous inconsistencies in how data is organized and analyzed. For example, some state systems only report the number of deaths and do not provide mortality rates; age-related mortality data is configured using non-standard age ranges. These and many other differences between how mortality data is reported make it difficult to provide direct comparisons and thus limits the use of valid benchmarks.

Connecticut³⁵, Vermont³⁶ and New Mexico³⁷ represent three state MRDD systems that have published mortality reports over the past few years that can provide approximate benchmarks for comparison with the Massachusetts DMR mortality data. Although the age groupings are different, Figures 10 and 11 below illustrate that the same general trend of increasing mortality is present for the Massachusetts, Connecticut and New Mexico MRDD state systems. It should be noted that the New Mexico system serves a more diverse population of persons with developmental disabilities whereas both the Connecticut and Massachusetts agencies serve only individuals with mental retardation.

Figure 10

**Mortality Rates by Age for the
MA DMR - 2003**



³⁵ *Health and Mortality Annual Report*, State of Connecticut Department of Mental Retardation, October 2003

³⁶ *Mortality among People Receiving Developmental Services in Vermont FY 2003*, Vermont Division of Developmental Services, 2003.

³⁷ *Mortality Review Committee Annual Report, State Fiscal Year 2002*, New Mexico Department of Health, Division of Health Improvement, October 30, 2002.

