Commonwealth of Massachusetts

Department of Mental Retardation

2004 Mortality Report

Prepared by

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Evaluation and Research (CDDER)

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Dear Colleagues and Friends:

Enclosed is the Department of Mental Retardation Annual Mortality Report for calendar year 2004. 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 death occurring in calendar year 2004 for all persons 18 years of age or older who have been determined to be eligible for DMR supports. This is the fourth year in which DMR has commissioned an independent review of all deaths.

The report is a significant component of the Department's quality management system and reflects DMR's ongoing commitment to reviewing and learning from critical information gathered regarding individuals within our system. 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 stat and national death statistics. The 2004 report includes a new 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

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Executive Summary

As part of its quality management system, the Massachusetts Department of Mental Retardation (DMR) has an established mortality review and reporting process. This process enables DMR to review the causes and circumstances of the deaths of individuals it supports. The information resulting from this process is used to inform the Department and target quality improvement efforts for the supports provided to individuals with mental retardation. 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 2004.

In the middle of the 2004 calendar year, the Massachusetts DMR served 32,114 individuals, 23,154 of whom were adults over the age of 18.[1] This is an increase in the client population of about 1.6%, or 360 people, since June 2003.

The Massachusetts DMR reported 439 deaths for DMR clients in the calendar year 2004, resulting in an average rate of death of 19.0 per thousand adults. This represents a non-significant increase of 8 deaths, the smallest annual increase seen in these reports since their start in 2000.

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, two-thirds of the deaths in the DMR population are of residents from Nursing Homes.

Age

Mortality rates are highly dependent upon age. The youngest age group (18-24 years old) showed the lowest rate of death (3.7 per thousand) and the oldest age group (85+ years old) had the highest mortality rate (229.3 per thousand). In general, mortality rates increase sharply with ages past 65 years. 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]

[1] DMR population statistics as of June 30, 2004 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

Gender

There were some changes noted in 2004 mortality statistics associated with gender. During 2004 the age at death was significantly lower in males than in females (6 year difference). Interestingly, while in prior years the rate of death for males was lower than for females, in 2004 the rates were almost identical with the proportion of male deaths increasing to match the larger proportion of males in the DMR population.

Residence

Consistent with findings from previous years, mortality rates in 2004 differ substantially by type of residential setting. Death rates are highest for those residing in Nursing Homes, and are lowest for those living independently or with family. Average age at death per residential setting is generally reflective of the age composition of the population within that residential setting.

Cause of Death

The top 3 causes of death remain unchanged from 2003. Heart Disease was the most common cause of death in the DMR client population for the fifth consecutive year, representing 16% of all deaths in 2004. Cancer was again the second leading cause responsible for 13% of all deaths. Aspiration Pneumonia was the third leading cause, representing 11% of all deaths. The rate of death for Influenza and Pneumonia increased in 2004, making it the fourth leading cause of death. Septicemia fell from the fourth leading cause of death in 2003 to a rank of seventh in 2004.

Benchmarks

Comparative data drawn from a variety of sources suggests that the patterns and trends of mortality for persons 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 2004. Overall, rates for individuals in the DMR population meet many more targets than the general Massachusetts population or the national population.

2004 Mortality Report

As part of its quality management system, the Massachusetts Department of Mental Retardation (DMR) has an established mortality review and reporting process. This process enables DMR to review the causes and circumstances of the deaths of individuals it supports. The information resulting from this process is used to inform the Department and target quality improvement efforts for the supports provided to individuals with mental retardation. 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 2004.

Mortality Review in DMR

2004 Mortality Report

This report includes information and data concerning all adults (persons 18 years old and older) served by DMR who were listed in the Consumer Registry System (CRS) and DMR clients who died during the 2004 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:

Clinical reviews are conducted by the DMR Mortality Review Committee for deaths of persons 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 DMR clients who die meet the criteria for a clinical review. This report includes both consumers whose death was reviewed, and those that were not.

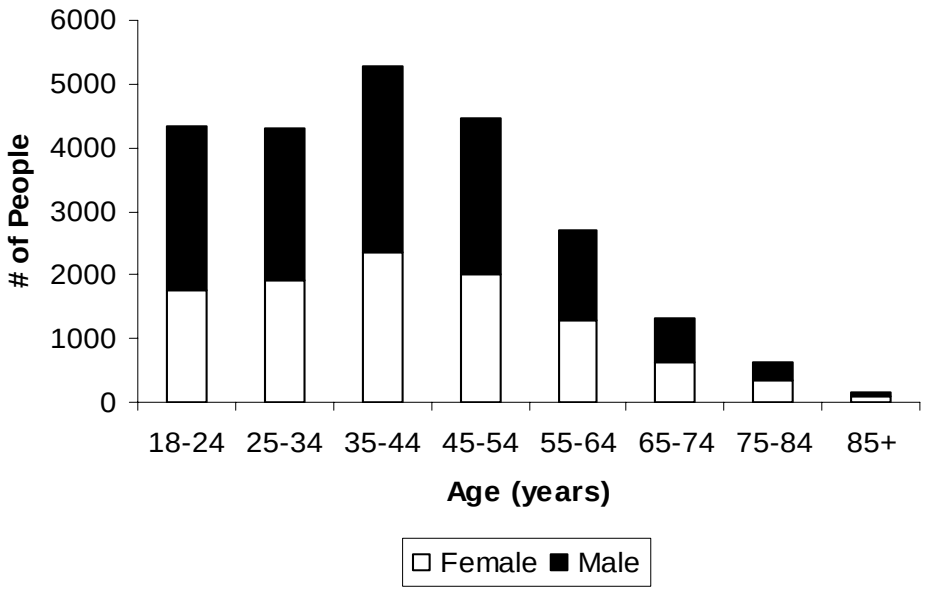
Overview of DMR Client Population

In the middle of calendar year 2004, the Massachusetts DMR served 32,114 individuals, 23,154 of whom were adults with mental retardation over the age of 18-yrs. The mid-year population (June) was used to model the average population across the entire year, since the population served by DMR tends to increase as the year progresses. In 2004, the mid-year adult client population increased by about 1.6%, or 360 people from June 2003.

Age Characteristics. Mortality and population statistics in this report are displayed only for adults (age 18 years and older) with mental retardation. As noted earlier, adults compose the majority of DMR's consumers.

Most adult Massachusetts DMR consumers, almost 60%, are between the ages of 18-45. However, 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 old. The populations within each age group are illustrated below in Figure 1.

Figure 1
DMR Consumer Population by Age and Gender
2004



Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1758	1919	2352	2018	1296	627	352	99	10421
Male	2577	2375	2930	2428	1407	680	278	58	12733
Total	4127	4359	5298	4322	2573	1306	653	157	23154

The DMR population tends to increase over time. In 2004, there were a relatively large number of newly eligible young adults, accounting for a 5% increase in the youngest age range (18-24 yrs.). The actual change in the DMR population between 2003 and 2004 within each age group is presented below in Table 1.

In addition to the 18-24 year old group, which contains the majority of newly eligible DMR clients, the 45-54 and 55-64 age groups also experienced relatively large population increases between 2003 and 2004. In the 55-64 age group the rate of growth

was more than double that in most of the other age groups. This increase most likely reflects the aging phenomenon that exists within the DMR population, something that has also been reported by MR/DD agencies in other northeastern states[3]. In the general population the 55-64 age group is also expanding as "baby boomers" move into the older age range.[4,5] It is likely that older age groups will continue to increase in the DMR consumer population due to this same effect, and as this more elderly cohort grows (65+), the number of deaths within DMR can be expected to increase as well.

