

Health and Mortality

ANNUAL REPORT

This is the third of a series of annual reports on trends and related information pertaining to the health and quality of care received by individuals with mental retardation served by the Connecticut State Department of Mental Retardation. Reports are scheduled for publication in the fall of each year and focus on an analysis of annual data, with a special emphasis on mortality trends and any significant or new initiatives pertaining to the management of consumer risk.

OCTOBER 2004

For the Period July 1, 2003 to June 30, 2004

Overview of DMR

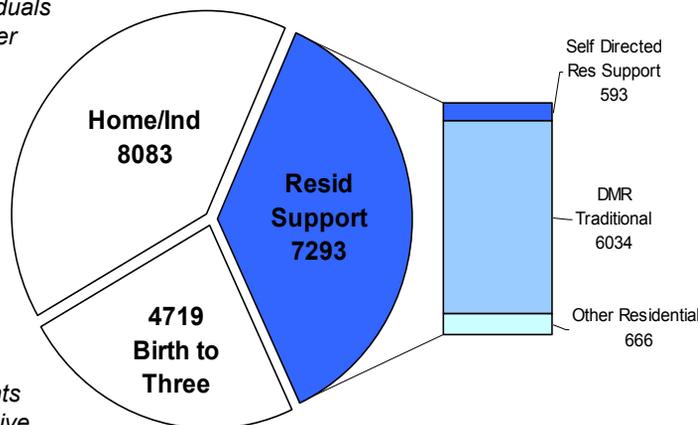
Mental retardation is a developmental disability that is present in about 1% of the Connecticut population. In order for a person to be eligible for DMR services they must have significant deficits in intellectual functioning and in adaptive behavior, both before the age of 18-yrs. As of June 30, 2004, 14,936 individuals with mental retardation were being supported by the department. DMR is also the lead agency for the Birth to Three System in Connecticut. This system serves infants and toddlers with developmental delays. Altogether, DMR assists approximately **20,000 individuals** and their families, providing a broad array of services and supports.

Figure 1

THE PEOPLE SERVED BY DMR FY 04

Over 8,000 individuals live at home, either independently or with their families.

About 5,000 infants and toddlers receive early intervention support through DMR's Birth to Three System.



Approximately 1/3 of the people served by DMR receive a funded residential support. Over 590 are managing these supports themselves, often with the assistance of their families. The majority of residential supports (over 6,000 people), however, are more traditional in nature, and include services provided in supported living, community living arrangements (group homes), community training homes and campus programs operated at regional centers and Southbury Training School. About 670 people are supported by other state or local government entities, including residential service in LTC facilities, DMHAS, and residential schools.

SECTION I

Mortality Trends

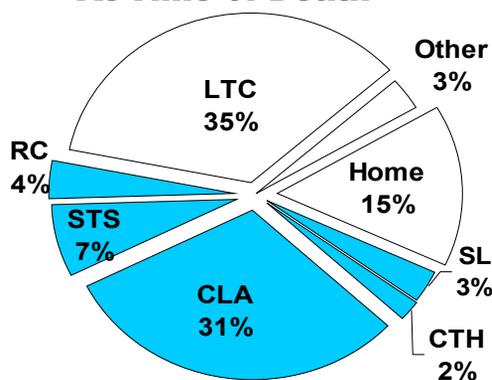
An important component of the risk management systems present within DMR involves the analysis and review of deaths to identify important patterns and trends that may help increase knowledge about risk factors and provide information to guide system enhancements. Consequently, DMR continues to collect information pertaining to the death of all individuals who are active clients of the department (n= 14,936). The following section provides a general description of the results of this analysis for Fiscal Year 2004 (July 2003 through June 2004).

Mortality and Residence

During the 12 month time period between July 1, 2003 and June 30, 2004 a total of **169** out of the 14,936 individuals served by DMR passed away. As can be seen in **Figure 2** (to the right) approximately half died while being served in a residential setting operated, funded or licensed by DMR (blue section of the pie). The other half were living at home (family home or independently), in a long-term care facility (e.g., nursing home), or other non-DMR operated or funded setting. This general pattern is consistent with that observed last fiscal year, although there was an increase in the relative percentage of deaths that occurred in CLAs, Community Training Homes and Long-Term Care facilities, regional centers, and STS. There was a slight decrease in the percentage of deaths that occurred in the Supported Living program and for individuals living at home.

