

Mortality ANNUAL REPORT

FEBRUARY 2007

This is the fourth of a series of annual reports on mortality 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 February 1 of each year and focus on an analysis of mortality data, with a special emphasis on mortality trends and any new initiatives pertaining to the management of individual risk.

**This report represents a review of the period between
July 1, 2004 to June 30, 2005**

The first part of the report **(SECTION I) MORTALITY TRENDS** includes demographic information on all deaths, some of which do not meet the specific DMR criteria for a formal mortality review by either the regional mortality review committees or state Independent Mortality Review Board (IMRB).

Part two of the report **(SECTION II) DMR MORTALITY REVIEW** includes information gleaned through the DMR clinical mortality review process.

Part three of the report **(SECTION III) LEADING CAUSES OF DEATH** includes national, state and DMR cause of death data and comparisons.

Part four of the report **(SECTION IV) BENCHMARKS** compares mortality data from past reports, CT DMR and MASS DMR and presents findings and trends identified through the mortality review process and review of other mortality data.

Overview of DMR

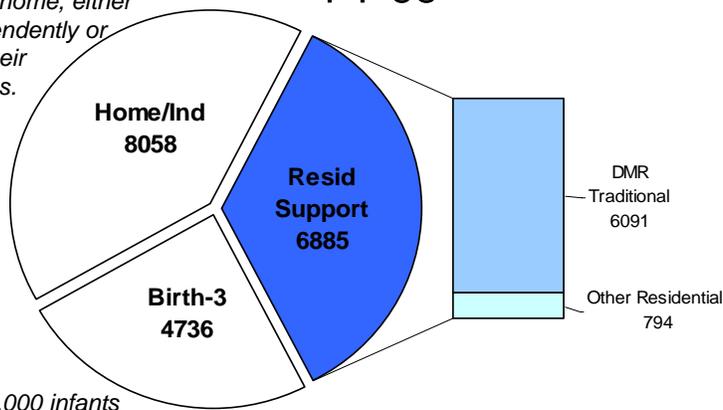
Mental retardation is a developmental disability that is present in about 1% of the Connecticut population. In order for a person to be eligible for DMR services they must have significant deficits in intellectual functioning and in adaptive behavior, both before the age of 18-yrs. As of June 30, 2005, **14,943** 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 05

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 1/2 of the people served by DMR receive a funded residential support. The majority of residential support services (over 6,000 people), are traditional in nature, with support services provided in supported living, community living arrangements (group homes), community training homes and campus programs operated at regional centers and Southbury Training School. Close to 800 people are supported by other state or local government entities, including residential services in skilled nursing facilities, DMHAS, DCF, DOC and residential schools. The majority of individuals served by the DMR system were male, white and living in a family home.

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= 14,943). The following section provides a general description of the results of this analysis for Fiscal Year 2005 (July 2004 through June 2005) and summarizes **all deaths (201)** reported to CT DMR.

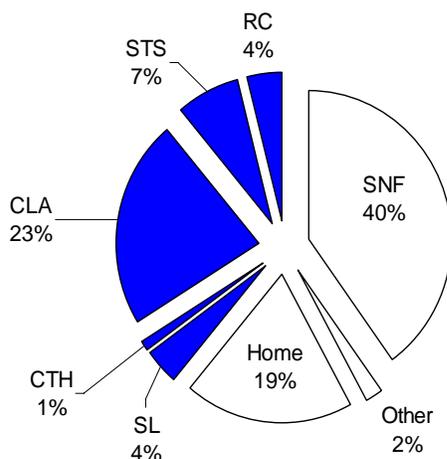
Mortality and Residence

During the 12 month time period between July 1, 2004 and June 30, 2005 a **total of 201** individuals served by DMR passed away **resulting in a mortality rate of 13.27**.

As can be seen in **Figure 2** (to the right) 39% died while being served in a residential setting operated, funded or licensed by DMR (blue section of the pie). 19% were living at home (family home or independently), and 42% resided in a skilled nursing facility (e.g., nursing home), or other non-DMR operated or funded setting.

For comparison purposes during FY 04 47% died in DMR residential settings: 35% resided in a SNF and 15% were living at home at the time of their death.