Table 1
Annual DMR Population change within Age group
A comparison of 2003 and 2004

	Gross Population Fluctuation[6]		
Age Group	**Individuals**	**% change within age group**	**Resulting % change in Overall DMR Consumer population**
18-24	+219	+5.3%	+1.0%
25-34	-37	-0.8%	-0.2%
35-44	+27	+0.5%	+0.1%
45-54	**+190**	**+4.4%**	**+0.8%**
55-64	**+206**	**+8.0%**	**+0.9%**
65-74	+95	+7.3%	+0.4%
75-84	+59	+9.0%	+0.3%
85-94	+32	+20.5%	+0.1%
Total	+791	----	3.5%

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

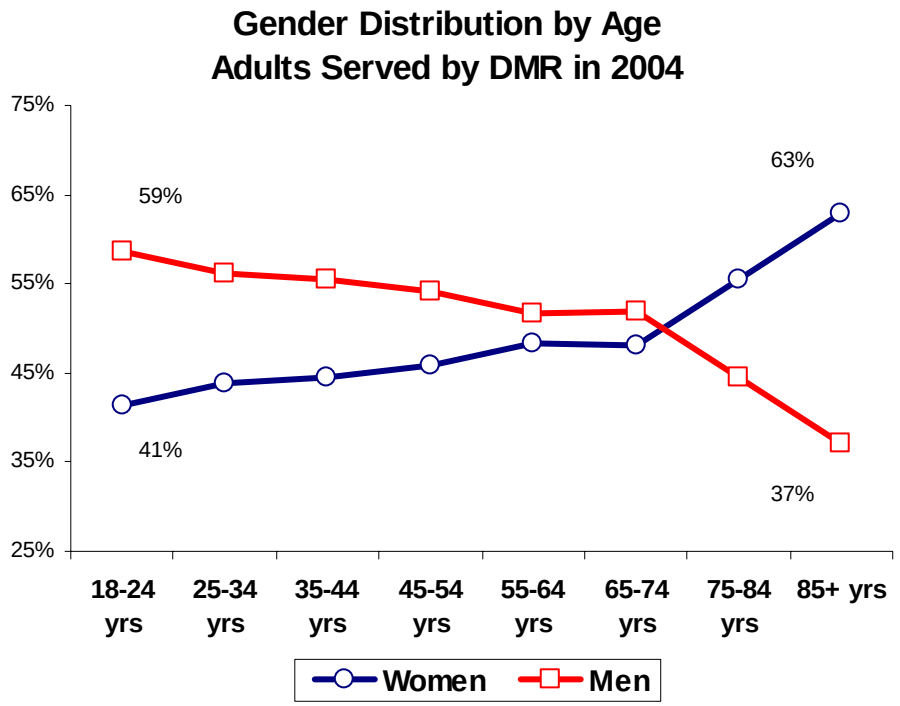
[4] Before the Boom: Trends in Long-Term Supportive Services for Older Americans with Disabilities, October 2002, Public Policy Institute, AARP

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

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

Gender Characteristics. The proportion of men and women served by DMR varies by age (see Figure 2 below). 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 reports from other states[7].

Figure 2

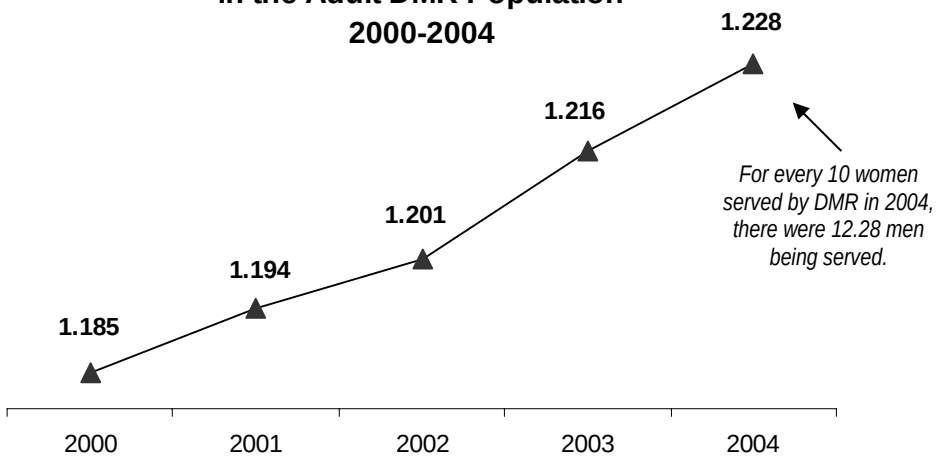


From 2000 to 2002, the gender gap in the elderly population was relatively stable. In 2003 and 2004, differences in the gender ratio for older age groups became more polarized, with an ever increasing proportion of the 65+ age groups represented by females. In the youngest age groups, however, 2004 population data shows a trend toward an increasing proportion of men compared to previous years.

Figure 3 shows the proportion of males to females in the DMR population over the past 5 years. The data show a consistent increase in the relative number of males in the DMR adult population. The 2004 population data continues the trend seen in 2003. For every ten females served by DMR in 2004, about 12.3 men were being served. Most of this increase can be attributed to the addition of newly-eligible DMR clients in the 18-24 age group. Given the higher proportions of young males entering into the population, overall gender ratios of males to females can be expected to increase over time.

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

Figure 3*



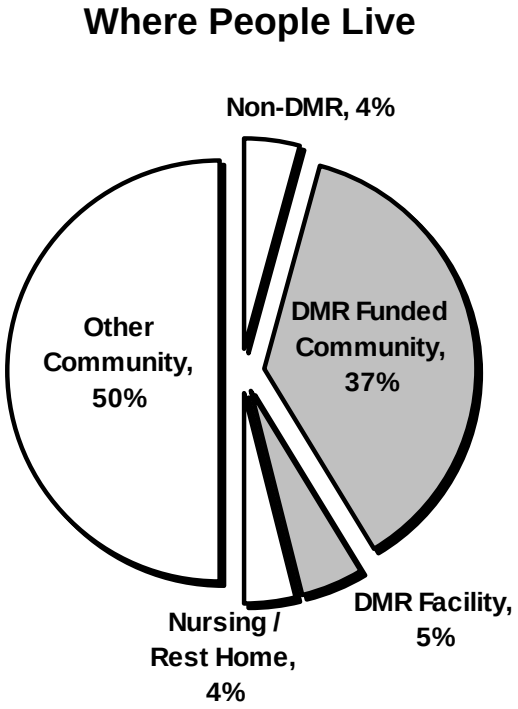
*Gender ratios displayed for 2000-2002 have been adjusted using the 2003 population methodologies

Residential Setting Characteristics

Adults served by DMR live in a variety of different residential settings. Some consumers receive residential support directly from DMR, while others live independently or with family, or may receive residential support from another state agency. 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).

In 2004, population percentages in each of the residential settings remain unchanged from 2003. About half of DMR consumers 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 residential settings.)

Figure 4



Mortality During 2004

Information is provided in this section on the deaths of persons with mental retardation who were 18 years of age or older at their time of death and who were determined to be eligible for DMR services and supports during calendar year 2004. Appendix A contains a detailed description of the methodology used to collect and analyze the information and data contained in this section.

For the calendar year of 2004 DMR received death reports for **439** individuals who met the criteria outlined above. This represents a crude death rate[8] of **19.0** persons per thousand.[9] The average age at death of adults in the DMR population during 2004 was 62.1 years of age.

Age

General mortality statistics are displayed in Table 2 by age group, including the number of persons who died, the relative percentage of deaths across DMR and the mortality rate. In 2004, the data shows consistency with previous years, displaying 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.

Table 2
Distribution of Deaths by Age Group, 2004

Age Range	No. Deaths	Percentage	Death Rate (No. per 1000)
18-24 yrs	16	4%	3.7
25-34 yrs	22	5%	5.1
35-44 yrs	36	8%	6.8
45-54 yrs	63	14%	14.2
55-64 yrs	97	22%	35.9
65-74 yrs	89	20%	68.1
75-84 yrs	80	18%	127.0
85 yrs & older	36	8%	229.3
Total	**439**	**100%**	**19.0**

[8] 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.

[9] 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.

Figure 5 shows the rate of death in each age group. The death rates are displayed in deaths per thousand, and adjust for size differences between the age groups. As illustrated, the rate of death systematically increases with age. After the age of 64 years, the death rate increases sharply, a trend consistent with the direct relationship between advanced age and risk of mortality.