Figure 11

**Comparison of Mortality Rates by Age for the
CT and NM MR/DD State Systems
2002/2003**

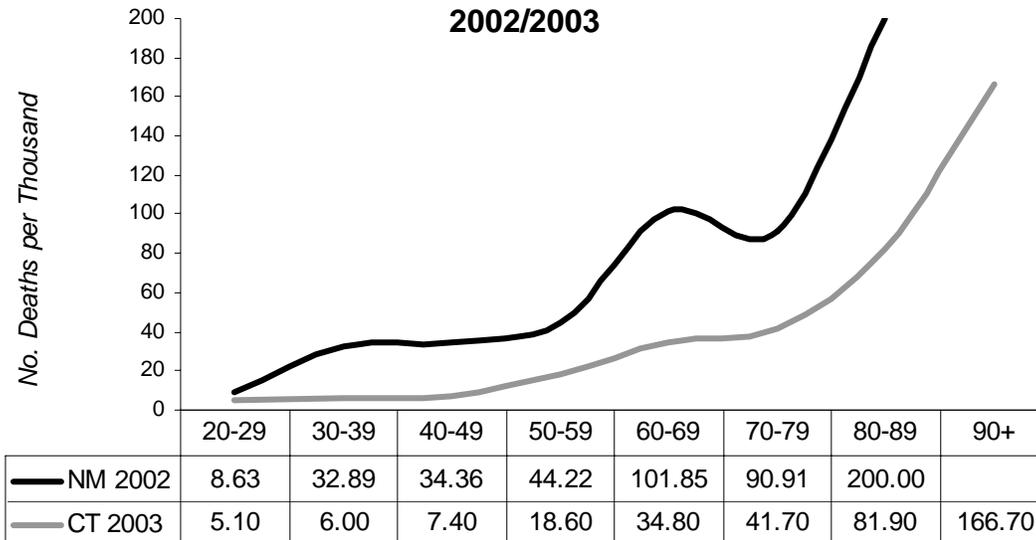


Figure 12

**General Patterns for Rate of Mortality
Massachusetts DMR and Connecticut DMR
2003**

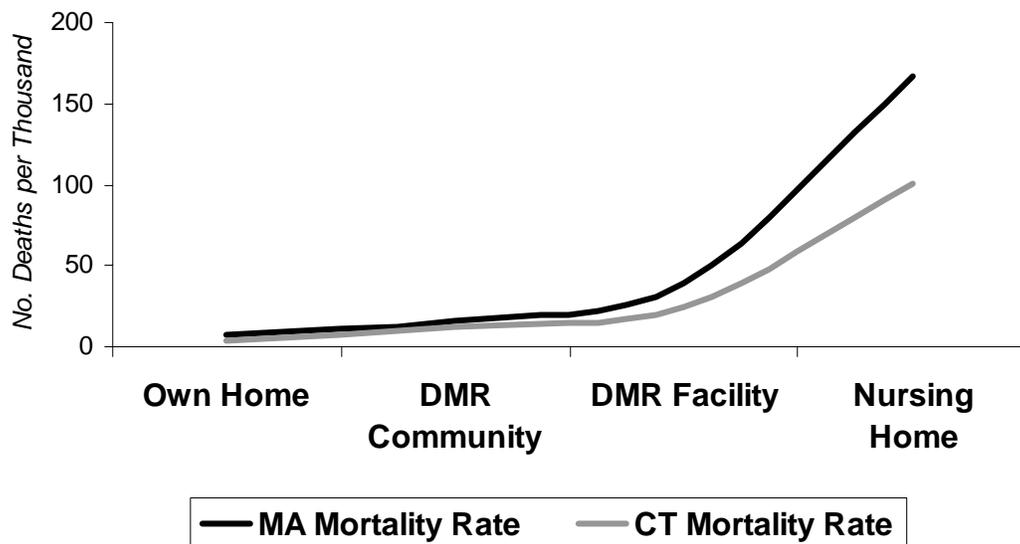
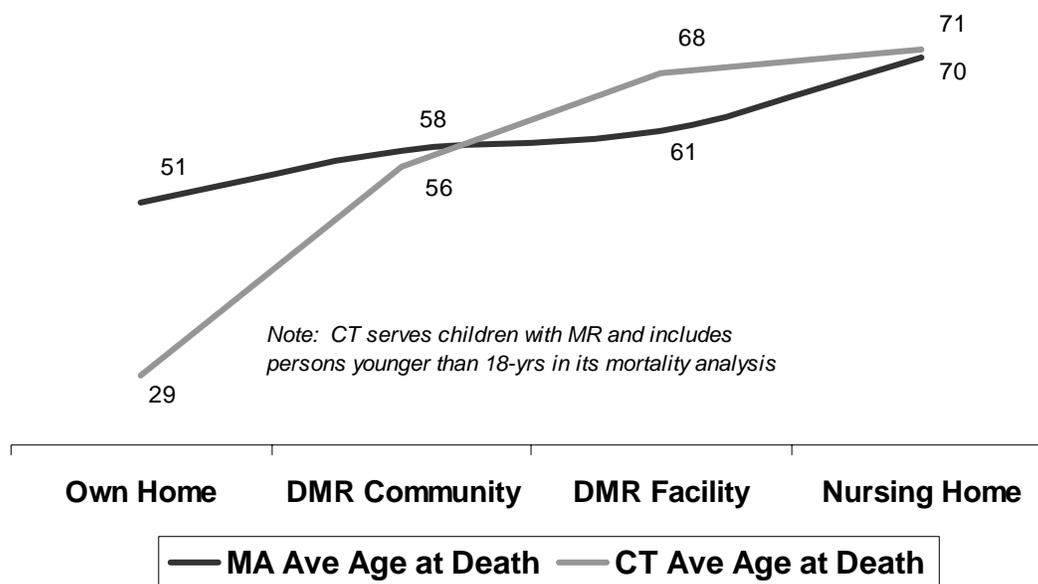


Figure 12 provides a comparison of mortality rates by type of residential setting³⁸ in both the Massachusetts DMR and Connecticut DMR. As can be seen a very similar pattern would appear to exist between the two state MR/DD systems. While the composition of the residential categories varies between the two states, this variation is minimal for the last two categories: facility and nursing home. Interestingly, the greatest difference would appear to take place in these two settings, with Connecticut showing a lower mortality rate for persons residing in both state facilities and nursing homes.

Figure 13 illustrates the average age at death by type of residential setting for the DMR state systems in both Massachusetts and Connecticut. As can be seen, there is a similar pattern for all residential types except for those individuals who live at home. However, it is important to note that the Connecticut DMR serves a substantial population of children (younger than 18-yrs), the vast majority of whom live at home with their families. The inclusion of this younger population in their mortality analysis results in a significantly younger average age of death for this group.

Figure 13
 General Patterns for Average Age at Death
 Massachusetts DMR and Connecticut DMR
 2003



³⁸ The residential definitions used in the mortality analyses by Massachusetts and Connecticut are not identical. Connecticut does not include supported living in its category of Community (providing data separately) whereas Massachusetts combines data for all community residential settings under this category.