Figure 2
Residence at Time of Death



SNF=skilled nursing facility, 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 2005

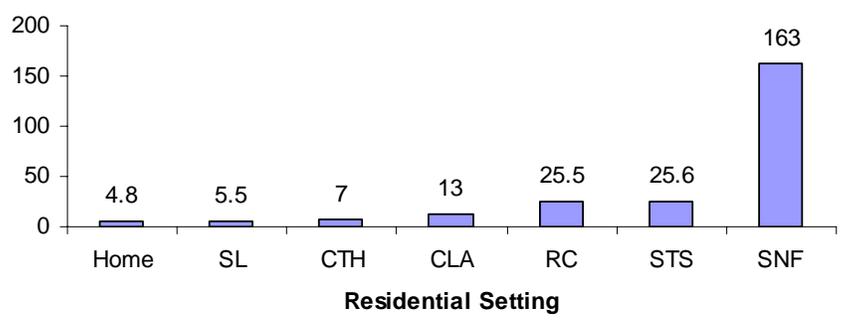


Figure 3 (graph on the left) shows the number of people who died for every 1000 people served in each type of residential setting. The average death rate¹ continues to show a predictable pattern. In general, the residential settings which provide less comprehensive direct medical care and supports (left side of Fig. 3) have a lower mortality rate than residential settings with increased levels of these supports. For example, individuals living in skilled nursing facilities, regional centers and at Southbury Training School tend to be older and have significant functional impairments and health care needs which require greater levels of supervision than individuals living in CLAs, supported living, independently or with their families. Most of the children served by DMR live at home with their families.

Where People Live	
Service Type	Number
FAM -	8097
CLA -	3612
SL -	1268
STS-	587
SNF-	491
CTH-	429
RC-	274
OTHER-	95

Figure 4

Number of Deaths by Where People Live

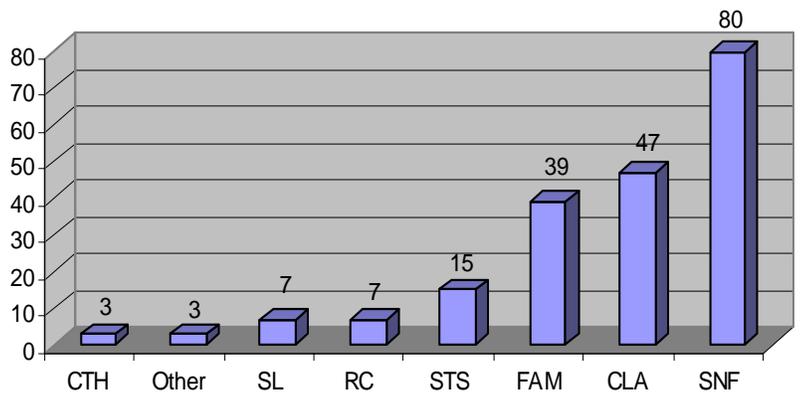


Figure 4 (above) depicts the actual number of deaths by where people live. It is interesting to note that the number of deaths that occurred on campus settings (RC and STS) when adjusted for population resulted in almost identical mortality rates (see Figure 3)

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).

Figure 5

**Mortality Rate by Where People Live
4 Year Trend**

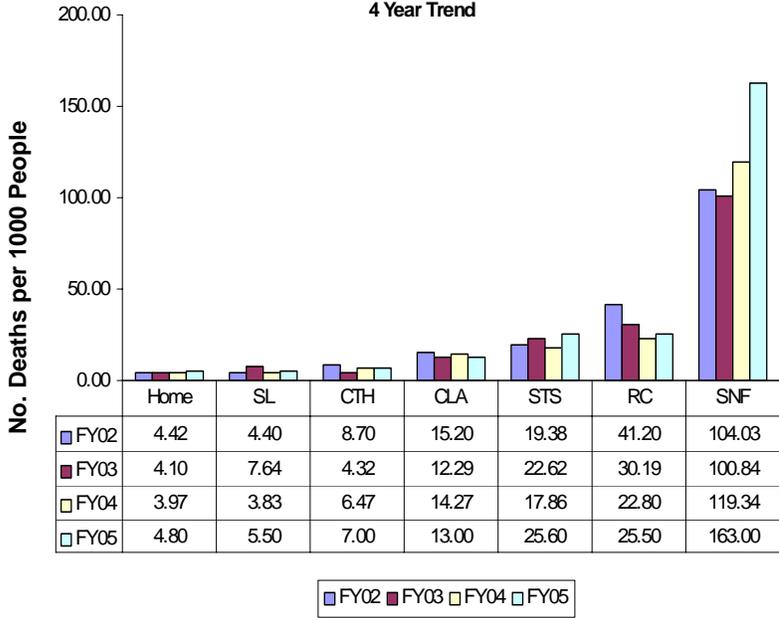


Figure 5 (graph to the left) compares the death rate (the number deaths per 1000 persons served) for the past four (4) fiscal years by type of residential setting.