Figure 5

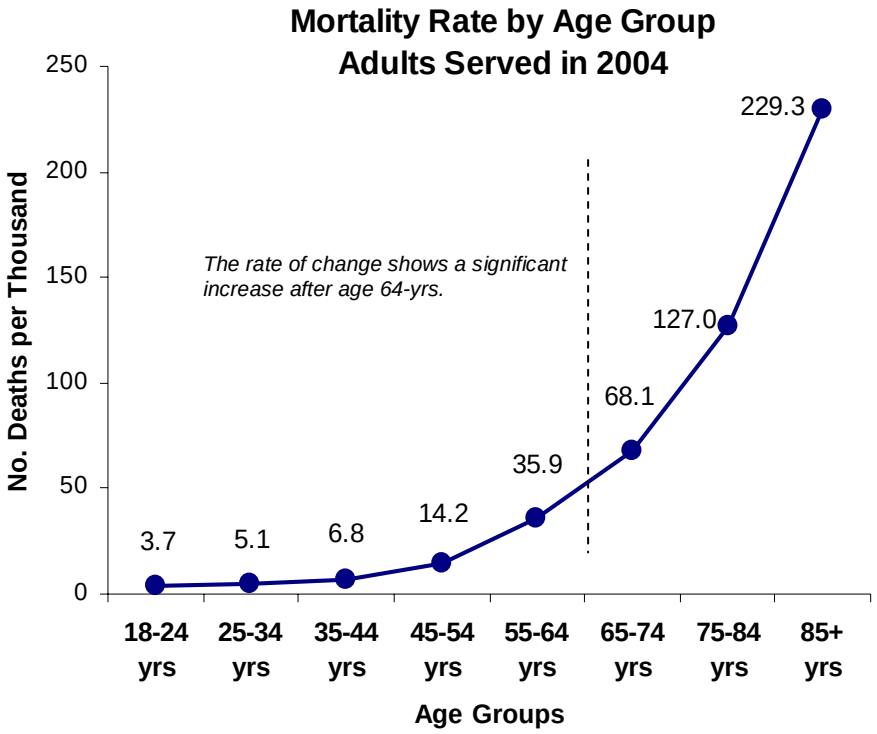
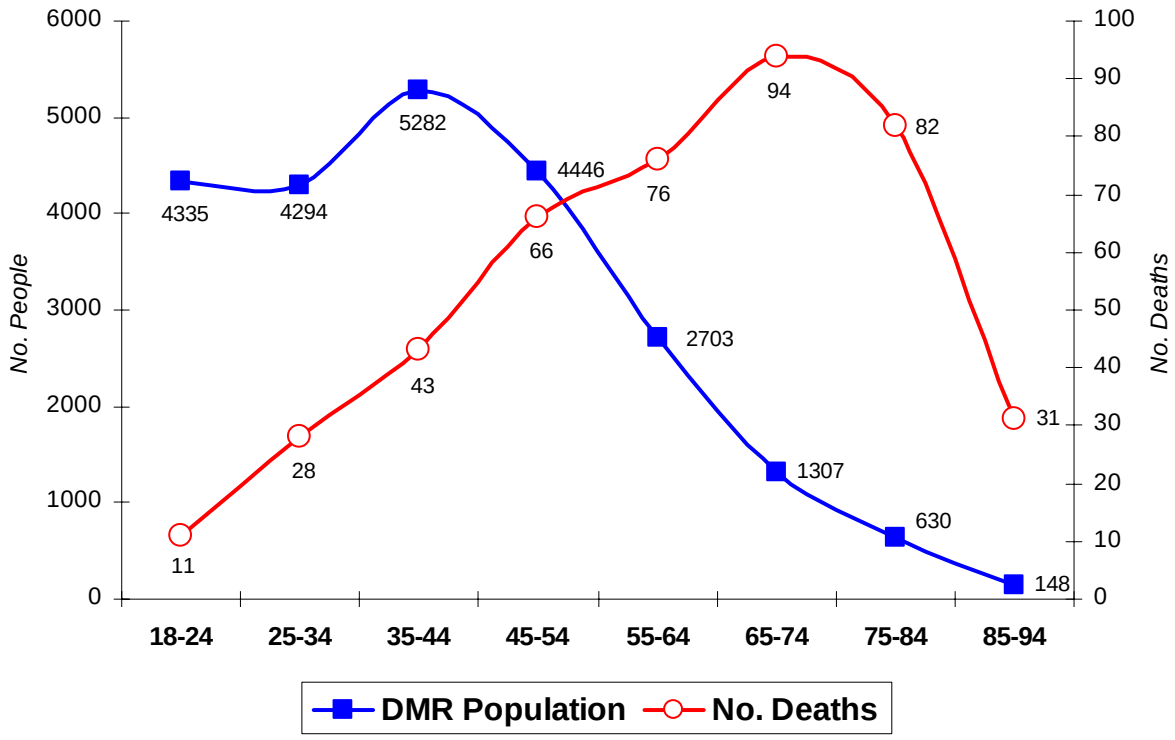


Figure 6 below illustrates the relationship between the size of the DMR population by age group and the corresponding number of deaths for those age groups. As can be seen, there is an inverse relationship between the size of the population in each age group and the number of deaths. As expected, the number of deaths is lowest for the younger age groups, and increases with age. The number of deaths begins to decrease in the 75+ age groups because of the decreasing size of the population in those groups. This trend is similar to the patterns found in the general adult population in the US.[10]

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

Figure 6
DMR Population and Deaths by Age Group
2004



Gender

As described in the Overview of the DMR Population, the gender distribution in the DMR population is not consistent over age. In addition, this population shows differences from the general Massachusetts population with a larger percentage of males in most age groups. 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 second year in a row, more men passed away in a calendar year than women. In 2000-2002, more women passed away than men. Since 2000, the proportion of male deaths has been increasing as the proportion of males increases in the overall DMR population. And, as shown in Figure 3 and noted in the previous section (Gender Characteristics), the last 5 years have shown a steady increase in the relative proportion of men receiving DMR services (the DMR population is currently about 55% male and 45% female). This year, for the first time, proportion of male deaths met, and evenly slightly surpassed, the proportion of males in the DMR population

Table 3
No. Deaths, Average Age at Death and Death Rate by Gender
2004

Gender	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
F	197	44.9%	65.4 yrs	18.9
M	242	55.1%	59.4 yrs	19.0

In 2004, there are some important shifts in the mortality statistics between genders. In the DMR consumer population, there are more females in the highest age groups, and therefore more females at higher risk of mortality. However, it appears that the increasing size of the male population of DMR clients may be compensating for this increased female "risk," resulting in a higher number of male deaths. However, and as can be seen in table 3, the rate of death for each gender was almost identical in 2004, representing a modest change from prior years.

Table 4
DMR Mortality Rate by Gender
2001-2004

	Mortality Rate	
Calendar Year[11]	Males	Females
2001	15.7	17.5
2002	16.1	20.2
2003	18.0	20.0
2004	19.0	18.9

The number of deaths was not the only difference in mortality between genders. In 2004 the age at death was significantly lower in males than in females (p=.0003)[12]. The average age at death for females increased by two and a half years from 62.9 years in 2003 to 65.4 years in 2004. In males, the average age of death decreased from 60.5 years in 2003 to 59.4 years in 2004. In the past few years, there has been a trend of slightly decreasing age of death in males and a more rapidly increasing age of death in females. The higher female to male average age at death is consistent with trends found in the general population both nationally and statewide. However, as the dominance of younger males in the DMR population increases gender-specific death rates may differ from those typically seen in the general population of the U.S. or Massachusetts.

[11] Revised mortality information is presented for 2001 and 2002
[12] One-tailed t-test with hypothesized mean difference of zero. T=3.503, df=437, p=0.0003)

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.

Differences in mortality statistics for these residential categories are displayed in Table 5 and Figure 7 below.

Age and Residence

In 2004, the average age at death was significantly different between residential settings.[13] Average age at death was lowest for DMR consumers living in their own home or with family (47.3 years) and highest for those residing in nursing home (71.3 years). Ages for other settings averaged between 59-68 years of age with about a 15 year standard deviation.

Table 5
Age and Mortality by Type of Residential Setting
For Adults Served by DMR
2004

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	11,617	4.0%	79	18.0%	47.3	6.8
DMR Community	8,587	9.5%	171	39.0%	59.9	19.9
Non-DMR	950	12.0%	16	3.6%	68.0	16.8
DMR Facility	1,109	24.6%	51	11.6%	68.5	46.0
Nursing Home	891	48.1%	122	27.8%	71.3	136.9
Total (Statewide)	23,154	9.0%	439	100%		
Average					62.1	19.0

[13] Analysis of Variance (ANOVA) F=31.2, df=4, p=<0.0001

In general, the age at death within each residential setting was 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. In 2004, as in previous years, the majority of deaths were for persons living in nursing homes. These findings regarding the relationship between type of residence and mortality are consistent with expectations and with trends present in other state mental retardation systems[14] since average population age tends to vary by type of residential setting.[15] The relationship between age, mortality and type of residential setting is further illustrated in Figure 7.

Own Home

During 2004, the subgroup of DMR consumers living in their own home or with family had the lowest mortality rate. The rate of death for this residential group was 6.8 per 1000, which was lower than the crude mortality rate of 8.9 per 1000 for the general population in Massachusetts.[16]

Consumers living in their own home or with family also had the youngest average age at death of any residential subgroup. This group of consumers is by far the youngest residential subgroup in this population and also has the smallest percentage of persons aged 65 years and older.

