

**Commonwealth of Massachusetts**

**Department of Mental Retardation**

## **2002 Mortality Report**

**Prepared by**

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## **Executive Summary**

As part of the Massachusetts Department of Mental Retardation's (DMR) formal Mortality Review process to improve the quality of services and supports while reducing the risks of harm, 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 three years. This report represents a review of the period between January and December of 2002.

In calendar year 2002, the Massachusetts DMR served over 32,000 individuals, 24,822 of whom were adults over the age of 18. This is an increase of about 3% from the prior year. In the same period, 405 deaths were reported for DMR clients, resulting in a rate of death of 16.3 per thousand. Both the total number of deaths and the overall statewide mortality rate have gradually risen over the past three years. The number of overall deaths reported within DMR for individuals eligible for services has risen from 322 in the year 2000 to 362 in 2001 to 405 during 2002. In a similar fashion, the overall mortality rate (no. deaths per thousand people served) has grown from 13.5 to 16.3 in the same three year time period.

However, this increase in rate of death is not evenly distributed throughout the population. The older population of persons served by DMR has also shown a relatively large increase (10% growth in persons 65-yrs and older). This more elderly group is most at risk of mortality. In the same time period the rate of death decreased slightly for the 45-64 age group, which is the largest group of individuals in the DMR population. These different trends are evidence of an aging population of DMR clients, which is further demonstrated in this report.

### **Age**

As expected, mortality rates varied by age, with the oldest age group exhibiting the highest mortality rate (206.1) and the youngest group showing the lowest rate (3.1). The findings for all age groups are similar to trends in other states.

### **Gender**

Slightly more women than men passed away during 2002, representing just over half of all deaths. Although women had a higher mortality rate than men, they also had a slightly higher average age at death. These differences are consistent with expectations since there are more women than men within the oldest age groups in the population DMR serves.

### **Residence**

There are substantial differences in mortality rates based upon the type of residential setting. The lowest mortality 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. Based upon the general age characteristics of each residential setting, individuals with the lowest risk were found to have the lowest rate of mortality and those with the highest risk to have the highest mortality rate.

## **DMR Regions**

There exist slight variations in mortality rates across regions: Three regions experienced mortality rates above the statewide average. The Northeast and Metro regions had rates that were less than the overall average. Two regions (Central and Northeast) had an average age at death higher than the statewide average. Variations in age distribution across regions correspond to increased mortality rates. Other predictors of increased rate of mortality such as severity of disability or mobility impairment are not part of the analysis for this report. Extreme caution must therefore be exercised before drawing any conclusions regarding the differences that are observed in mortality between DMR regions.

## **Cause of Death**

For the third year in a row, Heart Disease was the most common cause of death in the DMR client population, representing 21% of all deaths in 2002. Aspiration Pneumonia was the second leading cause at 12% of deaths. Septicemia and cancer were tied for third; cancer as a cause of death declined from previous years while septicemia increased. The rates of influenza pneumonia and accidents also decreased from prior years. Influenza Pneumonia dropped to the eighth leading cause of death. Accidents decreased and fell completely out of the top ten ranking.

There was a relatively large increase in Cardiopulmonary Arrest and Seizures as the reported cause of death during 2002. These are deaths that could be termed “sudden” and may or may not involve seizures. This increase could be partially determined by changes in reporting, with more conservative definitions becoming more widely used for Heart Disease, leading to more frequent classification of deaths due to sudden cardiopulmonary arrests rather than the result of a previously diagnosed condition.

## **Benchmarks**

Limited benchmark data is available from other state MR/DD systems due to differences in reporting practices. Using available data from Connecticut, this report indicates some similarity in patterns and trends regarding mortality within the Massachusetts DMR that are consistent with findings reported by the Connecticut DMR. For example, trends in mortality by residence type are similar when comparing Connecticut and Massachusetts.

## **Additional Sections**

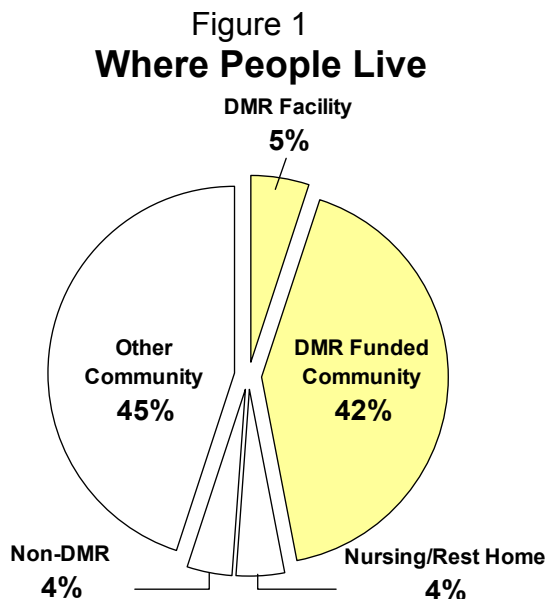
Additional sections include a summary of investigations, recent system enhancements and the methodologies used in this report.

## 2002 Mortality Report

The Massachusetts Department of Mental Retardation (DMR) has established a formal Mortality Review process as a means of improving the quality of services and supports and reducing the risk of harm to the over 24,000 individuals with mental retardation that it serves. 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 three years. This report represents a review of the period between January and December of 2002.

### Overview of DMR

The Massachusetts DMR served 24,822 adults with mental retardation at the end of calendar year 2002, an increase of about 3% from the prior year. As can be seen below in Figure 1, approximately half lived in residential programs operated, certified or funded by DMR. About the same number did not receive direct DMR residential support. Most of these individuals lived either independently or with family, in non-DMR settings or nursing homes.



### MORTALITY REVIEW

**2002 Mortality Report.** The first part of this report includes information and data concerning all adults (18-yrs old and older) served by DMR, who were listed in the Consumer Registry System (CRS) and who passed away during calendar year 2002. The data includes persons therefore who do not always meet the criteria for formal review by the Mortality Review Committee (see below).

**DMR Clinical Mortality Review Process.** Clinical reviews are conducted on the deaths of persons served by DMR who:

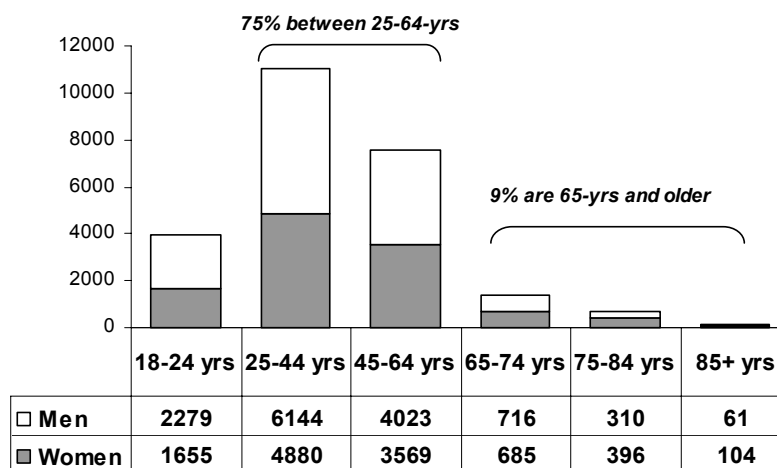
- Are at least 18-yrs of age
- Receive a minimum of 15-hrs of residential support that is provided, funded, arranged or certified by DMR
- Died in a day support funded or certified by DMR
- Died in a day habilitation program, or
- Died during transportation funded or arranged by DMR.

Information from Committee reviews is included in the latter part of this report.

DMR serves primarily adults (age 18-yr and older) who have mental retardation. The largest group of consumers (75%) falls between the ages of 25-yrs and 64-yrs. As can be seen in Figure 2 below, DMR also serves a relatively large number of senior citizens, with 9% - or almost 2,300 people – 65-yrs and older. Interestingly, in 2002 DMR served 165 individuals who were 85-yrs of age and older.