The average **Death Rate**¹ is expressed as the number of deaths per 1000 people served. It compares the number of deaths to the number of persons served in each type of setting (no. deaths /population X1000), and continues to show a predictable pattern:

Figure 2
Type of Residential Support At Time of Death



LTC = Long Term Care, RC = regional center, STS = Southbury Training School, CLA = community living arrangement (group home), CTH = community training home, SL = supported living, Home = live independently or with family.

Figure 3

Mortality Rate by Where People Live
 No. Deaths per 1000 People
 FY 2004

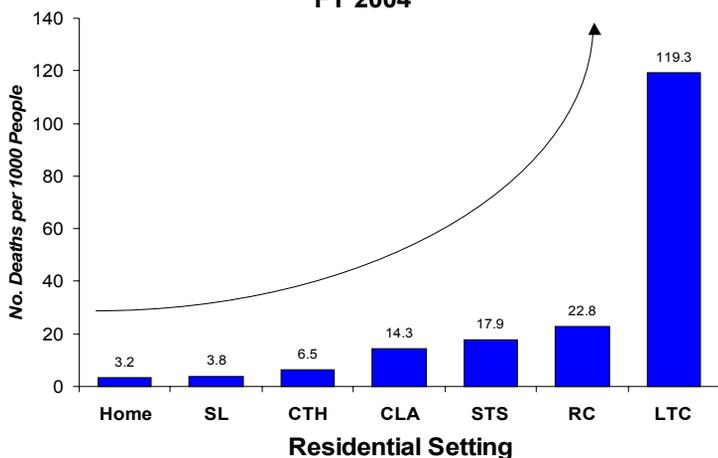


Figure 3 (graph on the left) shows the number of people who died for every 1000 people served in each type of residential setting. In general, the residential settings which provide less comprehensive care and supports (left side of Fig. 3) have a lower mortality rate than residential settings with increased levels of support.

For example, persons living in Long Term Care/Skilled Nursing Facilities along with those in Regional Centers and at Southbury Training School tend to be older and have significant disabilities and health care needs which require 24-hour nursing supervision.

¹ In this report we use the term "average death rate" to reflect what is more commonly referred to as the "crude" death rate in mortality and epidemiological research. It is computed by dividing the no. of deaths by the EOY population + no. deaths and multiplying by 1000 to generate a rate (no. per thousand).

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Figures 4 and 5 (two graphs to the right) compare the **number of deaths** within the population served by DMR and the **average death rate** for the most recent three (3) fiscal years. As can be seen, FY04 experienced an increase in the number of deaths and an increase in the mortality rate from FY03.