DMR Community

The DMR Community is the most mixed population in both age and level of service need. The 35-54 year olds make up the largest percentage of DMR consumers residing in this setting. However, there is also a significant elderly population in this residential category. The population of elderly (age 65+) within the DMR community category has been steadily increasing since 2000, and, a review of actual cases shows that in 2004 many of the deaths in this setting were of elderly DMR consumers.

The rate of death for DMR consumers living in DMR Community residences increased in 2004 to 19.9 per thousand from a rate of 16.0 per thousand in 2003. This rate is similar to the adjusted 2002 rate of 19.2 per thousand. As can be seen in Table 5, while the DMR Community cohort experienced the largest number and percentage of deaths within DMR, the substantially greater number of people living in that type of setting resulted in a death rate (19.9/1000) much lower than that experienced by persons living in DMR Facilities (46/1000) or in Nursing Homes (136.9/1000)

Other Residential Settings

The number of people living in the Non-DMR, DMR Facility and Nursing Home settings is relatively small, and in total represents under 15% of the total DMR population. It is important to note that such small population numbers can result in large annual

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

[15] 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.

[16] *Massachusetts Deaths 2003.* Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, June 2005.

fluctuations in the rate of death when compared by residential setting. Changes in rate should therefore be interpreted cautiously.

Non-DMR. The age composition of individuals residing in Non-DMR residences is very diverse. About one-third of the residents are between the ages of 18-24, while the remainder falls within older age groups. In 2004, the rate of death for consumers living in Non-DMR residences increased from 12.4 per thousand in 2003 to 16.4 per thousand in 2004. The average age at death increased 2.6 years to 68.0 years in 2004. As noted above, the small size of this population and its age diversity may be responsible for this fluctuation over time.

DMR Facilities. This residential category serves mostly older consumers (the majority of residents are over the age of 45-yrs). Because of the age difference from the overall DMR population, this subgroup may be more likely to experience a relatively higher rate of death than found in other residential settings. In the DMR facilities, 5 more deaths were reported in 2004 than in 2003. As a result, the rate of death increased from 39.6 per thousand to 46.0 per thousand, substantially higher than the rate found for all but the nursing home category. The average age at death for persons residing in DMR facilities also increased, rising by 8 years to 68.5 years during 2004.

Nursing Homes. Nursing homes serve the oldest population of DMR consumers, with about 60% falling between the ages of 55 and 84. In nursing homes, the rate of death sharply decreased from 167.2 per thousand in 2003 to 136.9 per thousand in 2004. Consistent with previous years, the rate of death in Nursing Homes continued to be 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[17]. As shown below in Table 6, Massachusetts DMR mortality rates in Nursing Homes were also lower than the US Nursing Home mortality rates across all age groups.

For the DMR Nursing Home population the average age at death did not change significantly from 2003. At 71.3 years, it is the oldest average age at death of any DMR residential setting and is reflective of the older population residing there.

[17] 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).

Figure 7
Relationship between Mortality Rate, Average Age at Death and Type of Residence
2004

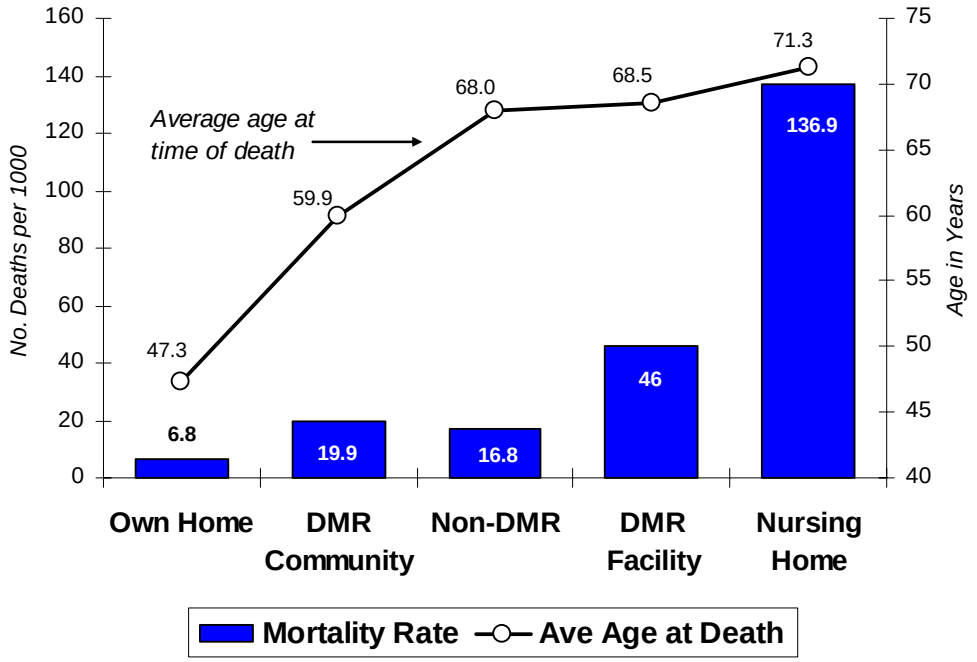


Table 6
Mortality Rate in Nursing Homes
A Comparison of US and MA DMR Populations

Age Group	Rate of Death (per thousand)	
	US 2002[18] (estimated)	DMR 2004
under 65	194.6	86.6
65-74	230.8	137.9
75-84	308.4	221.0
85+	544.2	243.2

[18] 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.

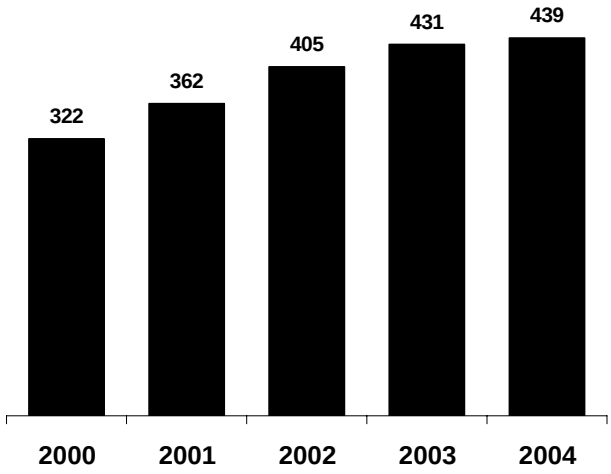
Trends Over Time

Mortality Rate. As can be seen in Table 7 and Figures 8 and 9 below, the number and rate of death for DMR consumers remained relatively stable between 2003 and 2004 with a non-significant increase of 0.1 deaths per thousand in 2004. The number of deaths increased by 9 consumers in 2004, the smallest annual increase since issuing mortality reports in 2000, halting the trend observed between 2000 and 2003.

Table 7
Mortality Trends in DMR[19]
2000 - 2004

Year	No. Deaths	Mortality Rate*[20] (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

Figure 8
Number of Deaths per Year
2000-2004



[19] 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.

[20] 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 9[21]
Statewide Mortality Rates
(Deaths per 1000)
2000-2004