Figure 2

**AGE & GENDER**  
**People Served by DMR**  
**2002**



The Massachusetts DMR has continued to experience a gradual shift in the aging of the population it serves, in a fashion similar to that being reported in other northeast states<sup>1</sup>. In fact in 2002 alone, the population over 65 years of age served by DMR increased by about 10% compared to the previous year while the overall consumer population within DMR grew by only 3%. This “aging in place” phenomenon is an especially important consideration when reviewing health and mortality within the population of persons served by DMR since age is the single most important determinant of mortality. As a population ages, increases in the mortality rate should be anticipated.

The proportion of men and women served by DMR varies by age. 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 containing over 40% as many women as men, a finding consistent with reported research from other states.<sup>2</sup> This gender difference is also an important consideration when

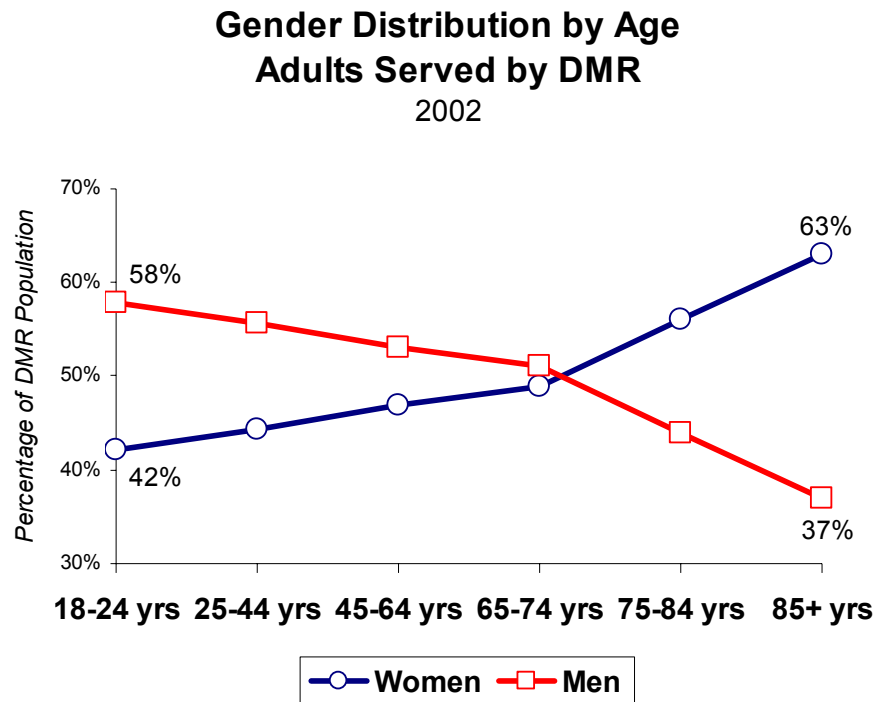
<sup>1</sup> State of Connecticut Department of Mental Retardation. *Aging Focus Team Report and Recommendations*, October 2003.

<sup>2</sup> Gruman, C. and Fenster, J. *A Report to the Department of Mental Retardation: 1996 through 2002 Data Overview*, April 2002.

reviewing mortality since there are substantially more women than men in the highest risk category: 85+ years of age.

Figure 3 below illustrates this shift by gender and age.

Figure 3



## Mortality During 2002

This section of the report provides information on all of the deaths of persons with mental retardation who were 18-yrs of age or older and who were determined to be eligible for DMR services and supports that occurred during calendar year 2002. Appendix A contains a detailed description of the methodology used to collect and analyze the information and data contained in this section.

During 2002 DMR received death reports for **405** individuals who met the criteria outlined above. This represents a crude death rate<sup>3</sup> of **16.3** persons per thousand.<sup>4</sup>

<sup>3</sup> The crude death rate is a measure of how many people out of every thousand served by DMR died within the calendar year. It is determined by multiplying the number of 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.

<sup>4</sup> Standard recommended by the U.S. Centers for Disease Control and Prevention, National Vital Statistics Report, *Age Standardization of Death Rates: Implementation of the Year 2000 Standard*, Vol 47, No. 3, 1998.

## Age

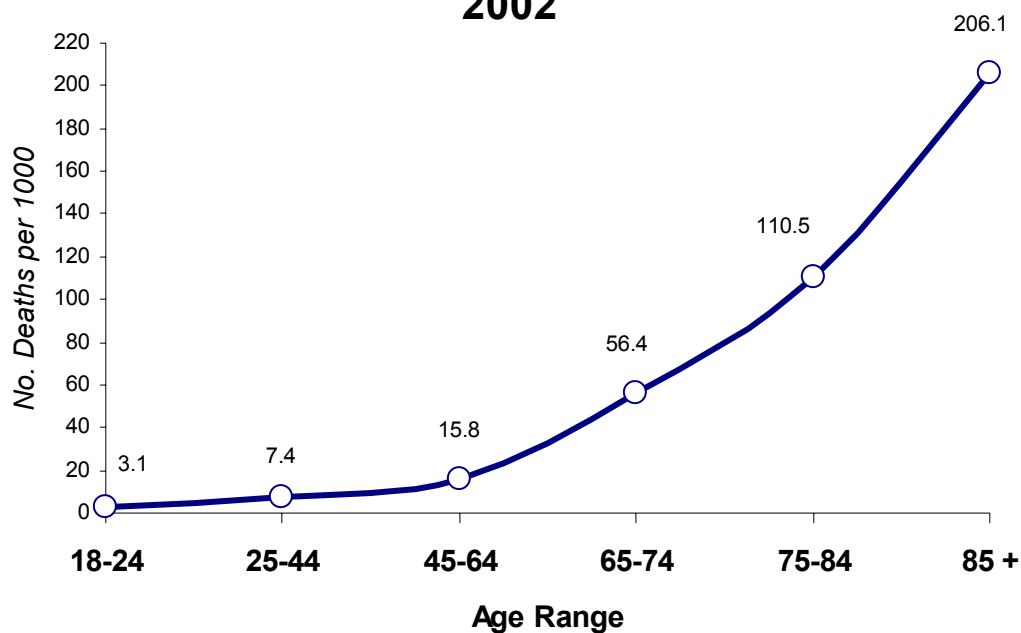
Table 1 presents the number of persons who died, the relative percentage of deaths and the mortality rate, by age group. As expected, mortality rates varied by age, with the oldest age group exhibiting the highest mortality rate and the youngest group showing the lowest rate. These differences and trends are illustrated in Figure 4, and follow expected patterns.

Table 1  
Distribution of Deaths by Age Group  
2002

Age Range	No. Deaths	Percentage	Death Rate (No. per 1000)
18- 24 yrs	12	3%	3.1
25-44 yrs	82	20%	7.4
45-64 yrs	120	30%	15.8
65-74 yrs	79	20%	56.4
75-84 yrs	78	19%	110.5
85 yrs & older	34	8%	206.1
<b>Total</b>	<b>405</b>	<b>100.0%</b>	<b>16.3</b>

Figure 4

## Mortality Rate by Age Group Adults Served by DMR 2002



## Gender

Slightly more women than men passed away during 2002, representing just over half of all deaths. As can be seen in Table 2, although women had a higher mortality rate than men, they also had a slightly higher average age at death. Although these differences are not statistically significant they are consistent with expectations since, similar to the general population, there are more women than men within the oldest age groups, *i.e.*, those that are at the highest risk of mortality.

Table 2  
**No. Deaths, Average Age at Death and Death Rate by Gender  
2002**

Gender	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
F	207	51%	62.0 yrs	18.3
M	198	49%	60.9 yrs	14.6

## Residence

People served by DMR live in one of five general types of residential settings: own 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.