A comparison of the leading causes of death as reported by the MR/DD state agencies in Massachusetts, Connecticut, Maryland³⁹, New Mexico⁴⁰ and Vermont is presented below in Table 11. As can be seen there is significant similarity across state systems with heart disease, cancer and respiratory diseases/disorders accounting for the top 3 leading causes in all five systems. It should be noted that fluctuations in rank are extremely sensitive due to the small numbers present in each category (*i.e.*, only one or two deaths can influence movement between ranks).

Table 11
Comparison of the Top 5 Leading Causes of Death
As Reported by Five State MR/DD Agencies

Rank	MA DMR 2003	CT DMR 2003	MD DHMH 2003	NM DH 2004	VT DDS 2003
1	Heart Disease	Heart Disease	Heart Disease	Respiratory & Aspiration Pneumonia	Heart Disease
2	Cancer	Cancer	Influenza & Pneumonia	Cancer	Respiratory & Pneumonia
3	Aspiration & Pneumonia	Respiratory & Pneumonia	Malignant Neoplasm (Cancer)	Heart Disease	Cancer
4	Septicemia	Nervous System	Other Respiratory	Sepsis	Alzheimer's & Seizures
5	CP Arrest/Seizures	Renal Failure	Septicemia	Accidents	Unknown

³⁹ Department of Health and Mental Hygiene Mortality Review Committee Annual Report, Calendar Year 2003, Maryland DHMH, Baltimore, MD, September 2004.

⁴⁰ Personal Communication, New Mexico Department of Health, January 2005.

APPENDICES

Appendix A: Methodology for Mortality Review and Analysis

Appendix B: Residential Codes and Definitions

Appendix C: Demographic Data

Appendix A

Methodology

The 2003 Mortality report analyzes information on all deaths occurring in calendar 2003 for all persons 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 2003 Mortality Report includes statistics on all deaths of persons who died in calendar year 2003 and whose Death Report was received by DMR by the end of January 2004. A total of 431 deaths were reported to have occurred between January 1, 2003 and December 31, 2003.

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, 2003.⁴¹ 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 431 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:

Crude Death Rate =

$$\frac{\text{(Number of persons who died in calendar 2003 x 1000)}}{\text{(No. Persons in CRS in June 2003)}}$$

⁴¹ CDDER relies on the accuracy of information about the number of persons 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 DMR consumers by region and type of residence used in the calculations of death rates were based on data as of June 30, 2003.

Appendix B: Residential Codes and Definitions

DMR Community

DMR-funded residential programs or state-operated group residences

3150	SPECIALIZED HOME CARE
3152	COMMUNITY RESIDENCE
3153	RESIDENTIAL SUPPORTS
3154	COMMUNITY ICF/MR-B
3155	SATELLITE RESIDENTIAL
3156	LIMITED GROUP RES
3157	STAFFED APT I
3158	STAFFED APT II
3159	SUPERVISED APT
3160	COOPERATIVE APT
3161	M.S.A. RESIDENTIAL SUPPORTS
3286	MODERATE RESIDENTIAL SUPPORTS
3975	TEMPORARY RESIDENCE
4156	STATE-OP LIMITED GROUP 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
4153	STATE-OP ICF-A

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 2003 DMR Adult population

SEX	Age	DMR Funded Community	DMR Facility	Nursing / Rest Home	Own Home	Non-DMR	Total
F	18-24 yr	140	0	19	1,423	123	1,705
M	18-24 yr	204	0	25	1,998	195	2,422
F	25-34 yr	619	7	46	1,205	35	1,912
M	25-34 yr	883	18	41	1,445	60	2,447
F	35-44 yr	992	95	40	1,151	81	2,359
M	35-44 yr	1395	120	38	1,312	74	2,939
F	45-54 yr	974	140	35	764	65	1,978
M	45-54 yr	1185	221	47	834	57	2,344
F	55-64 yr	579	105	104	405	51	1,244
M	55-64 yr	648	178	72	397	34	1,329
F	65-74 yr	256	82	104	160	27	629
M	65-74 yr	300	101	78	163	35	677
F	75-84 yr	117	36	137	51	22	363
M	75-84 yr	100	40	80	48	22	290
F	85+ yr	24	8	48	10	6	96
M	85+ yr	11	12	25	9	3	60
Total		8,427	1,163	939	11,375	890	22,794