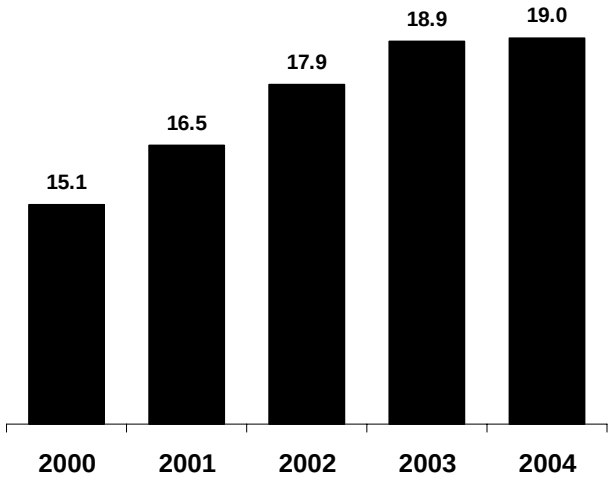


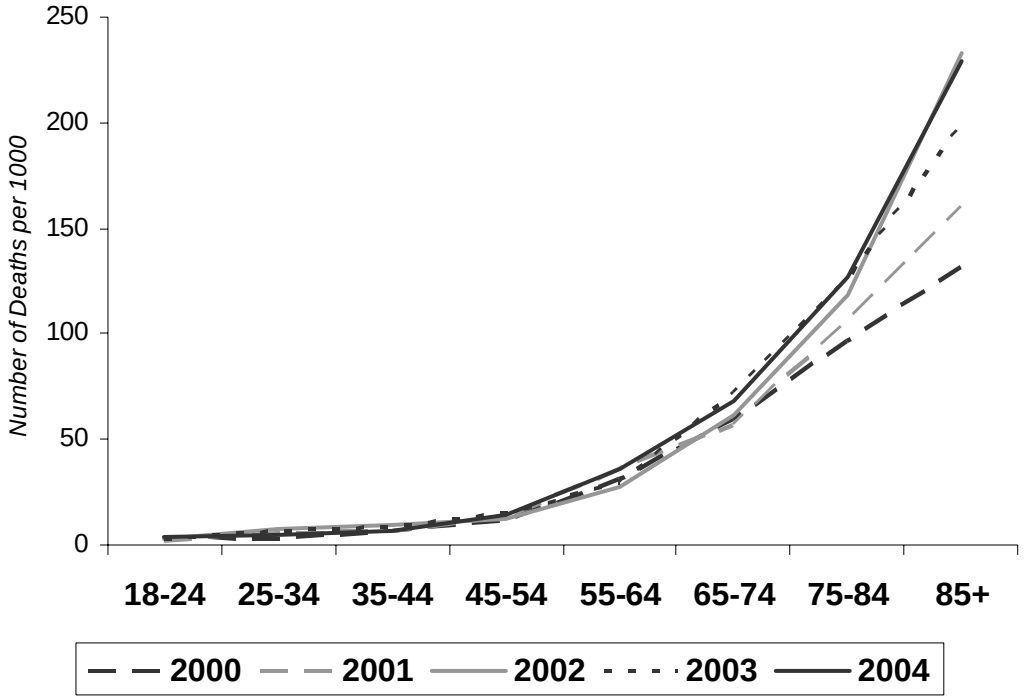
Table 7 also illustrates a trend of a gradual increase in the average age at death over the time. This suggests that DMR consumers may be experiencing a longer life expectancy than in previous years. This 2004 average age at death is similar to the average age at death reported in Connecticut for adult DMR consumers.[22]

The rate of death has varied across age groups over the past five years as illustrated in Figure 10. 2004 mortality rates by age group most closely model the adjusted mortality rates in 2002. As expected, the annual rate of death for adults varies little among the younger age groups. Rates for 2004 in the younger age groups 18-45 are slightly lower than in previous years. The rate of death for individuals over 65-yrs. varies noticeably across years, with a trend of increasing death rates in the elderly population. In the oldest age groups (age 75+), mortality rates are higher in 2004 relative to prior years. This age group is the smallest served by DMR, but also has the highest mortality risk.

[21] 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.

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

Figure 10
Comparison of Mortality Rate by Age Group Over Time
2000-2004



Causes of Death

The following section presents information about the causes of death for adults served by the Massachusetts DMR in 2004. 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 consumer was obtained from the DMR Death Report and in some cases the Death Certificate. In the case of persons subject to clinical mortality review, the cause was confirmed by the Mortality Review Committee.[23] See Mortality Review Process and Committee section for clinical review criteria.

Consistent with the recent trend 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."*[24]

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). To allow for better intercomparison 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 D).

The top ten causes of death in the DMR client population for 2004 are compared with data from four previous years and with state and national data in Table 8. The top 3 causes of death remained unchanged from 2003. For the fifth consecutive year, Heart Disease was the most common cause of death in the DMR client population, representing 19% of all deaths in 2004. This percentage is down from 22% of deaths in 2003. Cancer was the second leading cause of death with 12.5% of deaths. Aspiration pneumonia was the third leading cause, responsible for 11.2% of deaths. Influenza and Pneumonia (10.7%) followed as the fourth leading cause and Alzheimer's Disease

[23] 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.

[24] 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.

(8.9%) was fifth. Septicemia as a leading cause of death has fluctuated over the years, dropping to 7th place during 2004, a rank lower than those present in all previous years (2000-2003). Analysis of data in future years should be carefully reviewed to identify any continued decreases in septicemia and the possible emergence of a trend.

Table 8
Top 10 Leading Causes of Death

Rank	U.S. 2003[25]	MA 2003[26]	DMR 2000[27]	DMR 2001[28]	DMR 2002	DMR 2003	DMR 2004
1	Heart Disease *28.0%*	Heart Disease *26.0%*	Heart Disease	Heart Disease *21.2%*	Heart Disease *21.2%*	Heart Disease *22.3%*	Heart Disease *18.5%*
2	Cancer *22.7%*	Cancer *24.1%*	Pneumonia	Aspiration Pneumonia *12.3%*	Aspiration Pneumonia *12.3%*	Cancer *13.5%*	Cancer *12.5%*
3	Stroke *6.4%*	Stroke *6.0%*	Chronic Respiratory Disease	Cancer *12.7%*	Cancer & Septicemia[29] *10.1%*	Aspiration Pneumonia *12.3%*	Aspiration Pneumonia *11.2%*
4	Chronic Respiratory Disease *5.2%*	Chronic Respiratory Disease *4.9%*	Cancer	Septicemia *7.4%*	C-P Arrest/ Seizure[30] *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[30] *7.2%*	Alzheimer's *7.5%*
6	Diabetes *3.0%*	Alzheimer's Disease *2.9%*	Nephritis	Influenza and Pneumonia *6.1%*	Chronic Respiratory Disease *6.2%*	Chronic Respiratory Disease *6.0%*	C-P Arrest/ Seizure[30] *6.8%*
7	Influenza and Pneumonia *2.7%*	Diabetes *2.5%*	C-P Arrest/ Seizure[30]	Chronic Respiratory Disease *4.1%*	Influenza and Pneumonia *4.7%*	Alzheimer's Disease *5.3%*	Septicemia *6.6%*
8	Alzheimer's *2.6%*	Unintentional Injuries *2.5%*	Alzheimer's	C-P Arrest/ Seizure[30] *3.3%*	Nephritis *4.0%*	Influenza and Pneumonia *4.6%*	Chronic Respiratory Disease *5.7%*
9	Nephritis *1.7%*	Nephritis *2.3%*	Stroke	Accidents *3.3%*	Stroke *3.5%*	Stroke *4.2%*	Nephritis *3.6%*
10	Septicemia *1.4%*	Septicemia *1.8%*	Gastro-intestinal	Stroke *3.0%*	Congenital Defects *2.5%*	Nephritis *2.6%*	Stroke *3.6%*

[25] Data taken from latest published national report. Table 2. Percentage of total deaths, death rates, age-adjusted death rates for 2003, percentage change in age-adjusted death rates from 2002 to 2003 and ratio of age-adjusted death rates by race and sex for 15 leading causes of death for the total population in 2003: United States. (released ahead of entire report from NCHS)

[26] Most recent data available from *Massachusetts Deaths 2003.* Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, June 2005.

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

[28] 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.

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

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

Table 9 displays cause-specific mortality rates for major causes for 2001-2004[31,32]. Rates for the top three causes of death fell during 2004. Rates for causes of death that had been ranked lower in 2003 (*e.g.* Cardiopulmonary Arrest/Seizure, Alzheimer's, Nephritis) increased slightly to rates more similar to those found in 2002. Fluctuations are seen over the past five years for some of these causes, namely Cardiopulmonary Arrest/Seizure, Septicemia and Influenza and Pneumonia. 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. The rate of accidents, which fell out of the top ten ranking in 2002, remained low in 2004.

Table 9
Cause-specific DMR Mortality Rates
2001-2004

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

Cancer

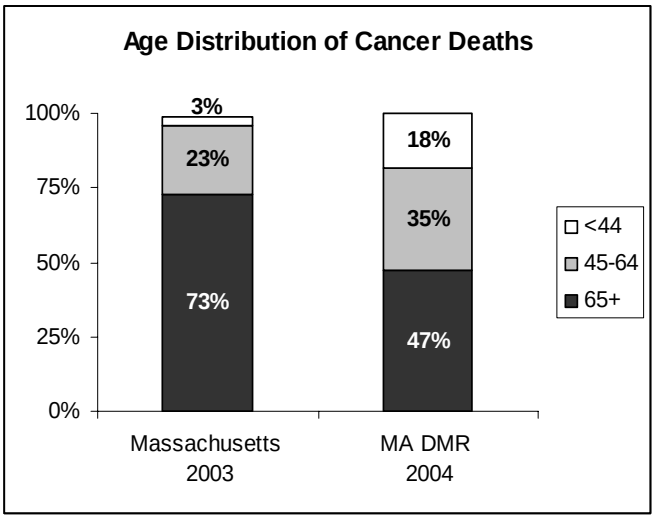
The rate of death from Cancer dropped slightly from 2.5 per thousand in 2003 to 2.4 per thousand in 2004. The leading types of cancer differed greatly from findings in 2003. Colorectal cancer was by far the most common cause of cancer deaths, with 10 deaths in 2004, representing the highest number of colon and rectum cancer deaths since the start of these reports in 2000. Cancers of the lung and of the stomach were tied for the second most deaths with 5 deaths from each. In previous years, the rate of death from lung cancer was lower than in 2004. The number of deaths from female breast cancer dropped steeply this year from 6 in 2003 to 2 deaths in 2004. Two deaths were from cancer of unknown etiology.