There are substantial differences in mortality rates based upon the type of residential setting using the categories described above. These differences are provided in Table 3 below. As can be seen the lowest mortality 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. This relationship between type of residence and mortality is consistent with expectations and with trends present in other state mental retardation systems<sup>5</sup> since average population age tends to vary by type of residential setting. However, it should be noted that the rate of death in nursing homes for *DMR clients* is much lower than the rate of death of 353 per thousand in Massachusetts Nursing Homes in 2001<sup>6</sup>.

<sup>5</sup> State of Connecticut Department of Mental Retardation. *Health and Mortality Report*, November 2002.

<sup>6</sup> 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).

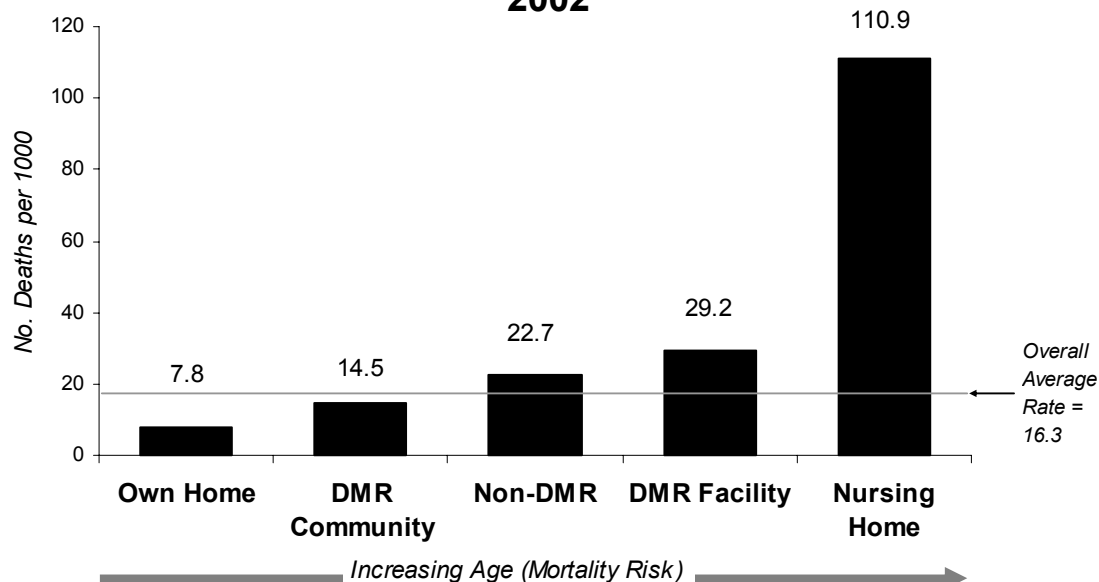
In general the population of individuals who live at home and those who receive supports in community settings tend to be younger than persons residing within DMR facilities and nursing homes. Consequently, and as can be seen in Figure 5, individuals with the lowest risk have the lowest rate of mortality and those with the highest risk have the highest mortality rate.

Table 3  
**Distribution of Deaths by Type of Residence  
2002**

Residence Type	Population	No. Deaths	Percent of Deaths	Death Rate (n/1000)	Average Age at Death
Own Home	11,270	88	22%	7.8	50.5
DMR Community	10,506	152	38%	14.5	60.1
Non-DMR Residence	882	20	5%	22.7	47.0
DMR Facility	1,163	34	8%	29.2	70.8
Nursing Home	1,001	111	27%	110.9	71.8
Total (Statewide)	24,822	405	100%	16.3	61.5

Figure 5

**Mortality Rate by Residential Setting  
Adults Served by DMR  
2002**



A further illustration of this relationship can be seen by comparing Figure 5 above with Figure 6 and the series of pie charts below (Figures 7-9). As can be seen,

the percentage of individuals who are 65+ years of age follows the exact same pattern as the mortality rate. In addition, 75% of the deaths for persons 18-24 yrs of age occurred for those who lived at home. In contrast, 70% of the deaths for persons age 85+ took place within DMR facilities or nursing homes and about 76% of the deaths for persons between 25 and 44-yrs of age occurred within the group living at home or within DMR Community settings.

Figure 6

**Percent of Population 65+ yrs  
by Residential Setting  
2002**

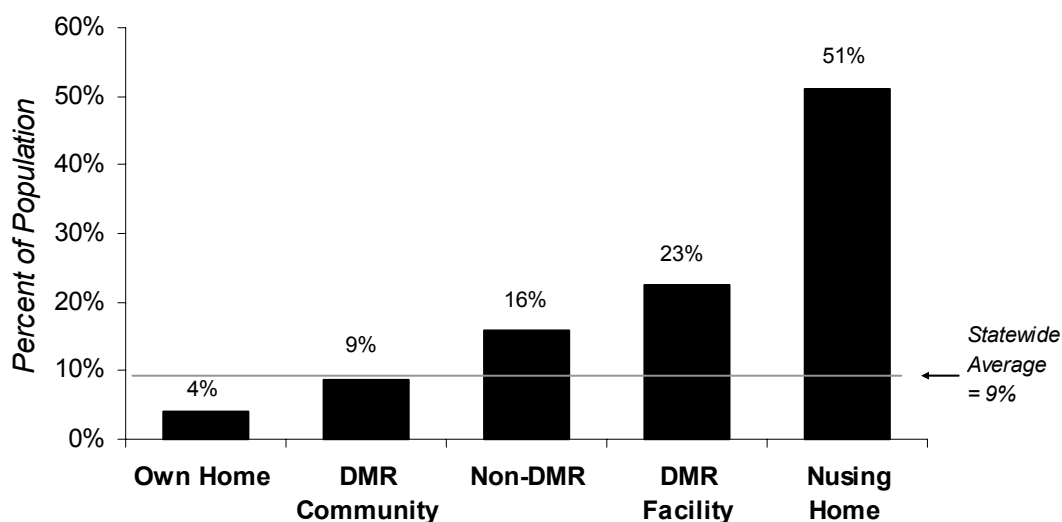


Figure 7

**Distribution of Deaths for  
18-24 yr Age Group**

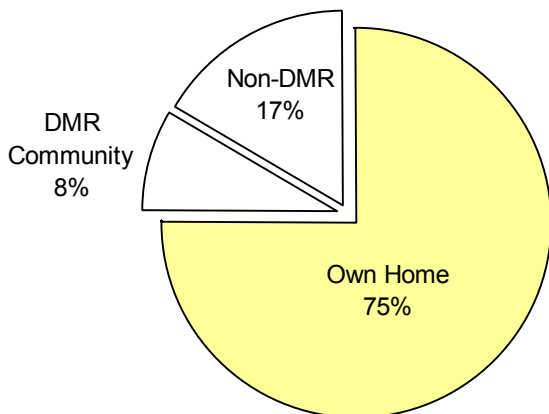


Figure 8

**Distribution of Deaths for  
85+ yr Age Group**

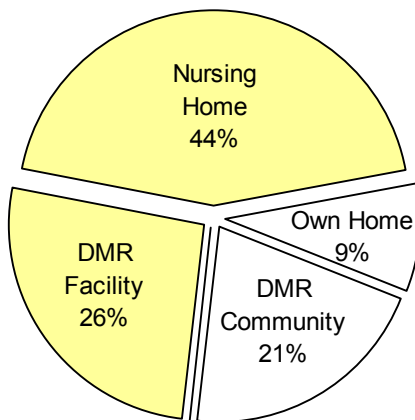
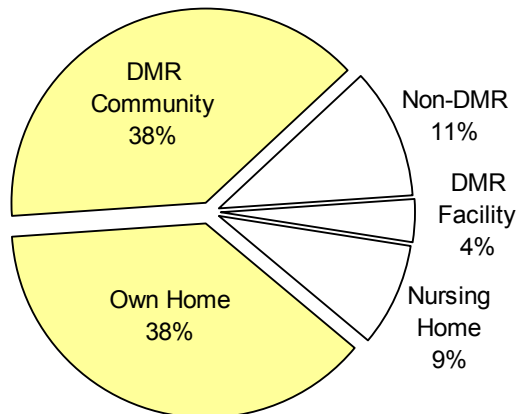