Mortality data over the past four years indicate that mortality rates are consistently higher in skilled nursing facilities than other residential settings and mortality rates are lowest in family homes (see Fig 5).

Age and compromised health of the individuals living in these programs are most likely related to the increased mortality rate in skilled nursing facilities.

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

Figures 6 and 7 compare the **number of deaths** for FY 2001-2005 within the population served by DMR and the **average death rate** during these years. Over this 5 year period of time there has been only slight variations in the number of deaths and mortality rate with the mortality rate averaging 12/1000.

Figure 6

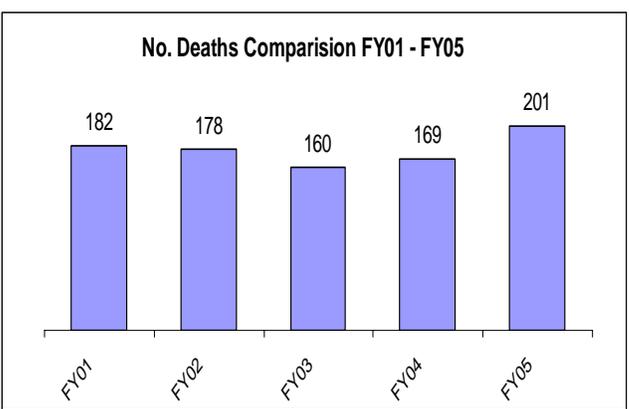
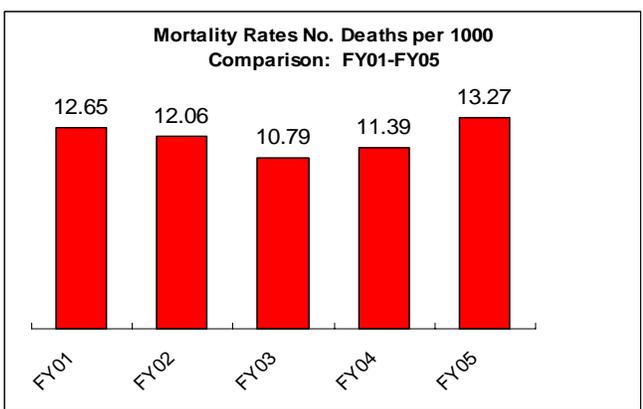


Figure 7



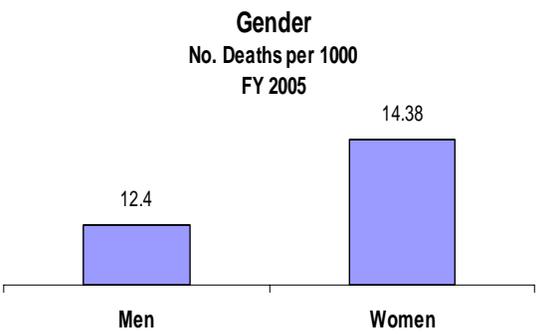
Mortality and Gender

As can be seen in **Table 1**, during Fiscal Year 05, more men died than women. However, as in FY 04 **women had a greater mortality rate 14.4 – than men 12.4**. This may be due to the fact that women in DMR tend to be older than the men. The percentage of men and women served by the CT DMR system was identical to last FY (56%men – 44% women). **For every woman served by DMR there were 1.2 men.**

Table 1

Mortality Rate by Gender				
GENDER	All Individuals Served by DMR	No. Deaths	Percentage of Deaths	Rate (No. Deaths Per 1000)
Men	56%	106	53%	12.40
Women	44%	95	47%	14.38
Total	100%	201	100%	13.27