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

[32] This analysis is based on relatively small numbers of DMR consumers and is therefore subject to rate fluctuations based on minor changes in the number of deaths from year to year for any given cause.

Similar to 2003, the rate of death from cancer in the DMR population is higher than the national and statewide general population rate of 1.9 per thousand[33]. In the Massachusetts general population, lung and colorectal cancer were the top two causes of cancer deaths in 2003. Breast cancer is ranked third for females and cancer of the prostrate is third for males. In 2004, the DMR population had higher rates of colorectal cancer, but lower rates of lung, prostate and female breast cancer than those found in the general population of Massachusetts.

Figure 11[34]



The age distributions for cancer deaths also differ between the Massachusetts DMR and the state general population. In Massachusetts, almost two-thirds of cancer deaths occur in the elderly. In the Massachusetts DMR, there is a higher prevalence of cancer deaths 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[35,36,37] (e.g. leukemia, colorectal, oropharygeneal, testicular) and the appearance of cancers at significantly younger ages (e.g. colorectal cancer around age 35[38]) in individuals with mental retardation of certain etiologies.

Cause of Death by Age Group

Tables 10 and 11 compare causes of death by age-specific groupings for the DMR population in 2004 with the Massachusetts population in 2003.[39] Consistent with data from previous years, the cause of death in the younger DMR age group varies from statewide general population data. 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

[33] National and Massachusetts cancer rates from *Massachusetts Deaths 2003.* Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, June 2005

[34] In Figure 22, Massachusetts data includes ages 1-44 in the "<44" group, whereas MA DMR includes ages "18-44" in this group.

[35] 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.

[36] 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.

[37] 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.

[38] 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.

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

population. Findings over the past 5 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.

Deaths from heart disease and cancer are more common in older age groups in the general population, but appear at younger ages in the DMR population. In 2004, more individuals served by DMR died from Heart Disease in the younger age groups than in previous years. Alzheimer's Disease appears as one of the top three causes of death in more age groups in 2004 than in previous years. Aspiration Pneumonia continues to be more prevalent in the DMR community than in the general population, a trend present in previous years.

Table 10
Cause of Death by Age Group for DMR
2004
(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	CLRD, Cancer, Heart Disease	CP Arrest/ Seizure, Heart Disease	Alzheimer's	Alzheimer's, Aspiration Pneumonia, Cancer, Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease
2				Aspiration Pneumonia, Heart Disease, Septicemia		Cancer	Aspiration Pneumonia	Influenza & Pneumonia	Cancer
3			Cancer			Aspiration Pneumonia	Influenza & Pneumonia	Stroke, Cancer, CLRD	Aspiration Pneumonia

* CLRD = Chronic Lower Respiratory Disease

Table 11
Cause of Death by Age Group for Massachusetts Population
2003[40]

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

* CLRD = Chronic Lower Respiratory Disease

[40] Mortality information from 2003 was the most recent available from the state of Massachusetts.

In the 75-85 age group deaths from Cancer decreased and as a result it moved out of the top 3 in 2004. In all age groups above the age of 65, Pneumonia became a more prevalent cause of death in 2004.

In the 65-74 age group, Aspiration Pneumonia replaced Septicemia as the third leading cause of death. In the 75-85 and 85+ groups, deaths from Influenza and Pneumonia became more prevalent in 2004 compared to prior years.

In the 55-64 age group, deaths from Alzheimer's disease and Aspiration Pneumonia became more prevalent. This age group also had 6 deaths from accidents, the most of any age group in 2004. The accidents were mostly related to falls. In the 45-54 age group, there was a decrease in deaths from Cancers, and an increase in deaths from Alzheimer's Disease. The 35-44 age group saw Cancer move into the top three causes of death, and saw Aspiration Pneumonia deaths decrease. The 25-34 age group saw an increase in deaths from health conditions typically seen in older age groups, including CLRD, Cancer and Heart Disease. In past years, congenital conditions were the major cause of death for this age group.

In general, 2004 saw a somewhat greater incidence of Influenza and Pneumonia and Alzheimer's Disease as causes of death.

Cause of Death by Residence

The populations residing in different residential settings tend to have different age and health characteristics, and in turn, the cause of death differs by residential setting.

Table 12
Major causes of death for DMR Community[41]

Rank	Cause of Death	Number of Deaths	Rate of Death
1	Heart Disease	32	4.08
2	Cancer	23	2.68
3	Aspiration Pneumonia	21	2.45
4	Septicemia	16	1.86
5	C-P Arrest/ Seizure	15	1.75

Individuals in the DMR Community show higher rates of death from seizures and Aspiration Pneumonia than individuals living in their own home. This may be an artifact of population differences, e.g., higher rates of seizure disorders and swallowing disorders in individuals living in DMR community programs. Individuals requiring more structured and intensive supports such as those provided in this residential category may also have an increased prevalence of other co-morbidities that influence the causes of death, especially as compared to persons living at home or with their family.

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

However, absent formal risk adjustment for health-related characteristics it is not possible to determine with any certainty why these and other differential patterns related to causes of death are present.

Rates of death from septicemia appear much lower for individuals residing in the DMR Community than for DMR clients residing in Nursing Homes, but higher than the rate of Septicemia for individuals living in their own home or with family. The overall rates of death from Cancer were lower in individuals living in the DMR Community than the rate for the general population in Massachusetts.

Table 13
Major causes of death for DMR consumers in their Own Home[42]

Rank	Cause of Death	Number of Deaths	Rate of Death (per thousand)
1	Influenza & Pneumonia	15	1.29
2	Cancer	13	1.12
	Heart Disease	13	1.12
4	Stroke	6	0.52
5	CLRD	4	0.34
	Nephritis	4	0.34

During 2004, DMR consumers residing in their own home or with family saw higher rates of Influenza and Pneumonia than in previous years. The other high ranking causes appear to be similar to the causes of death for the general population in Massachusetts.

Table 14*
Major causes of death for DMR consumers 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	Cancer
3	Alzheimer's Disease	Cancer, Aspiration Pneumonia	Septicemia

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

Although only about one thousand DMR consumers resided in Nursing homes in 2004, almost thirty percent of all DMR deaths occurred in this type of setting. Almost all of the deaths from Alzheimer's Disease were of residents in nursing homes. In addition, there were higher rates of death from Heart Disease, Influenza and Pneumonia, Aspiration

[42] The DMR consumer may have passed away in a setting other than their own home, however, consumers are categorized by their primary residential setting.

Pneumonia and Chronic Lower Respiratory Disease for DMR consumers residing in Nursing Homes.

Heart Disease was the top cause of death in the Non-DMR setting and represented a total of 4 deaths in 2004. In the DMR Facilities, Aspiration Pneumonia accounted for14 deaths, Cancer 7 deaths and Septicemia 6 deaths.

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 the Regional and/or Central Review Committee for analysis, confirmation of cause of death and follow-up if indicated. During 2004, 222 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 outlined by the Massachusetts General Law, chapters six and thirty-eight.[43]

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

[43] "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."

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 2004 there were 20 deaths investigated by one or more of the agencies identified above, four (4) of which also involved law enforcement investigation. Twenty-one (21) cases were generated concerning these 20 deaths, of which only one case was substantiated. Two of the complaints in 2004 were generated as a result of individual deaths occurring in 2003. As can be seen in Table 15, the number of investigations decreased since 2002.

Table 15
Summary of Investigations
1999 to 2004

Type of Activity	1999	2000	2001	2002	2003	2004
DMR Investigation	7	5	5	14	9	5
DPPC Investigation	5	1	2	2	4	6
DPH Investigation	2	1	8	10	10	9
District Attorney/Law Enforcement Investigation	0	3	1	3	2	4
Other/dismissed[44]	5	3	5	4	2	1
Total Number of Deaths Investigated	19	13	21	33	27	20
No. Substantiations	0	0	1	2	2	1

Benchmarks

The use of benchmarks, including comparative data for other populations and/or from other state disability systems, is an important mechanism for helping to understand analytic findings such as those presented in this report. Benchmarks allow the reader to place findings *in context* and answer important questions such as "Is this finding unusual or is it what we should expect?," For benchmarks to be truly useful however, they need to be based on a population that is very similar to the one under study (in this case, persons with mental retardation) and they need to be based on similar data and methods. Unfortunately there is a relative dearth of valid benchmarks for use in comparing the results of this analysis of mortality in persons served by the Massachusetts DMR.