Figure 9

**Distribution of Deaths for  
25-44 yr Age Group**



### DMR Regions

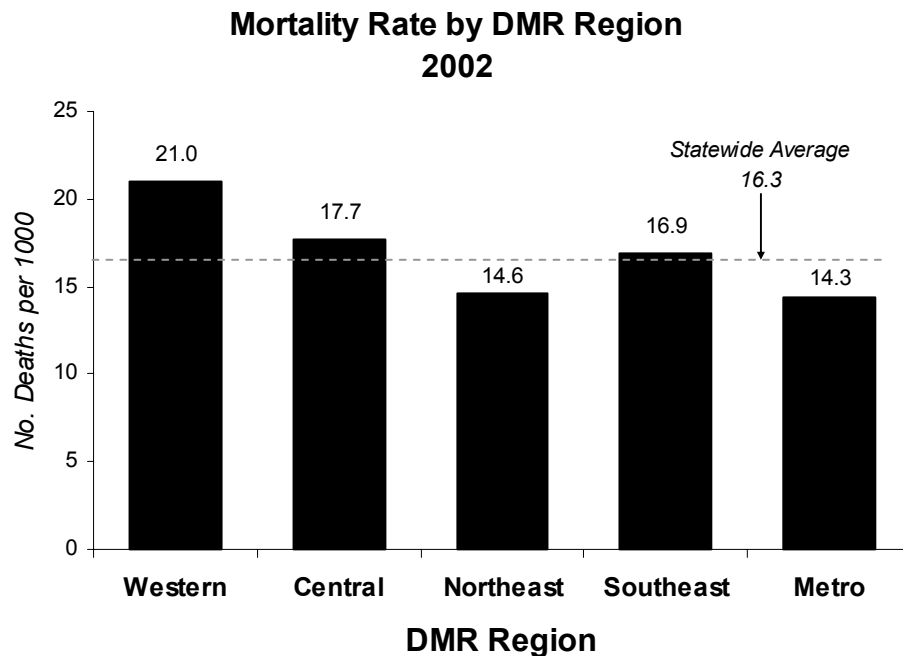
During 2002 there were five administrative regions in the Massachusetts Department of Mental Retardation: Western MA (Region 1), Central MA (Region 2), Northeast (Region 3), Southeast (Region 5) and Metro (Region 6). Appendix C contains summary information regarding the population of individuals served by each of these regions.

Mortality rates by region and associated information are presented below in Table 4 and Figure 10. During 2002, three regions experienced mortality rates above the statewide average. The Northeast and Metro regions had rates that were less than the overall average. Two regions (Central and Northeast) had an average age at death higher than the statewide average.

**Table 4**  
**Regional Comparison**  
**Population, Deaths, Mortality Rate and Average Age at Death**  
**2002**

Region	Population	No. Deaths	Rate (n/1000)	Ave Age at Death
Western	3,044	64	21.0	60.1
Central	4,455	79	17.7	62.9
Northeast	4,529	66	14.6	63.3
Southeast	4,983	84	16.9	61.3
Metro	7,811	112	14.3	60.3
Statewide	24,822	405	16.3	61.5

Figure 10



When comparing mortality rates across regions (or any other variable) there are a number of important considerations that must be taken in account. While the age of the population is clearly an important determinant of risk for mortality for all individuals, research has also shown that within the population of persons with mental retardation the level and type of disability- and especially the presence of significant impairments in mobility - also greatly impact risk of mortality.<sup>7</sup> Absent data related to these two population characteristics extreme caution must be exercised before drawing any conclusions regarding the differences that are observed in mortality between DMR regions.

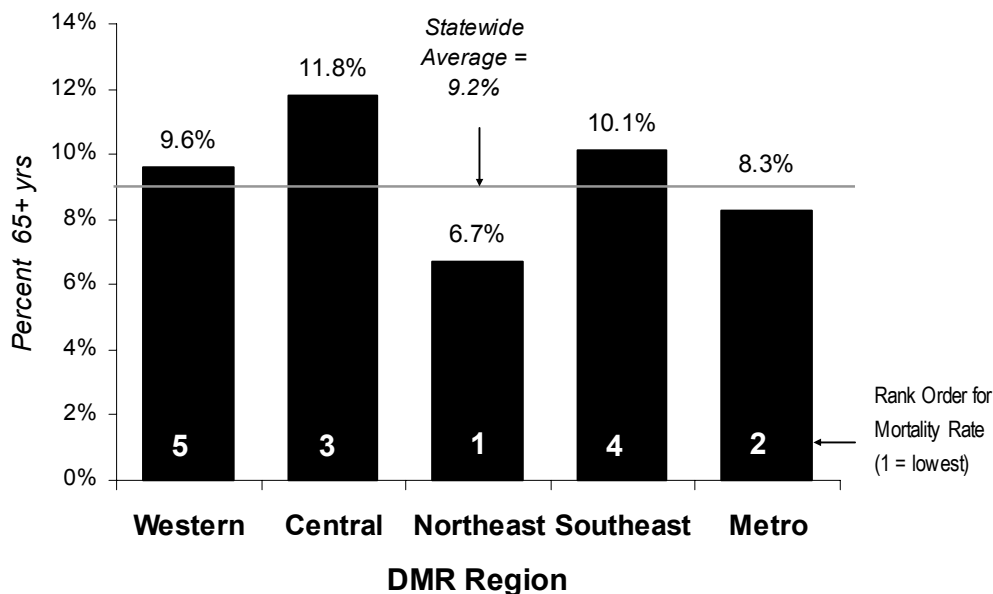
For example, Figure 11 illustrates the relative percentage of the population served by the regions that is at highest risk of mortality, *i.e.*, 65 years of age and older. As can be seen, three of the regions have a higher proportion of older persons. Interestingly, all three of these regions also have the highest mortality rate. This same relationship holds for the population of persons 75 years of age and older.

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

Sutherland, G, Murray, A. & Iacono, T. Health Issues for Adults with Developmental Disability. *Research in Developmental Disabilities*, Vol 23, Issue 6, December 2002.

Figure 11

**Comparison Across DMR Regions  
Percent of Population 65 yrs and Older**



**Trends Over Time**

**Mortality Rate.** Both the total number of deaths and the overall statewide mortality rate have increased over the past two years as illustrated below in Figures 12 and 13. The number of overall deaths reported within DMR has risen from 322 in the year 2000 to 362 in 2001 to 405 during 2002. In a similar fashion, the overall mortality rate (no. deaths per thousand people served) has grown from 13.5 to 15.0 to 16.3 in the same three year time period.