Figure 8



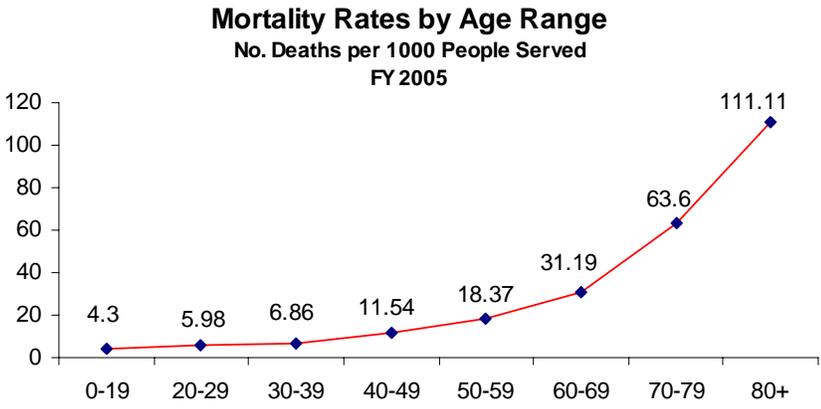
Mortality and Age

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 9** (to the right) by the middle of the fifth decade there is an increase in the mortality rate with a dramatic rise noted after the age of 65 years.

This finding is consistent with previous mortality data and is in line with the trends observed in the general population. The average age of death for people served by CT DMR has increased from 1991-2005.

Figure 9



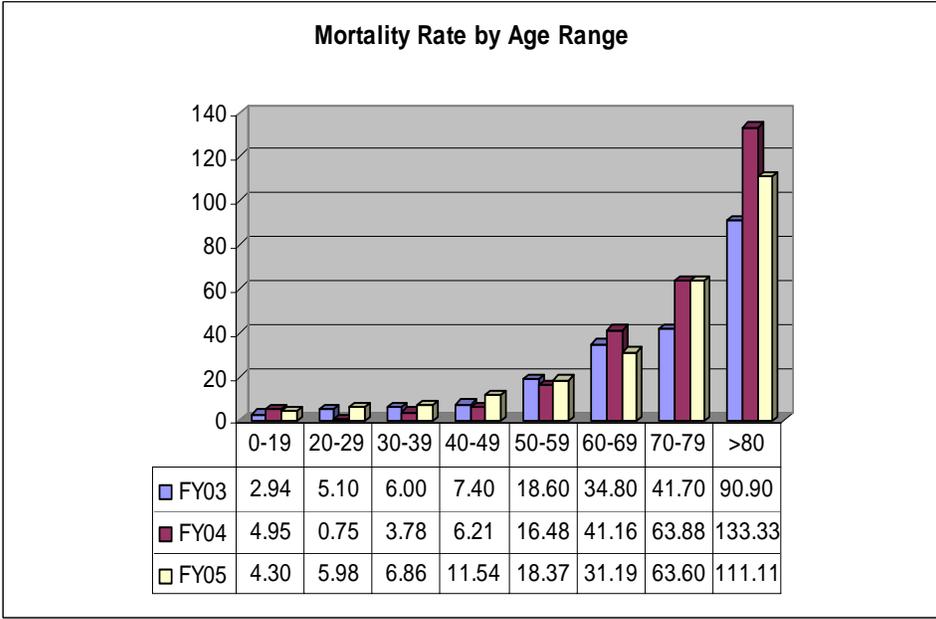
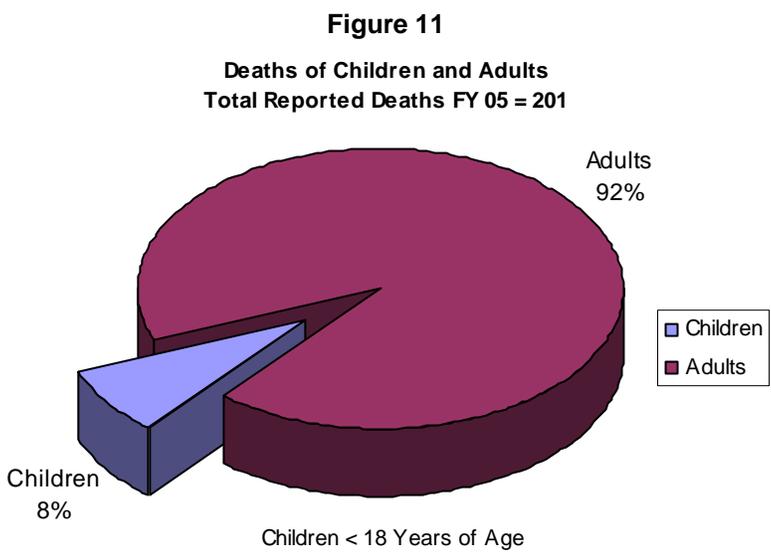


Figure 10 (above) illustrates mortality rate by age range.