Figure 4

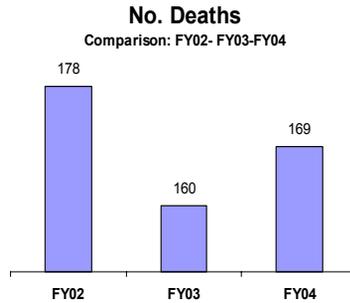


Figure 5

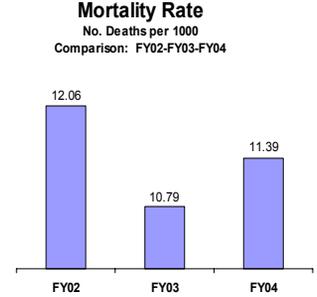


Figure 6
Mortality Rate by Where People Live
3 Year Trend

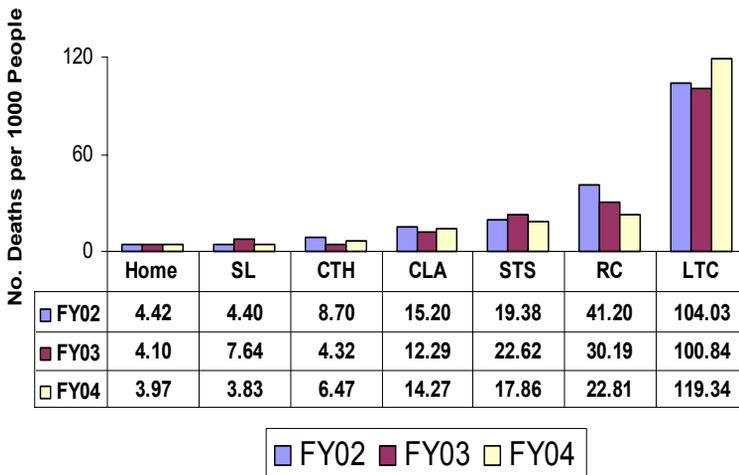


Figure 6 (graph to the left) compares the death rate (the number deaths per 1000 persons served) for the past three (3) fiscal years by type of residential setting.

In FY04, the death rate slightly decreased from FY03 and FY02 in campus settings (regional centers, STS), in supported living arrangements, and people living at home.

Caution must be exercised in reviewing this data since the actual number of deaths in each of these settings was relatively small. The differences across these time periods are therefore most likely not statistically significant.

Gender and Mortality

As can be seen in Table 1 and Figure 7 below, during Fiscal Year 2004 the percentage of deaths for men and women were almost identical (51% and 49%). This is a change from the gender relationship observed in FY03, when the death rate for men far surpassed the death rate for women.

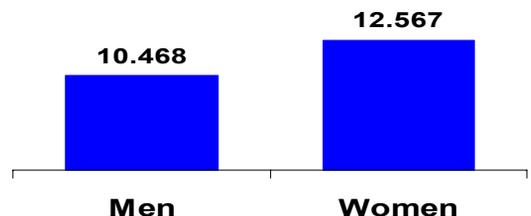
Table 1
FY04 Mortality Rate by Gender

GENDER	All Individuals served by DMR	No. Deaths	Percent of Deaths	Rate (No. Deaths per 1000)
Men	56%	87	51%	10.468
Women	44%	82	49%	12.567
Total	100%	169	100%	11.391

Figure 7

GENDER

No. Deaths per 1000
FY 2004



Age and Mortality

The relationship between **age** and **mortality** demonstrates the expected trend, with the mortality rate increasing as people served by DMR get older. As seen in **Figure 8** (to the right) in the **late 50's** there is a dramatic rise in the mortality rate. This finding is consistent with previous mortality data and is in line with the trends observed in the general population.