Figure 12  
**3 Year Trend  
Number of Deaths  
2000 - 2002**

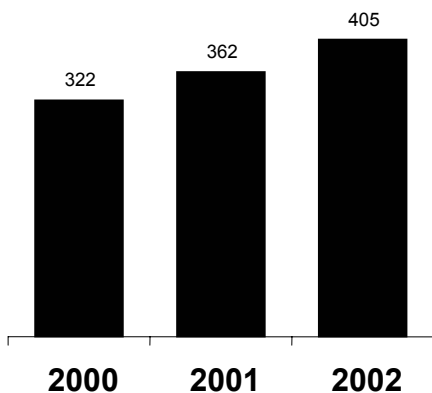
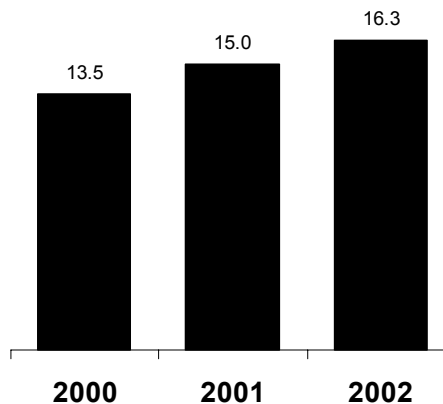
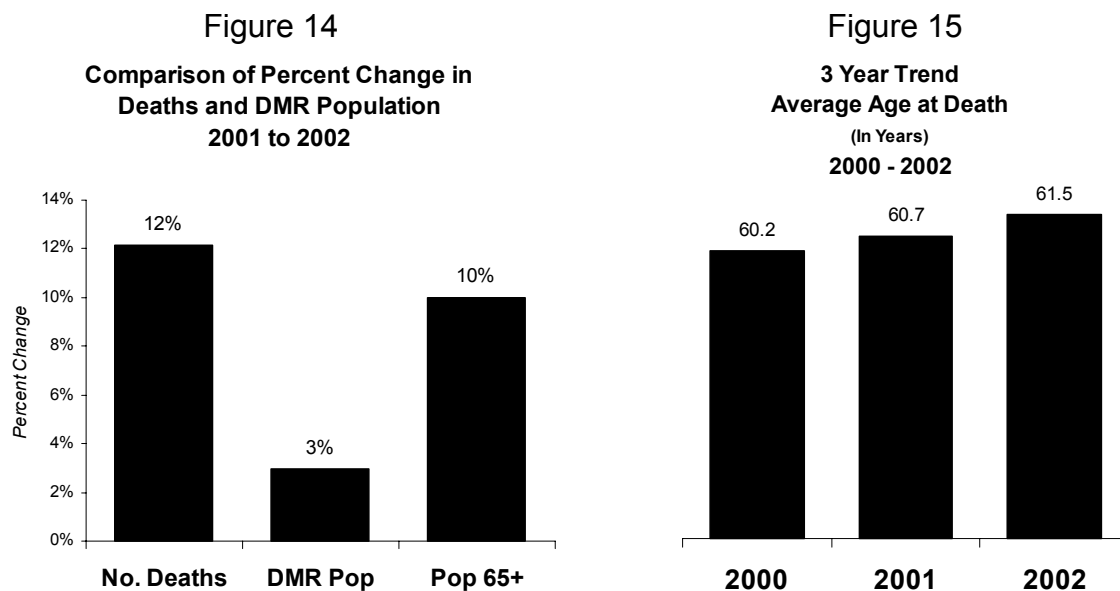


Figure 13  
**3 Year Trend  
Overall Mortality Rate  
(No. Deaths per Thousand)  
2000 - 2002**



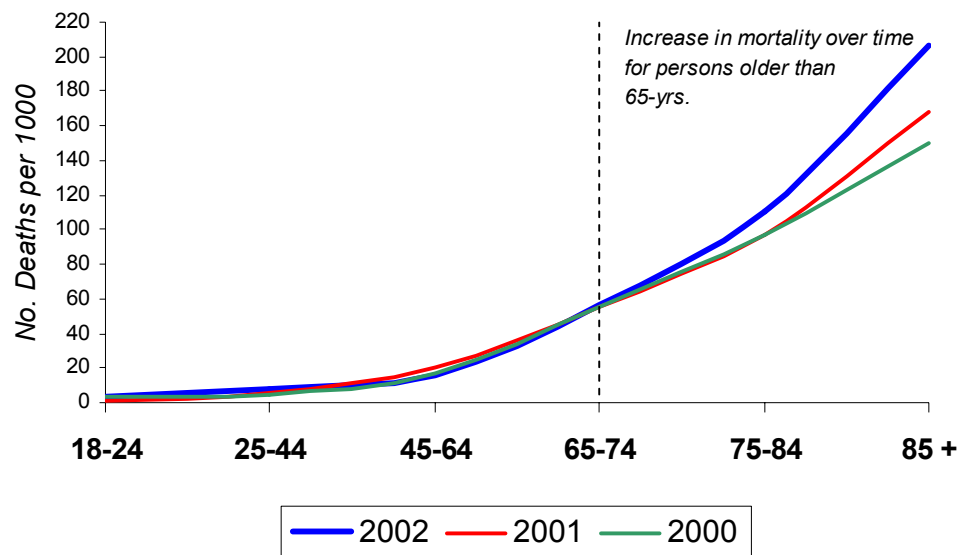
Figures 14 and 15 illustrate trends related to age and mortality. As can be seen in Figure 14, the percentage of change in the number of deaths is more closely associated with the change in the more *at risk* portion of the DMR population, *i.e.*, persons 65 years of age and older. Between 2001 and 2002 overall deaths increased by 12%. During the same time period, the number of individuals in the older age range grew by 10%, compared to only a 3% increase in the overall DMR population. In addition, as seen in Figure 15, the average age at death has slowly risen over the three year time period, suggesting that a larger proportion of individuals are dying at an older age.



**Age.** Figure 16 compares the mortality rate by age groups across 3 years. As can be seen, the mortality rate has remained relatively steady between 2000 and 2002 for persons under the age of 65-yrs. However, it shows an increase for older individuals, particularly those in the 75+ age range. This increase is most pronounced for 2002. As noted earlier in the report, the DMR population is aging, with this segment of the overall population served by DMR growing at the fastest rate, and, as noted above, may be contributing to the rising number of deaths and the increase in the average age at death.

Figure 16

### Mortality Rate by Age Group Comparison Across 3 Years 2000 - 2002



**Residential Setting.** Figure 17 compares the mortality rate by residential setting for 2002, 2001 and 2000. As can be seen, there are two potential trends that may require further study and analysis. First, the death rate appears to show a steady increase over time in Non-DMR programs<sup>8</sup>. This trend is present not only for the mortality rate, but also for the total number of deaths that have occurred in this type of residential setting. Table 5 provides additional information regarding this finding.

<sup>8</sup> Non-DMR residential settings served approximately 880 individuals in 2002. They represented programs that were not operated, funded or certified by DMR but served persons eligible for DMR services. They included residential schools, DMH and MCB group homes, adult foster care funded by DMA and DPH hospitals. This category also included a variety of other settings such as respite homes and temporary residences that are not included in the other categories.

Figure 17

### Mortality Rate by Residential Setting Adults Served by DMR 2002

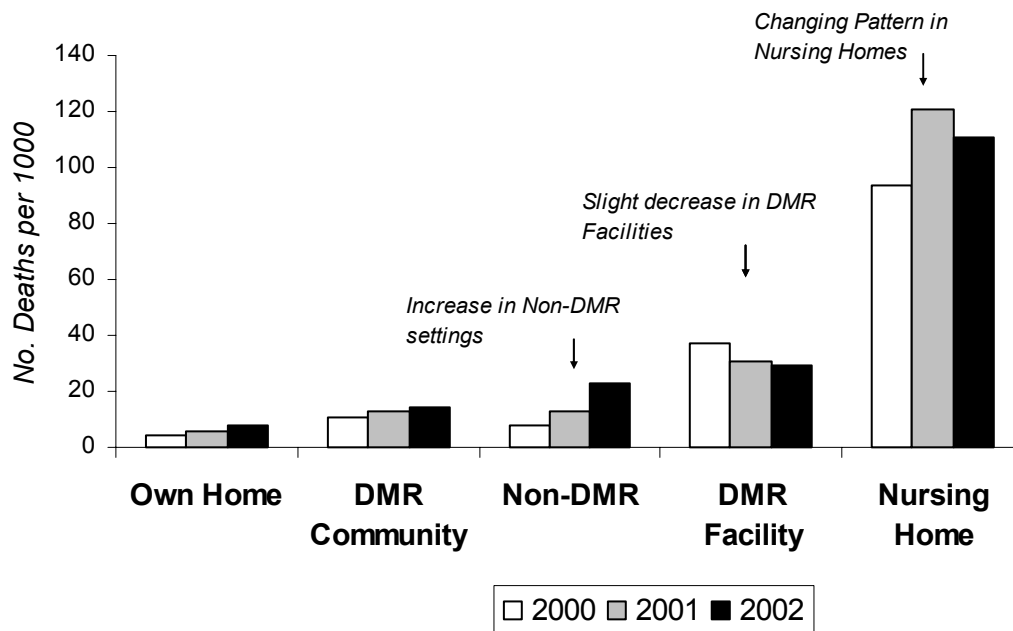


Table 5  
3 Year Trend for Non-DMR Residential Settings  
2000 – 2002

Variable	2000	2001	2002
No. People Served	643	792	882
No. Deaths	5	10	20
Death Rate (n/1000)	7.8	12.6	22.7
Ave Age at Death (yrs)	47	58	47