It is important to recognize that individuals with mental retardation have a variety of secondary conditions (co-morbidities) that place them at higher risk for mortality than the general population. Consequently, the use of general population benchmarks is not always useful, even when adjusted for age. Therefore, CDDER has focused on comparative mortality data from other state MR/DD agencies, where appropriate, as well as on limited research/literature that can be used for comparative purposes. It

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

should be noted that most state MR/DD systems do not routinely publish mortality data as does Massachusetts. Those that do, often configure the data differently, making specific and direct comparisons difficult.[45] Finally, published research is often directed at answering very specific questions that are usually quite different from the focus of this report. Such research therefore has limited utility in providing meaningful benchmarks.

Cause of Death Benchmarks. A review of research literature and state agency reports concerning the leading causes of death in persons with mental retardation shows general consistency with the findings in this 2004 Mortality Report. For example, Table 16 provides data from a recent report issued by the Virginia Inspector General[46] that reviewed deaths within institutional settings for 2000 through 2001.

Table 16
Leading Causes of Death for Persons with MR
In Virginia Institutional Settings
2000-2001

Rank	Cause of Death	Percent
1	Cardiac	38.5%
2	Respiratory	23.1%
3	Infection	15.4%
4	Neoplasm Nervous System Genitourinary	7.7% (each)

A 2001 report[47] on mortality among adults with developmental disabilities in Illinois found that heart disease was the major cause of death in their MR/DD population. The study also reported that this population experienced a higher proportion of deaths due to pneumonia/influenza, septicemia and aspiration pneumonia than the Illinois general population.

Table 17 below presents data on the leading causes of death from a 2003 Mortality Report[48] that covers the population of persons served in state facilities and community-based programs licensed by the Maryland Developmental Disabilities Administration. Again, the findings are very similar to those present in the Massachusetts DMR.

[45] A review of national mortality reports published by state MR/DD agencies indicates that only a handful of state DD agencies report externally on mortality within their systems. There are currently no accepted conventions for collecting, organizing and analyzing the data that is reported. This lack of consistency makes it difficult to provide direct comparisons and thus limits the use of valid benchmarks.

[46] Rea, A.S. *Study of all deaths occurring October 2000 to September 2001 in Mental Health and Mental Retardation Institutions operate by the Commonwealth of Virginia*, Office of the Inspector General, Virginia, 2002.

[47] Hsieh, K. Residential characteristics, social factors and mortality among adults with developmental disabilities. *ADDVANTAGE*, Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, Vol 12, 2, Fall 2001.

[48] Brandt, N. *Mortality Review Committee Annual Report: 2003*. University of Maryland School of Pharmacy, September 2004.

Table 17
Leading Causes of Death
Maryland DDA 2003 Mortality Report

Rank	Cause of Death	Percent
1	Heart disease	21%
2	Influenza & pneumonia	19%
3	Malignant neoplasms	14%
4	Other respiratory	9.5%
5	Septicemia	10%

A recent study[49] of the mortality of Wyoming citizens with developmental disabilities on Medicaid found that diseases of the respiratory system and influenza/pneumonia as a cause of death were "more common in the DD population by marked amounts" than in the general Wyoming population. Although the findings are based on a small sample, the study found that almost two times as many persons with DD died from chronic respiratory disease and about three times as many from influenza/pneumonia than the general population.

A further comparison of the top four leading causes of death as reported by the MR/DD state agencies in Connecticut[50], New Mexico[51] and Vermont[52] is presented below in Table 18. This comparison illustrates significant similarity across state systems with heart disease, cancer and respiratory diseases/disorders representing the major causes of death in all four 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), and therefore all of these benchmarks must be viewed with caution.

Table 18
Comparison of the Top 4 Leading Causes of Death
As Reported by Four State MR/DD Agencies

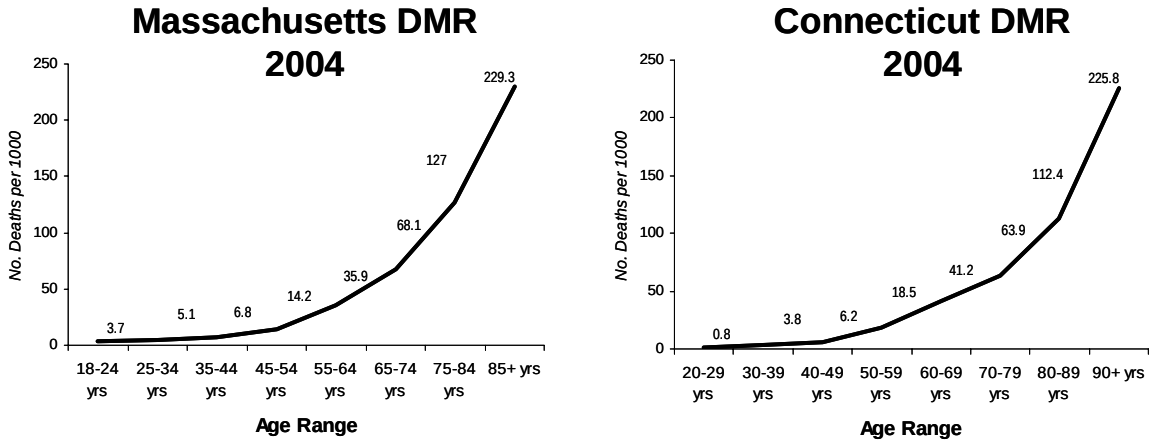
Rank	MA DMR 2004	CT DMR 2004	NM DH 2004	VT DDS 2003
1	Heart Disease	Heart Disease	Respiratory & Aspiration Pneumonia	Heart Disease
2	Cancer	Respiratory	Cancer	Respiratory & Pneumonia
3	Aspiration Pneumonia	Nervous System	Heart Disease	Cancer
4	Influenza and Pneumonia	Cancer	Sepsis	Alzheimer's & Seizures

[49] Newman, C, Heath, D & Olaveson, J *Living Well With CMS Funding: A Study of Mortality in Wyoming, 2004.* Cited at www.qualitymall.org, 2006.
[50] *Health and Mortality Review: 2004 Annual Report*. Connecticut Department of Mental Retardation, 2005.
[51] Personal Communication, New Mexico Department of Health, January 2005.
[52] *Mortality among People Receiving Developmental Services in Vermont FY 2003*, Vermont Division of Developmental Services, 2003.

The benchmarks reviewed above therefore present findings that are quite consistent with the findings re: the leading causes of death within the Massachusetts DMR population. They strongly suggest that the leading causes of death for persons with MR/DD are represented primarily by factors associated with heart disease, respiratory conditions (including aspiration pneumonia), cancer, nervous systems disorders (e.g., Alzheimer's and seizures) and septicemia. Differences in specific rankings most likely reflect variations in how causes are grouped and the relatively small number of cases upon which the analyses are based.

Mortality and Age Benchmarks. As noted in last year's report the Connecticut DMR[53], provides similar annual mortality data to that published by the Massachusetts DMR. Although the age groupings are different, Figure 12 below illustrates that the same general trend of increasing mortality with age is present for both the Massachusetts and Connecticut state systems, once again suggesting that the findings for the Massachusetts DMR in 2004 are not unusual.

Figure 12
Comparison of 2004 Mortality Rates by Age
Massachusetts DMR and Connecticut DMR



Mortality and Residence Benchmarks. 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.[54] Connecticut serves a residential population similar to that of the Massachusetts DMR. However, the Connecticut DMR provides some residential services to children with mental retardation

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

[54] 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 one other state, Connecticut, which presented mortality data according to this variable. However, Connecticut breaks out its data into more residential categories than does Massachusetts. For the purposes of this report, and in an effort to make the benchmark more closely aligned with Massachusetts, only the group home data is listed for Connecticut Community category.

who are included in the base for computing mortality rates. The influence of this age difference on resultant mortality rates is not known, but should be taken into consideration when comparing the mortality rates by residence for these two state systems.

Table 19 below provides 2004 mortality rates (no. of deaths per 1000 people served) by type of residential setting for both the Connecticut and Massachusetts DMR agencies. As can be seen, the Connecticut rates are somewhat lower than those in Massachusetts for all of the residential categories. The most marked difference occurs for the DMR Facility category. The patterns across residential types are, however, quite similar with the lowest rates evident for persons living in their own home and the highest rates present for those individuals living in nursing homes.