Figure 8

Mortality Rate by Age Range
No. Deaths per 1000 People Served
FY 2004

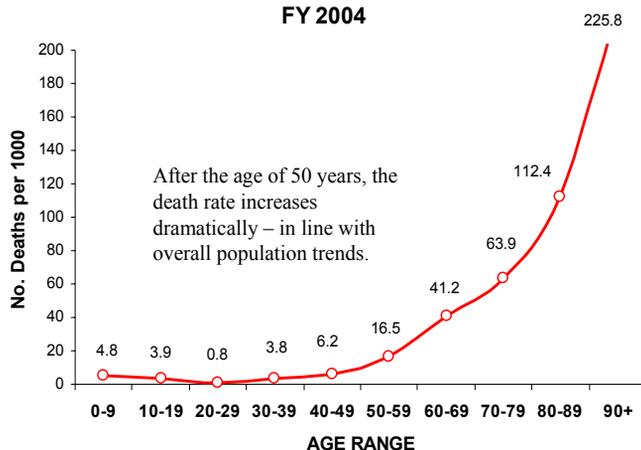


Figure 9

Mortality Rate by Age Range
Comparison of FY03 and FY04

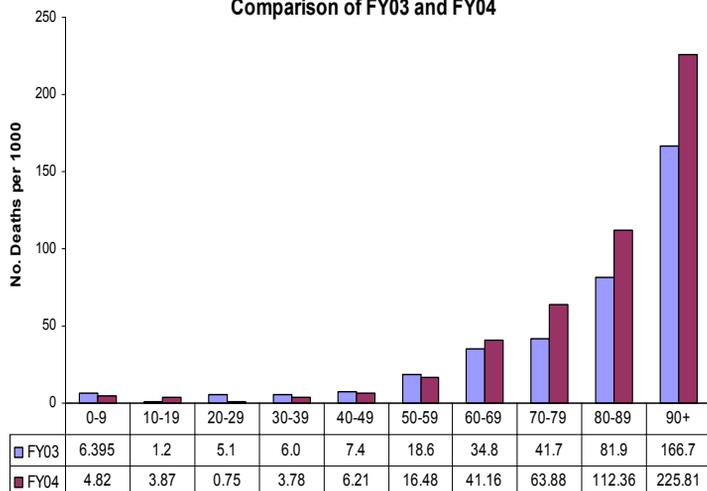
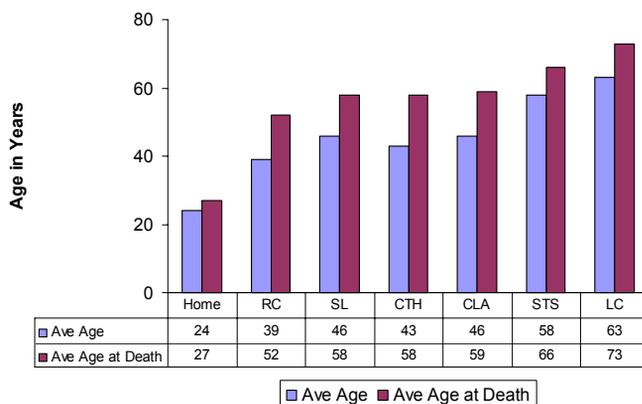


Figure 9 (to the left) compares the age trends for FY04 with those observed in FY03. As can be seen, the death rate in FY04 increased for people over the age of 60.

It should be noted that individuals living at home (especially those living with their family) are generally younger than the other persons served by DMR. The oldest group served by DMR are living in LTC facilities. As expected, they experience the highest death rate.

Figure 10

Comparison of Ave Age of Population and Average Age at Death by Residence
FY04



As can be seen in **Figure 10** (to the right) there is a relationship between the average age of the population living in each type of residential setting and their average age at death. The largest difference between the two variables exists in Supported Living, CLAs, CTH's, RC and STS where the average age of death is more than 10-yr's higher than the average age of the population living in those settings.

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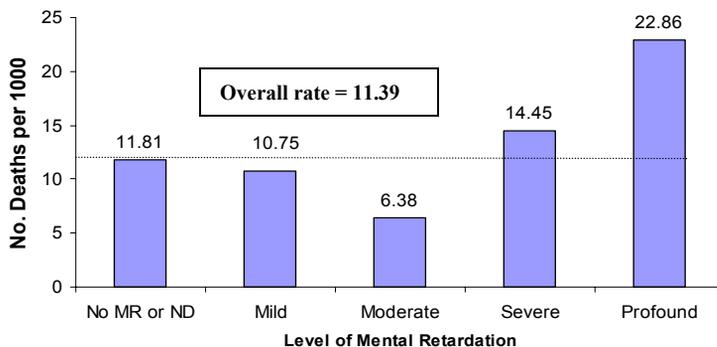
Level of Disability and Mortality

In addition to age and gender, **level of mental retardation** is another factor that affects life expectancy. Persons with more severe levels of disability typically have many co-morbid conditions/medical diagnoses which put them at greater risk. Risk factors such as epilepsy, cerebral palsy, mobility and eating impairments tend to have a significant effect on morbidity (illness) and mortality (risk of death).

As can be seen in **Figure 11** (to the right), the relationship between level of mental retardation and mortality shows the same trend as observed in FY03. Persons with the most significant levels of mental retardation (severe and profound) have a much higher rate of mortality. This trend is in line with expectations.