Second, the mortality rate within DMR Facilities<sup>9</sup> has shown a small but consistent decrease over the past two years. As can be seen in Table 6, this change has occurred while the population within DMR Facilities has been gradually reduced and the average age at death has increased.

<sup>9</sup> DMR Facilities include state-operated institutions funded by DMR that provides services as an intermediate care facility (ICF/MR).

Table 6  
3 Year Trend for DMR Facilities

Variable	2000	2001	2002
No. People Served	1260	1171	1163
No. Deaths	47	36	34
Death Rate (n/1000)	37.3	30.7	29.2
Ave Age at Death (yrs)	67.1	68.1	70.8

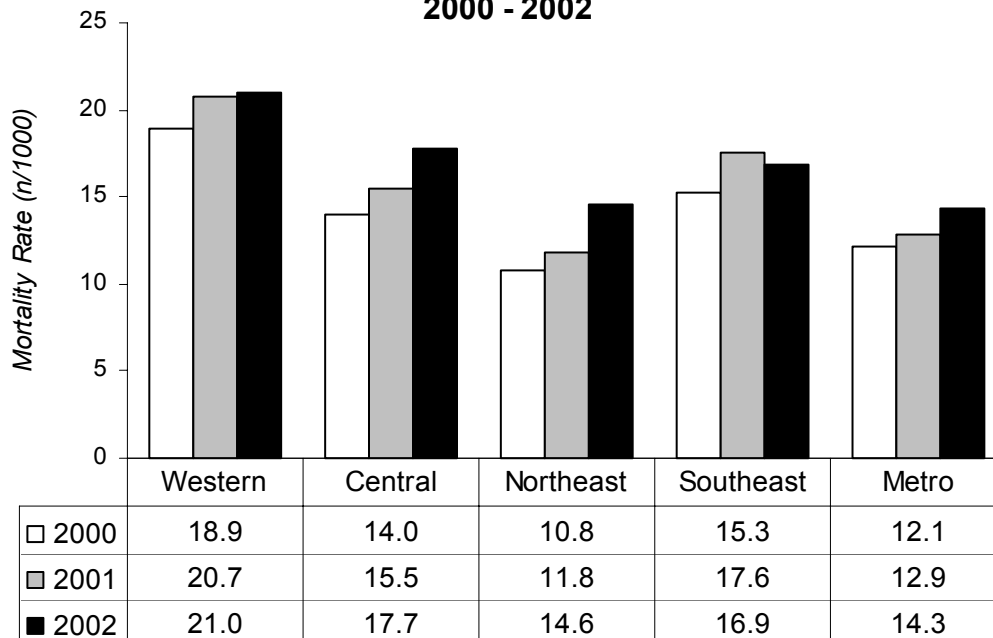
In contrast, death rates in long-term care facilities, including nursing homes and rest homes, have not followed a clear trend. Over the three year time period analyzed in this review the mortality rate for DMR consumers living in these settings has fluctuated, increasing in 2001 and then declining the following year (see Table 7 below). It should be noted that this population has also been decreasing and the average age at death has been increasing.

Table 7  
3 Year Trend for Nursing Homes

Variable	2000	2001	2002
No. People Served	1199	1028	1001
No. Deaths	112	124	111
Death Rate (n/1000)	93.4	120.6	110.9
Ave Age at Death (yrs)	66.0	66.9	71.8

**Regional Changes.** Figure 18 illustrates the 3 year trend in mortality rate across the five DMR regions. As can be seen, a slight increase is observed for four of the five regions. The Southeast region experienced a slight decrease in the mortality rate from 2001 to 2002.

Figure 18  
**Mortality Rate by Region**  
**3 Year Comparison**  
**2000 - 2002**



## 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.<sup>10</sup>

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 in both the current report and in the 2001 report. As with past reports, deaths due to pneumonia are distinguished into two types: pneumonia due to

<sup>10</sup> In some cases, additional reports were available to confirm the cause of death, such as toxicology or medical examiner reports. In three cases it was not possible to determine the cause of death from the information made available to DMR; in these cases a cause of "unknown" was assigned.

acute infection (Influenza and Pneumonia) and pneumonia due to aspiration of liquids and solids (Aspiration Pneumonia).

Table 8 lists the top ten causes of death in the DMR client population for 2002 and compares these with data from three previous years as well as state and national data. For the third year in a row, Heart Disease was the most common cause of death in the DMR client population, representing 21% of all deaths in 2002. Also consistent with previous years, Aspiration Pneumonia was the second leading cause at 12%. During 2002 septicemia and cancer were tied for the third ranking. It should be noted that cancer as a cause of death declined while septicemia increased (cancer deaths fell from 1.91 deaths per thousand in 2001 to 1.65 deaths per thousand in 2002 and deaths from septicemia grew from a rate of 1.12 per thousand in 2001 to 1.65 per thousand in 2002.)

Table 8  
Top 10 Leading Causes of Death

Rank	U.S. 2002	MA 2001 <sup>11</sup>	DMR 1999 <sup>12</sup>	DMR 2000	DMR 2001 <sup>13</sup>	DMR 2002
1	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease
2	Cancer	Cancer	Pneumonia	Pneumonia	Aspiration Pneumonia	Aspiration Pneumonia
3	Stroke	Stroke	Chronic Respiratory Disease	Chronic Respiratory Disease	Cancer	Cancer & Septicemia <sup>14</sup>
4	Chronic Respiratory Disease	Chronic Respiratory Disease	Cancer	Cancer	Septicemia	C-P Arrest/ Seizure <sup>15</sup>
5	Accidents	Influenza and Pneumonia	Septicemia	Septicemia	Alzheimer's	Alzheimer's
6	Diabetes	Alzheimer's	Gastro-Intestinal	Nephritis	Influenza and Pneumonia	Chronic Respiratory Disease
7	Influenza and Pneumonia	Unintentional Injuries	Nephritis	C-P Arrest/ Seizure <sup>15</sup>	Chronic Respiratory Disease	Influenza and Pneumonia
8	Alzheimer's	Diabetes	Alzheimer's	Alzheimer's	C-P Arrest/ Seizure <sup>15</sup>	Nephritis
9	Nephritis	Nephritis	Seizure-related	Stroke	Accidents	Stroke
10	Septicemia	Septicemia	Accidents	Gastro-intestinal	Stroke	Congenital Defects

<sup>11</sup> Most recent data available from Massachusetts Department of Public Health: *Massachusetts Deaths 2001* (May 2003)

<sup>12</sup> Causes of death for DMR consumers in 1999 and 2000 were based on information provided to DMR on the DMR Death Report and/or Mortality Review Form.

<sup>13</sup> Causes of death in 2001 were assigned by clinicians based on the Death Report, Mortality Review and in 25% of cases confirmed by Death Certificates.