Table 19
Comparison of 2004 Mortality Rates by Residence Type
Connecticut DMR and Massachusetts DMR

Residence Type	*Mortality Rate No. Deaths per 1000*	
	MA DMR	**CT DMR**
Own Home	6.8	4.0
DMR Community	19.9	14.3
DMR Facility	46.0	17.9
Reg Centers		22.8
Nursing Home	136.9	119.3

A study conducted in the State of New Jersey[55] on persons with developmental disabilities found that within this population those individuals who resided in nursing homes had a much higher risk of mortality than other disabled persons. However, the nursing home group also had a significantly higher proportion of risk variables associated with mortality. This finding, along with the generally higher age of the nursing home cohort may help explain the increased mortality rate for the DMR nursing home population in both Connecticut and Massachusetts as noted above.

Mortality and Gender Benchmarks. Published mortality data from both Connecticut and Maryland are used for comparative purposes for reviewing the distribution of deaths by gender in Massachusetts. These data are presented below in Table 20 and suggest that a similar ratio of male to female deaths is present in all three state systems. Because the relative distribution of males to females within the MRDD population served is not included (not known), any differences in the relative percentages could simply reflect differences in the base population.

[55] Lerman, P, Apgar, DH, & Jordan, T Deinstitutionalization and mortality: Findings of a controlled research design in New Jersey. *Mental Retardation*, V 41, 4, August 2003.

Table 20
Comparison of Mortality by Gender
Massachusetts DMR, Connecticut DMR and Maryland DDA

Gender	*Percent of Deaths*		
	MA DMR 2004	**CT DMR** 2004	**MD DDA** 2003
Male	55%	51%	53%
Female	45%	49%	47%

Healthy People 2010 Objectives. A series of health objectives contained in Healthy People 2010 (HP2010) were issued by the U.S. Department of Health and Human Services in 2000 and were distributed as a set of health-related goals for the nation to achieve by the year 2010. The initiative built upon recommendations in previous Surgeon General's reports and *Healthy People 2000: National Health Promotion and Disease Prevention Objective.* 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 targets for mortality rates to be met by the nation and individual states.

Table 21 below displays data associated with 28 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 to children and child-birth were not included.

Statistics from 2002 were used for the US objectives to ensure increased accuracy.[56] The objectives related to mortality rates in Healthy People 2010 are based upon a measure "per 100,000 people." The Massachusetts DMR serves a small population (about 23,000 individuals) relative to state and national populations. Smaller populations such as this are subject to more variability from year to year in their mortality rates. For example, one additional death can inflate the DMR annual death rate over 4 points on a scale of 100,000 people. To compensate for this variability, death rates in this section were averaged over the past four years (2001-2004). This method allowed for a broader view of the status of the population and minimizes 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 four years. Since it is not possible to have a death rate under 1.1 per 100,000 for DMR over four years due to the small size of the population, these smaller rates are not directly compared.

[56] Preliminary US rates for 2003 have been released, however because they have not yet been finalized, 2002 rates are used to ensure accuracy.

Overall, rates for individuals in the Massachusetts DMR population meet many more 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.[57].

The rates of death from lung and prostate cancer for the DMR population were well within the HP2010 targets. Rates of cervical, oropharyngeal and malignant melanoma were higher than the 2010 targets, but represent only 3, 4 and 5 cases respectively across the past 4 years. Rates of colorectal and female breast cancer were significantly higher than the 2010 target and Massachusetts and national rates.

Rates of death for diabetes-related deaths were 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 what is targeted in the objectives.

For chronic obstructive pulmonary disease, the objectives focus only on adults over the age of 45. In this category, DMR was very close to the target and displayed rates much lower than the general population in Massachusetts. Rates of death from Cirrhosis were higher than the targeted objectives.

Comparison of DMR data with the objectives contained in Healthy People 2010 may serve as one of many different benchmarks for use in identifying priorities for further review and/or strategic intervention.

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

Table 21
Target Status for Selected Healthy People 2010 Mortality Objectives[58]

Objective Number	**HEALTHY PEOPLE 2010 OBJECTIVE** *Rates per 100,000 population; MA and US are Age-adjusted*	TARGET 2010[59]	DMR 2001-2004	DMR TARGET STATUS	MA 2003[59]	US 2002[59]
3-1	Overall Cancer death rate	158.6	219.8	●	193.5	193.5
3-2	Lung Cancer	43.3	13.2	✓	54.6	54.9
3-3	Female Breast Cancer (per 100,000 females)	21.3	49.2	●	24.5	25.6
3-4	Cervix (per 100,000 females)	2.0	7.4	●	1.3	2.6
3-5	Colorectal Cancer	13.7	25.3	●	18.8	19.7
3-6	Oropharyngeal Cancer	2.4	4.4	●	2.5	2.7
3-7	Prostate Cancer (per 100,000 males)	28.2	20.2	✓	26.6	27.9
3-8	Malignant Melanoma	2.3	5.5	●	3.1	2.6
5-5	Diabetes-related deaths	46	14.3	✓	61	78
12-7	Stroke Deaths	50	65.1	●	46	56
26-3	Drug-induced deaths	1.2	0.0	✓	13.3	9
13-14	HIV-infection Deaths	0.7	--[60]	✓*	3.4	4.9
24-10	Chronic Obstructive Pulmonary Disease Deaths (age 45+)	62.3	62.6	O	106	118.9
26-2	Cirrhosis Deaths	3.2	10.1	●	8.3	9.4
	Injuries					
15-3	Firearm- related	3.6	0.0	✓	3.1	10.4
15-8	Poisonings	1.5	--[60]	✓*	13.1	9.2
15-9	Hanging, strangulation or suffocation	3.3	0.0	✓	4.5	4.4
15-13	Unintentional injuries (Accidents)	17.1	27.7	●	20.6	36.9
15-15	Motor vehicle crashes	8.0	--[60]	✓*	7.8	15.2
15-24	Drowning	0.7	--[60]	✓*	0.7	1.3
15-25	Residential fire deaths	0.2	0.0	✓	1.2	1.1
15-27	Falls	3.3	11.0	●	3.5	5.6
15-32	Homicide	2.8	--[60]	✓*	2.2	6.1
18-1	Suicide	4.8	--[60]	✓*	6.5	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

[58] 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.

[59] Data 2010 the Healthy People 2010 Database. CDC Wonder website: http://wonder.cdc.gov. Goals revised January 2006.

[60] Too few deaths occurred to be statistically reliable (i.e. only 1-2 deaths occurred from this cause over the 4 years). Because of the small population size, a rate lower than 1.1 per 100,000 was not possible in the DMR population during this time period.

APPENDICES

Appendix A

Methodology

The 2004 Mortality report analyzes information on all deaths occurring in calendar 2004 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 2004 Mortality Report includes statistics on all deaths of persons who died in calendar year 2004 and whose Death Report was received by DMR by the end of January 2005. A total of 439 deaths were reported to have occurred between January 1, 2004 and December 31, 2004.

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, 2004.[61] 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 439 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:

$$\text{Crude Death Rate} = \frac{(\text{Number of persons who died in calendar 2003} \times 1000)}{(\text{No. Persons in CRS in June 2004})}$$

[61] 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, 2004.

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
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 2004 DMR Adult population

SEX	Age	DMR Funded Community	DMR Facility	Nursing / Rest Home	Own Home	Non-DMR	Total
F	18-24 yr	138	0	25	1467	128	1,758
M	18-24 yr	215	2	25	2126	209	2,577
F	25-34 yr	614	4	50	1208	43	1,919
M	25-34 yr	860	16	39	1406	54	2,375
F	35-44 yr	1000	84	39	1145	84	2,352
M	35-44 yr	1396	96	34	1325	79	2,930
F	45-54 yr	983	130	33	795	77	2,018
M	45-54 yr	1236	220	53	852	67	2,428
F	55-64 yr	611	105	104	421	55	1,296
M	55-64 yr	715	179	60	413	40	1,407
F	65-74 yr	255	79	97	164	32	627
M	65-74 yr	297	101	77	172	33	680
F	75-84 yr	124	37	112	58	21	352
M	75-84 yr	106	34	69	48	21	278
F	85+ yr	26	10	54	5	4	99
M	85+ yr	11	12	20	12	3	58
Total		8,587	1,109	891	11,617	950	23,154

Appendix D

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 E

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 F

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.