Figure 11

Mortality Rate by Level of Disability
for Persons Served by DMR
FY 2004



No MR (not mentally retarded) or ND (not determined) category Includes children receiving DMR services through the Birth-to-Three system who are too young to test for mental retardation and adults for whom the DMR has limited responsibility under the Federal Nursing Home Reform Act (OBRA 87) who do not have mental retardation. It may include some DMR clients who were DMR clients prior to Connecticut's current statutory definition of mental retardation.

SECTION II

DMR Mortality Review

IMPORTANT NOTE: During FY 2004 (July 1, 2003 to June 30, 2004) 102 cases were formally reviewed by DMR Mortality Review Committees. The information presented in the next section summarizes **ONLY** those deaths that were reviewed by the committees and therefore the data and data analysis will differ from the information discussed in section 1 (Mortality Trends).

DMR policy establishes formal mechanisms for the careful review of consumer deaths by local regional **Mortality Review Committees** and a central **Independent Mortality Review Board – (IMRB)**. This latter board, includes representatives from a number of outside agencies as well as a consultant physician. During FY04 a total of **102 cases** were reviewed by the central IMRB and/or these local committees. A total of 28 cases were referred by local committees to the IMRB for review, and an additional 17 cases of the remaining 74 closed at the local level were reviewed for quality assurance purposes by the IMRB. Therefore, **45 cases** received a full review by the IMRB.

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IMPORTANT FINDINGS/TRENDS IDENTIFIED AS A RESULT OF THE MORTALITY REVIEW PROCESS:

Community Hospice Support

Is routinely provided for persons served by DMR in all types of residential settings, including regional centers (RC), Southbury Training School (STS), community living arrangements (CLA), community training homes (CTH), and for individuals receiving supported living services when death is anticipated, usually due to the diagnosis or presence of a terminal illness.

During the FY04 review period, **hospice support** was provided to persons in **36 of the 102 cases** reviewed (**35%**), a slight decrease from the **36%** rate noted last fiscal year.

Autopsies

Autopsies are performed by the Office of the Chief Medical Examiner (OCME) for those deaths in which the OCME assumes jurisdiction or by private hospital pathology departments when DMR requests and the family consents to the autopsy.

Of the **102** deaths reviewed in FY04, **30** requests for autopsies were made. This represented **29%** of all deaths. **A total of 16 autopsies were performed in FY04.** This represented **16%** of all deaths.

Private hospital based pathologists performed eleven autopsies (**11%**). The OCME accepted jurisdiction and performed autopsies for the other five deaths (**5%**).

The autopsy rate decreased in FY04 to **16%** from the FY03 rate of **21%**. The autopsy rate for Connecticut DMR – **16%** exceeds the national average autopsy rate of **11.7%** reported in 2002 by the Columbus Organization following a survey of selected MR/DD state agencies across the country. The autopsy rate in Connecticut reflects the fact that the Department of Mental Retardation collaborates with the OCME and hospital based pathologists throughout the state.

Predictability

In **70%** of the cases reviewed (**n=71**), the death was anticipated and related to previously diagnosed conditions. In another **22%** of the cases (**n=22**) the individual's death was not anticipated, but was directly related to an existing diagnosis. In **9 % (n=9)** the death was not anticipated and not related to previously known or existing diseases or medical conditions. **Causes for these unanticipated deaths are as follows:**

Myocardial Infarction	-	4
Respiratory Failure	-	3
Seizure Disorder	-	1
Sub-dural hematoma	-	1

DNR

Do Not Resuscitate (DNR) orders are medically indicated when individuals are determined to be terminally ill (e.g., end stage cancer) or are in the final stages of an irreversible or incurable condition such as Alzheimer's Disease.

DMR has an established procedure which requires that specific criteria must be met along with a special review process for all DNR orders to be issued/implemented for persons who are placed and treated under the direction of the Commissioner.