<sup>14</sup> Septicemia and Cancer were tied for 3<sup>rd</sup> leading cause of death among DMR clients in 2002.

<sup>15</sup> Includes sudden deaths reported as cardio-pulmonary arrest whether or not seizure was present.

During 2002, the rates of influenza pneumonia and accidents also decreased from prior years. Influenza Pneumonia dropped to the eighth leading cause of death at a rate of 0.77 per thousand, down from 0.91 in 2001. Accidents decreased and fell completely out of the top ten ranking, dropping from 0.50 per thousand people in 2001 to 0.36 per thousand in 2002.

There was a relatively large increase in Cardiopulmonary Arrest and Seizures as the reported cause of death during 2002. These are deaths that could be termed “sudden” and may or may not involve seizures. The rate of these sudden deaths rose from 0.50 per thousand in 2001 to 1.5 per thousand in 2002. It should be noted that this increase could be partially determined by changes in reporting, with more conservative definitions becoming more widely used for Heart Disease. This would lead to more frequent classification of deaths due to sudden cardiopulmonary arrests rather than the result of a previously diagnosed condition.

Tables 9 and 10 compare causes of death by age-specific groupings for the DMR population in 2002 and the Massachusetts population in 2001.<sup>16</sup> As can be seen, the cause of death varies in the younger age groups. 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. It should be noted that the rate of accidents as a cause of death in the DMR population is extremely low across all age groups.

The causes of death in the 45-64 age group are more consistent with those found for the general population. In this group cancer and heart disease rank the highest, in a fashion that parallels the general population. However, within the 55-64 year old group Alzheimer's assumes the top ranking as a cause of death in the DMR population, but does not appear as a leading cause of death in the general population. Deaths due to Aspiration Pneumonia appear to be a more important cause of death in the DMR population than within the general population. Both cancer and stroke assume a lower ranking as a cause of death for DMR than for the general population of Massachusetts.

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<sup>16</sup> The most current data available for the Massachusetts population was for the year 2001.

Table 9  
**Cause of Death by Age Group for DMR  
2002**

Rank	Age range (years)							
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+
1	Not enough data to rank	CLRD*	Heart Disease	Cancer	Alzheimer's	Heart Disease	Heart Disease	Aspiration Pneumonia
2		Sepsis	Sepsis	Heart Disease	CP Arrest / Seizure	Cancer	Aspiration Pneumonia	Heart Disease
3		Congenital defects	Aspiration Pneumonia	CP Arrest / Seizure	Heart Disease	Aspiration Pneumonia	Cancer	CLRD*

\* CLRD = Chronic Lower Respiratory Disease

Table 10  
**Cause of Death by Age Group for Massachusetts Population  
2001**

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

\* CLRD = Chronic Lower Respiratory Disease

## **Mortality Review Process and Committee**

Clinical mortality reviews are completed by DMR for all deaths involving individuals (a) 18-yrs of age and older, (b) who receive a minimum of 15-hrs of residential support provided, funded, arranged or certified by DMR, c) who died in a day support funded or certified by DMR (d) died while participating in a day habilitation program, or (e) died during transportation funded or arranged by DMR. Those reviews are then submitted to either the Regional or Central Mortality Review Committee for analysis, confirmation of cause of death and follow-up if indicated. During 2002, 186 required reviews were completed and analyzed by the Regional and/or Central Mortality Review Committee, resulting in 100% compliance with DMR policy. Two additional cases that did not meet the criteria for review were also reviewed at the request of DMR.

## Investigations

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.<sup>17</sup>

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 2002 there were 29 deaths investigated by one or more of the agencies identified above, three of which also involved law enforcement investigation. Of these 29 cases, two were substantiated. In addition, there were 14 autopsy requests and eight autopsies actually performed during the year. In four cases the autopsy confirmed the reported cause of death. In the remaining cases the autopsy identified the cause of death (2), changed the cause (1), or was unable to provide any additional meaningful information (1). Table 11 provides information regarding the number of investigations, the agencies involved and the disposition in 2002 and prior years.<sup>18</sup> As can be seen, over time there has been a trend toward increased investigation and autopsies for the review and evaluation of deaths of persons served by DMR, although the relative percentage of investigations that actually result in a substantiation of abuse, neglect or omission has remained relatively low.

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<sup>17</sup> "Any death in which the Chief Medical Examiner takes responsibility for determining the cause and manner of death, to include all cases of suspected homicide, suicide, accidental drug overdose, or sudden and unexpected natural deaths."

<sup>18</sup> The information provided in Table 11 was provided by the Massachusetts DMR and did not undergo any independent validation by CDDER.

Table 11  
**Summary of Investigations and Autopsy Information**  
**1999 to 2002**

Type of Activity	1999	2000	2001	2002
DMR Investigation	7	5	5	14
DPPC Investigation	5	1	2	2
DPH Investigation	2	1	8	10
District Attorney/Law Enforcement Investigation	0	3	1	3
Other/dismitted	5	3	5	4
Total Investigations	19	13	21	33
No. Substantiations	0	0	1	2
No. Autopsies (Medical Examiner)	NA	0	7	8

## Benchmarks

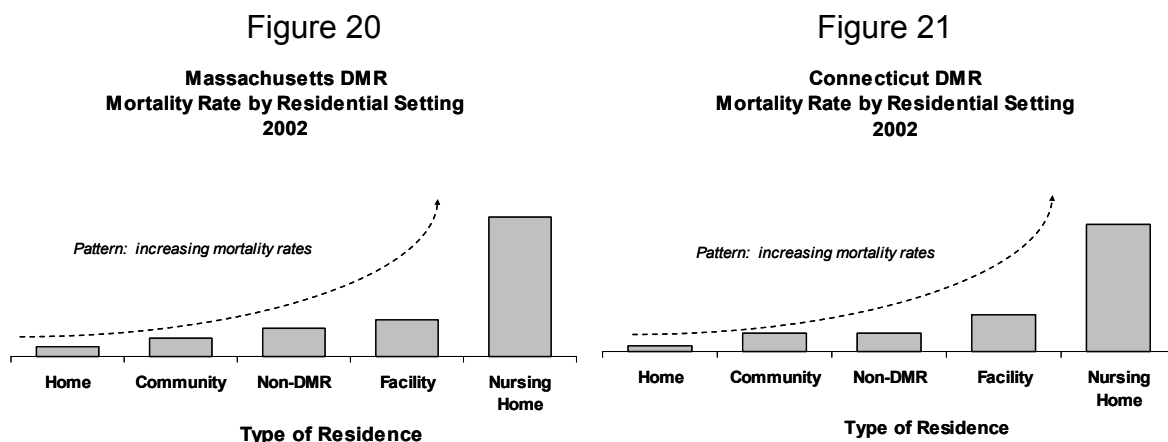
Due to the presence of significant disabilities and myriad co-morbid conditions within the population of individuals served by DMR extreme caution must be exercised when attempting to compare mortality rates and causes of death with other populations (*i.e.*, populations not composed primarily of persons with mental retardation). Unfortunately, very few state MR/DD systems publish comparable mortality reports; consequently there is a relative dearth of objective data and information that can be used as valid benchmarks for the Massachusetts DMR. In addition, data that is available from other states very often addresses different population groups (*e.g.*, the more expansive developmental disabilities population that includes individuals with a variety of disabilities, not just mental retardation) or the data is configured such that direct comparisons are not possible (*e.g.*, different age groupings, substantial differences in how the service system is structured or variations in service and residential support definitions).