The data over the past three FY's reveals a consistent pattern of increasing mortality rates with each successive decade of life.

As mentioned earlier the vast majority of children and younger individuals served by DMR live at home whereas the oldest group served by DMR are living in SNFs and as expected, they experience the highest death rate.



RELATIONSHIP BETWEEN MORTALITY AND COMPLEX HEALTH CONDITIONS

Factors which seem to affect life expectancy are age, gender, and the need for enhanced nursing medical supports to address complex health conditions

As expected individuals who require intensive (24 hour per day skilled nursing/medical supports) due to co-morbid conditions such as cerebral palsy, epilepsy, severe intellectual disability, mobility and/or eating dysfunction (leading to pulmonary disease) had a higher mortality rate than individuals who had fewer health concerns.

MEDICAL CONDITION REQUIRING	% OF ALL DEATHS	DEATH RATE
SKILLED NURSING/MED SUPPORTS:	50%	75.4
LESS INTENSIVE NURSING/MED SUPPORTS:	24%	30.0
MINIMAL NURSING/MED SUPPORTS	26%	5.2

As noted in the chart above the death rate for individuals requiring intensive skilled nursing and medical supports due to complex medical conditions had a mortality rate of (75.4) which far exceeded the death rate for individuals needing less intensive nursing /medical supports (30) and those requiring minimal to no nursing support (5.2) to address their health needs. Therefore, placement in the community or a facility were not the determining factor in the death rate, but rather the level of health supports needed for each individual due to their specific health related risk factors

SECTION II DMR Mortality Review

IMPORTANT NOTE: During FY 2005 (July 1, 2004 to June 30, 2005) 152 cases were formally reviewed by DMR Mortality Review Committees/Board. The information presented in this section summarizes ONLY THOSE DEATHS THAT WERE REVIEWED BY THE COMMITTEE/BOARD and therefore the data and data analysis will differ from the information discussed in Mortality Trends (Section I).

THE MORTALITY REVIEW PROCESS

Connecticut law (which comprises statutes and executive order) currently requires DMR to review the death of anyone for whom it has direct or oversight responsibility for medical care. The review must cover the events, overall care, quality of life issues, and medical care preceding the death to assure that a vigorous and objective evaluation and review of the circumstances surrounding untimely deaths takes place.

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The mortality review process is designed to identify issues and concerns that may have compromised the medical, health or overall care provided to individuals served by DMR and to trigger corrective action and reduce further risk.

Therefore, CT DMR has established a **two tier mortality review process** as part of its quality assurance system. A **regional mortality review committee** and a **statewide independent mortality review board (IMRB)**.

Mortality committee and Independent review board membership

Members of the regional mortality review committees are appointed by the regional or training school Director. Members of the Independent Mortality Review Board (IMRB) are appointed by the DMR Commissioner and include a State Medical Examiner, community based independent physician, representatives from the State Office of Protection and Advocacy, Department of Public Health and a private provider agency.

The criteria for regional mortality review are as follows:

- *The death of any individual for whom the department bears direct or oversight responsibility for medical care.*

The criteria for an IMRB mortality review are as follows:

- *Determined necessary by the regional mortality committee (medical or care concerns, post mortem examination or investigation of abuse/neglect etc.)*
- *Assume immediate jurisdiction and conduct an expedited review when determined necessary by the Commissioner or the OPA Director if it is likely that the death occurred because of abuse of neglect or on the request of the Director of Quality Assurance and/or the Director of Health and Clinical Services.*
- *Quality assurance mortality reviews are conducted for 10-15% of cases closed at the regional level*

The mortality review process seeks to address the following questions

- Was the death anticipated or unexpected?
- Could this death have been prevented?
- Are there systems issues identified in the course of the review?
- Are there case specific issues identified in the course of the review?
- What actions should DMR take to improve the health and safety of individuals?