Of the 102 cases reviewed in FY04, **75 people (or 73%)** had DNR orders in place at the time of death. Of these, **66 (65%)** were formally reviewed by DMR and met the established criteria. In the remaining **9 cases (9%)**, the individuals lived in a Long-term Care facility and DMR was not notified prior to the implementation of the DNR orders. **However, all of these cases would have met DMR criteria.** All facilities that did not comply with the departments policy were contacted and received additional training regarding requirements for notification and review of DNR orders by DMR.

Risk Factors

Mobility impairments and need for special assistance when eating are well known risk indicators that place individuals at significantly higher risk of morbidity and mortality. The mortality review process therefore looks carefully at the presence or absence of these two risk indicators.

Of the **102** individuals reviewed, **52** – or **50% were non-ambulatory**. **41**, or **41%, were not able to eat independently**. Further analysis indicates that **54** individuals (**54%**) had one of these risk indicators and (**41%**) had both indicators present.

As in FY03, the majority of individuals who died had one or more of the identified risk indicators present at the time of death.

Context: Manner of Death.

According to Connecticut State law, the Office of the Chief Medical Examiner (OCME) determines the cause of death and the manner of death: *natural, accident, suicide, homicide* or *undetermined*.

For those deaths in which the OCME does not assume jurisdiction, pronouncement is made by a private physician. In these cases the manner of death must be classified as natural. According to state statute any other manner of death must be determined by the OCME.

Of the 102 cases reviewed during FY04, **100, (97%) were classified as due to natural causes**. The other cases were determined to be the result of an accident. Two of these accidental deaths were classified as cardiopulmonary arrest secondary to aspiration during eating. The cause of death in the third case was a sub-dural hematoma, which resulted from an automobile accident.

Table 2
FY04 Manner of Death

Manner of Death	No.	Percent
<i>Natural</i>	99	97.1%
<i>Accident</i>	3	2.9%
<i>Homicide</i>	0	0%
<i>Suicide</i>	0	0%
<i>Undertermined</i>	0	0.0%
Total	102	100.0%

Neglect.

There were a total of **9** allegations of abuse and neglect that occurred within 6 months of death for the cases reviewed. Neglect was substantiated in **5** of these cases and another remains under investigation.

Case #1: involved care provided in a hospital emergency department

Case #2: involved the quality of care provided by private agency staff

Case #3: involved the care provided at a sub acute healthcare setting

Case #4: involved the documentation and medical records at a hospital

Case #5: involved the quality of care provided by private agency staff

In case #1&3 the Department of Public Health conducted investigations, which resulted in citations.

It is important to note that in no instance was the substantiated neglect directly contributory to the death.

SUMMARY OF FINDINGS **for deaths that were reviewed in FY04**

- **35%** of the people had **Hospice** support.
- **16%** had an **Autopsy**.
- **9%** of the deaths were **Not Anticipated** and not related to the existing diagnosis.
- **73%** had a **DNR** order. All but 5 met DMR criteria.
- **50%** of the people could **Not Walk** (i.e., were non-ambulatory).
- **41%** could **Not Eat** without assistance.
- **97%** of all the deaths reviewed were due to **Natural** causes.
- **3** death was classified as **Accidental**.
- **5** cases involved substantiated **Neglect** within 6-mo. of the death.

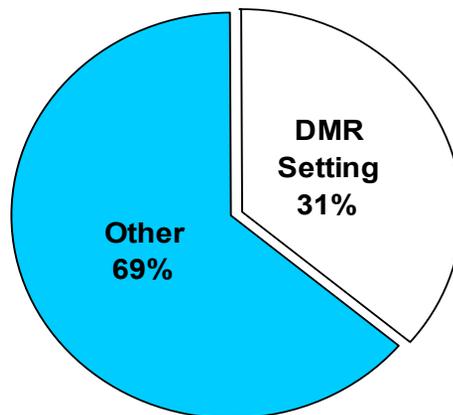
Location at Time of Death

As can be seen **Figure 12** (pie chart below), almost **70%** of all deaths reviewed by mortality review committees during FY04 occurred outside of a DMR-operated, licensed or funded residential setting, an increase in the proportion of persons dying outside of a DMR-setting compared to FY03. **Table 3** below shows both the number of individuals who died and the percentage by location.