Connecticut does operate a service and support system for persons with mental retardation that is relatively similar to that of Massachusetts. Connecticut also has published reports on mortality.<sup>19</sup> When comparing Massachusetts to Connecticut it is important to note that the population included in Connecticut's mortality reports includes children (low risk cohort) and therefore the overall

<sup>19</sup> *Health and Mortality Report*, Connecticut Department of Mental Retardation, Hartford, CT, November 2002.  
[www.dmr.state.ct.us](http://www.dmr.state.ct.us).

statewide mortality rates cannot be appropriately compared. In addition, the specific types of residential categories and age groupings used by Connecticut in its mortality reports are not identical to those contained in the Massachusetts reports. Nonetheless, a review of general patterns (not specific mortality rates) can provide some meaningful information against which the patterns and trends in the Massachusetts DMR can be potentially evaluated.

For example, the pattern of mortality by type of residential setting for these two state mental retardation systems is very similar. As can be seen below in Figures 20 and 21, in both state systems the mortality changes in the same fashion based upon the type of residence. However, and as noted above, the residential types are NOT identical. For example, Connecticut separates out supported living from group homes whereas Massachusetts combines data for all community based residential settings.<sup>20</sup> In addition, the types of settings included in the Non-DMR category vary state to state, but both do include residential schools and special care facilities. The closest approximation occurs for persons living in ICF/MR Facilities, where the mortality is almost identical (29.2 and 29.7 deaths per thousand for Massachusetts and Connecticut, respectively).



Similarities also exist with regard to the leading causes of death. As displayed in Table 9, heart-related conditions/events, pneumonias (including aspiration) and Alzheimer's disease were cited as the top three causes of death for many of the age categories. In the Connecticut DMR, heart disease, respiratory disease (including pneumonia) and nervous system disorders (including Alzheimer's) were ranked as the first, second and third leading causes of death in 2002.<sup>21</sup>

<sup>20</sup> While not exactly comparable, only data from the group home portion of the Connecticut community system is presented above since that cohort is the single largest component of the Massachusetts DMR Community grouping.

<sup>21</sup> Connecticut DMR did not break out causes by age groupings.

Therefore, available, but limited benchmarks suggest that some of the patterns and trends regarding mortality within the Massachusetts DMR are consistent with findings reported by the Connecticut DMR.

## **System Enhancements**

**Data collection and data integrity.** In 2002, DMR further improved upon the process of confirming the number of deaths by comparing the number of deaths reported through the electronic death reporting system to the deaths that were recorded in the DMR Consumer Registry System. A quarterly tracking process was initiated that enabled on-going reconciliation of the 2 databases to assure that all deaths were reported and documented as required by the established criteria.

In 2002, a monthly tracking system was initiated to assure that those cases requiring clinical reviews were completed in a timely fashion.

The revision of the clinical mortality review form resulted in more consistent and thorough information regarding health care history, events leading up to the death and supplementary documentation. This led to a more thorough clinical review process and better use of the time and expertise of the Central Mortality Review Committee.

DMR's current mortality review system is structured so that Regional Mortality Review Teams close uncomplicated death reports and only refer those cases with unresolved questions or that meet specific criteria that require further review by the Central Mortality Review Committee. Reports for all cases closed on a regional level are forwarded to the Central Committee.

In 2002 a process was initiated whereby the Director of Health Services in collaboration with the Central Mortality Review Committee confirmed the cause of death, based upon all the relevant information submitted.

**Service delivery system.** The strategic management workgroup continued its work on recommendations to enhance the quality and coordination of health care services to individuals with mental retardation. Data from the mortality review process, particularly with respect to causes of death, interventions and chronology informed much of the work of the group.

The Department initiated "Living Well", a quarterly newsletter focusing on prevention, early intervention and treatment of health care issues. The newsletter is mailed directly to every home in the DMR system. Topics selected for inclusion in the newsletter were selected from several of the key issues that emerged as a result of the mortality review process.

## **APPENDICES**

- Appendix A:       Methodology for Mortality Review and Analysis
- Appendix B:       Residential Codes and Definitions
- Appendix C:       Demographic Data

## Appendix A

### Methodology

The 2002 Mortality report analyzes information on all deaths occurring in calendar 2002 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, which according to DMR policy, must be completed within 24 hours of an individual's death. The 2002 Mortality Report includes statistics on all deaths of persons who died in calendar year 2002 whose Death Report was received by DMR by the end of January 2003. A total of 405 deaths were reported to have occurred between January 1, 2002 and December 31, 2002.

The data used to calculate death rates per 1000 by age group, region and type of residence were supplied by the DMR CRS of December 2002.<sup>22</sup> The CRS contains information on every person eligible for DMR supports, including those who may not be receiving DMR services currently. In addition DMR made Mortality Review forms and clinical notes available to CDDER for verification of information about the individuals subject to clinical mortality review.

DMR provided the following information for all 405 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
- Rolland class membership status
- Boulet class membership status

To determine the reliability of the mortality data that was provided to CDDER a comparison sample was drawn from the Department of Public Health. This was accomplished by creating a 10% stratified randomized sample of the 405 deaths reported by DMR. This sample was used to draw Death Certificates from the

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<sup>22</sup> 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 December 2002.

## *2002 Mortality Report*

DPH Office of Vital Statistics. The information from this sample was then compared across the DMR Death Report, DMR Mortality database and the DPH Death Certificate to review consistency between all three data sources.

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 =

$$\frac{(\text{Number of persons who died in calendar 2002} \times 1000)}{(\text{No. Persons in CRS in December 2002})}$$

Age-Specific Death Rate =

$$\frac{(\text{Number of deceased in an age category} \times 1000)}{(\text{No. Persons in CRS in age category})}$$

Appendix B

**Residential Codes and Definitions**

<b>DMR Community</b>	A DMR-funded residential program or state-operated group residence. (Residential codes 3153, 4156 and 4157)
<b>DMR Facility</b>	A state-operated institution funded by DMR that provides services as an intermediate care facility. (Residential codes 3200 and 4000)
<b>Nursing Home</b>	A long-term care facility providing nursing care. This category also includes rest homes. (Residential code 3000)
<b>Own Home</b>	Residents live at home with family members or independently in the community. (Residential codes 0000 and 9999)
<b>Non-DMR</b>	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 (includes any residential codes not cited above).

## Appendix C

## Demographic Data

## Age and regional distribution of the 2002 DMR Adult population

SEX	Age	Western	Central	Northeast	Southeast	Metro	Total
F	18-24 yr	215	343	312	323	462	1,655
M	18-24 yr	256	421	515	430	657	2,279
F	25-44 yr	563	713	989	998	1,617	4,880
M	25-44 yr	781	1,008	1,178	1,161	2,016	6,144
F	45-64 yr	466	644	602	719	1,138	3,569
M	45-64 yr	471	800	628	848	1,276	4,023
F	65-74 yr	91	151	102	141	200	685
M	65-74 yr	92	182	92	151	199	716
F	75-84 yr	55	90	50	103	98	396
M	75-84 yr	30	69	42	69	100	310
F	85+ yr	16	23	12	27	26	104
M	85+ yr	8	11	7	13	22	61
Total		3,044	4,455	4,529	4,983	7,811	24,822

## Age and Residential Distribution of the 2002 DMR Adult population

SEX	Age	DMR Funded Community	DMR Facility	Nursing / Rest Home	Own Home	Non-DMR	Total
F	18-24 yr	180	1	22	1,336	116	1,655
M	18-24 yr	253	0	25	1,817	184	2,279
F	25-44 yr	2,175	107	88	2,410	100	4,880
M	25-44 yr	2,991	148	85	2,808	112	6,144
F	45-64 yr	1,863	241	151	1,191	123	3,569
M	45-64 yr	2,133	404	118	1,262	106	4,023
F	65-74 yr	294	76	127	151	37	685
M	65-74 yr	325	101	81	168	41	716
F	75-84 yr	131	35	147	54	29	396
M	75-84 yr	116	33	84	52	25	310
F	85+ yr	29	6	51	12	6	104
M	85+ yr	16	11	22	9	3	61
Total		10,506	1,163	1,001	11,270	882	24,822