In addition, the DMR death reporting procedure requires that all deaths are reported to a **Nurse Investigator (NI)** assigned to the DMR Division of Investigations who **conducts a Medical Desk Review** (an abbreviated mortality review) to determine the need for an immediate comprehensive review by the regional mortality committee or independent mortality review board or if an immediate investigation of the death is warranted

Options for the Nurse Investigator

If further review is indicated the NI will forward the Medical Desk Review based on preliminary record/documents to the DMR Director of Investigations and Director of Health Services and the Director of Health and Clinical Services

Refer to the abuse/neglect system if abuse of neglect is suspected according to DMR abuse/neglect policies and procedures

Refer for expedited regional or IMRB review if systems deficiencies are identified or suspected

Refer for routine mortality review as defined in DMR procedure

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

Community Hospice Support

State of the art palliative and hospice care provide end of life support, hope and comfort to individuals either in home or in a hospital setting. The concept of end of life planning including hospice care has been embraced by the CT DMR and is routinely requested and provided for individuals served by DMR in all settings, including regional centers, campus, community living arrangements, community training homes, supported living. Once again in FY 2005 the DMR system was able to serve people through the final stages of terminal illness in their homes.

- **hospice supports were provided for 52 individuals or 34% of individuals prior to their death.**
 - **Of the 91 deaths that were anticipated as a result of a known condition/diagnosis: 57% of these individuals received hospice support services prior to their death.**
- **Provision of hospice supports for FY 2005 (34%) compares favorably with last years 35%.**

Autopsies / Post mortem examinations

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.

The percentage of autopsies performed over the past 3 years has declined slightly as the number of sudden unexpected deaths has declined. The mortality review committees continue to encourage autopsies in cases of unexpected deaths to establish cause of death and for quality improvement. Of 152 deaths reviewed:

Total number of post mortem examinations performed:	20 (13%)
Number of post mortem examination performed by OCME:	9 (6%)
<i>Percentage of the post mortem examinations performed by OCME:</i>	<i>(45%)</i>

Once again the post mortem rate for CT DMR (13%) 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.

NUMBER OF AUTOPSIES (DMR)

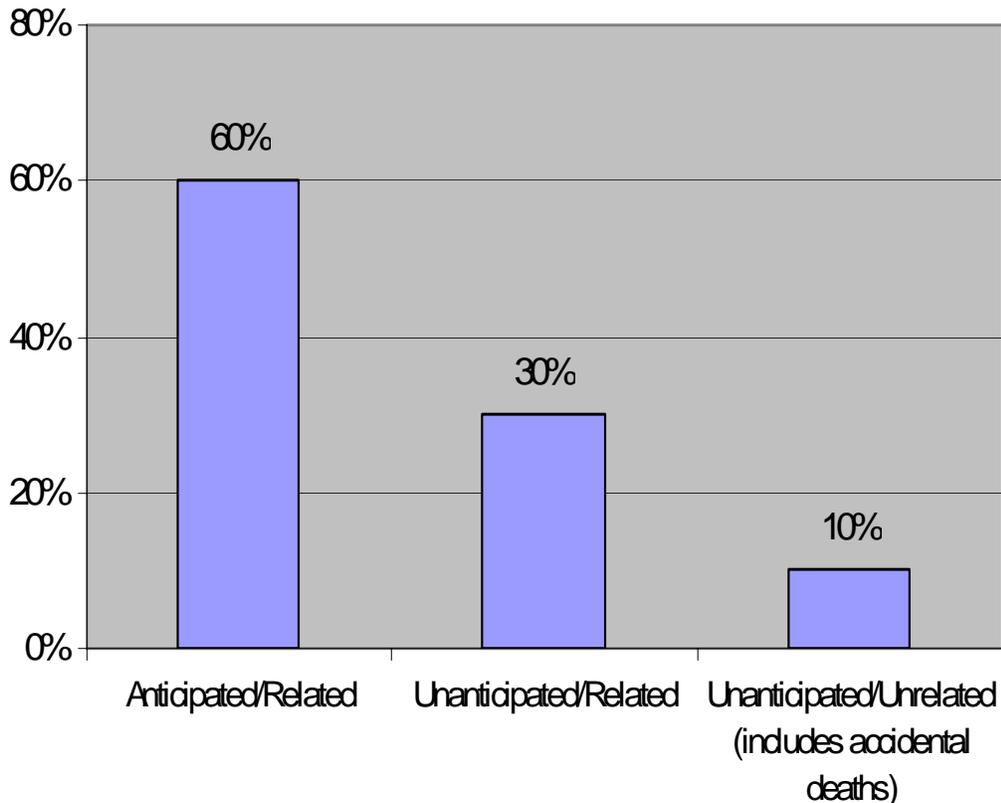
FY 03	28	21%
FY 04	16	16%
FY 05	20	13%

Predictability

Analysis of the mortality review data indicates a relationship between underlying /previously diagnosed medical conditions and a individual's death. In the majority of cases individuals died as a result of a known or previously diagnosed medical condition/disease (see Figure # 12 below)