Table 3
LOCATION AT TIME OF DEATH

LOCATION *	No.	Percent
<i>Hospital</i>	36	35%
<i>Hospital ER</i>	4	4%
<i>Hospice Facility</i>	3	3%
<i>Nursing Home</i>	27	26%
<i>Family Home</i>	0	0%
<i>Other Community</i>	0	0%
Subtotal Non-DMR	70	69%
<i>DMR Campus</i>	5	5%
<i>STS HCU</i>	5	5%
<i>CLA</i>	18	18%
<i>CTH</i>	1	1%
<i>Sup Lvng</i>	3	3%
Subtotal DMR	32	31%
Total	102	100%

Figure 12
Where People Died
FY 2004 Mortality Reviews



KEY: Location of Death

Hospital = Admission to the Hospital as an inpatient, death occurred in the hospital.

Hospital ER = Admitted to the Emergency Department, Died during ER treatment, was not admitted to the hospital.

All Other = Died at place of residence (Pronounced in the persons residence or other community location), For example a Day Program.

SECTION III

Leading Causes of Death

IMPORTANT NOTE: Seasonal variations in mortality require consistency when conducting comparative analyses and therefore the following data regarding the Leading Causes of Death for persons served by DMR will be provided based on a Calendar Year (2003) basis. This will allow more direct comparison to Connecticut and national mortality benchmarks developed for the general population.

A review of **Connecticut DMR data for Calendar Year 2003** illustrates that heart disease was the leading cause of death followed by pneumonia/lung diseases. More specifically, during 2003:

29%	<i>of deaths were due to</i>	Heart Disease	<i>including</i>	Acute MI (4%), CHF (6%), Dysrhythmias (4%), CAD (5%)
19%	<i>of deaths were due to</i>	Pneumonia/Lung Diseases	<i>including</i>	Aspiration Pneumonia (7%), Pneumonia (4%)
16%	<i>of deaths were due to</i>	Nervous System Diseases	<i>including</i>	Alzheimer's (11%), Epilepsy (4%)
15%	<i>of deaths were due to</i>	Cancer	<i>including</i>	Wide variety of primary origin sites
4%	<i>of deaths were due to</i>	Digestive System Diseases	<i>including</i>	Intestinal obstruction and liver disease
2%	<i>of deaths were due to</i>	Renal Failure		

For the remaining 15% of deaths there were a variety of causes including septicemia, diabetes mellitus, cerebral vascular disease, and aneurisms, none of which individually exceeded more than 1-2% of the deaths reviewed during 2003.

Table 4 (below) compares the leading causes of death for individuals served by DMR during Calendar Year 2003 with two benchmarks for the general population. As can be seen, heart disease is the no. 1 cause of death for all three reference groups. However, respiratory disorders were the 2nd leading cause of death within the DMR population, cancer was the 2nd leading cause of death within the general population.

This data demonstrates the continued role played by respiratory disorders and nervous system disorders as leading causes of death in persons with mental retardation when compared to the general population. This finding is most likely influenced by the risk indicators discussed earlier in this report. For example, the high prevalence of mobility and eating impairments, severe seizure disorders as well as the prevalence of increased risk for Alzheimer's Disease in persons with Down Syndrome.

Table 4
Leading Causes of Death

Rank	Connecticut DMR Calendar Year 2003	Connecticut Calendar Year 2002 (most recent available)	U.S. Calendar Year 2002
1	Heart Disease (29%)	Heart Disease	Heart Disease
2	Respiratory Disorders (19%)	Cancer	Cancer
3	Nervous System Disorders (16%)	Respiratory Disorders	Cerebrovascular Disease (incl Stroke)
4	Cancer (15%)	Accidents	Chronic Respiratory Diseases

It is noteworthy that the role of accidents appear to play less of a role as a cause of death in persons served by DMR than for the general population living in Connecticut.

As with other data presented in this report, caution must be exercised in reviewing this information due to the relatively small sample size (number of deaths). Differences that occur from year to year are therefore not likely to be statistically significant.