Figure 12

Predictability of Death



- Death was anticipated and related to a preexisting diagnosis: 60%
- Death was unanticipated but related to a preexisting diagnosis: 30%
- Death was unanticipated and unrelated to a preexisting diagnosis: 10% (includes accidental deaths)
- Death was anticipated and related to a pre-existing diagnosis in 100% of SNF cases

This data reveals that in the vast majority of cases individuals underlying medical conditions were identified on routine or specialty medical examination(s)/consultations and that they were receiving appropriate treatment prior to death based on the findings of the regional mortality review committees and IMRB

Advanced age was the strongest predictor of death within the CT DMR system, second to mobility impairments. In general people living in SNFs have the greatest probability of death due to anticipated/related pre-existing conditions.

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DNR

Per Connecticut State Statute CT DMR has an established procedure which requires that **specific criteria must be met along with a special review process** for all withholding cardiopulmonary resuscitation (DNR) orders to be issued/implemented for persons who are placed and treated under the direction of the Commissioner of DMR.

Do Not Resuscitate (DNR) orders are medically indicated when an individual's attending physician and another physician (second opinion) have diagnosed that an individual is in the final stages of a terminal disease or condition or is permanently unconscious based upon appropriate tests and studies. This confirmation by the attending physicians that an individual has a terminal disease or condition is reviewed by DMR. For the 152 mortality cases reviewed:

104 cases had DNR orders in place - 68%
All 104 cases met the established DNR review criteria - 100%
95 cases DNR orders were formally reviewed by DMR - 91%

DMR was not notified prior to the implementation of the DNR orders in 9 cases or (9%). In all of these cases the individuals resided in skilled nursing facilities or were hospitalized. **However during the CT DMR mortality review process it was determined that all cases met established DMR criteria.** All facilities/hospitals that did not comply with the department's reporting policy were contacted and additional training regarding requirements for notification and review of DNR orders by DMR was provided.

Risk Factors

Mobility impairments, dysphagia and swallowing risks requiring the need for special assistance when eating are well known risk indicators that place individuals at a significantly higher risk of morbidity and mortality than the general population. Therefore during the mortality review process the presence or absence of these two risk indicators are carefully analyzed. As in past years the FY 2005 data revealed that there is a relationship between these risk factors and mortality rates (noted below).

Of the 152 individuals reviewed:

MORTALITY POPULATION

- **51% were not able to ambulate independently**
- **41% were not able to eat independently**
- * **Excludes Family Homes**

GENERAL DMR POPULATION

- 18% were not able to ambulate independently**
- 26% were not able to eat independently**
- * **Excludes Family Homes**

•37% or 56 individuals who died were non-ambulatory and required assistance for eating, therefore, required total care in the functional areas of eating and ambulation

As in FY 04 the majority of individuals who died had at least one of these identified risk factors present at the time of their death 53% (81)

It is well documented in the literature that the more compromised the individual's level of mobility, the greater the likelihood of death. This continues to be true based on the analysis of the mortality cases reviewed by the regional and statewide committees/board.*

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 152 cases reviewed during FY05, **145, (95%) were classified as due to natural causes.** The other cases were determined to be the result of an accident.

Table 2
FY05 Manner of Death

<i>Manner of Death</i>	No.	Percent
<i>Natural</i>	145	95%
<i>Accident</i>	7	5%
<i>Homicide</i>	0	0%
<i>Suicide</i>	0	0%
<i>Undetermined</i>	0	0%
<i>Total</i>	152	100%

The deaths determined by the OCME to be accidental in nature were a result of:

Choking (2) : asphyxia due to a foreign body
 Fall (2): subdural hematoma secondary to a fall, cervical fracture secondary to a fall
 Trauma (1): trauma during a medical procedure
 Burn (1): severe burn (scalding water)
 Drowning (1): drowning body of water

SUMMARY OF FINDINGS *for deaths that were reviewed in FY05*

- 34% of the people had Hospice support in place
- 13% had an Autopsy.
- 10% of the deaths were Not Anticipated and not related to an existing diagnosis.
- 68% had a DNR order. All met DMR criteria.
- 51% of the people could Not Walk independently (i.e. were non -ambulatory)
- 41% could Not Eat without assistance.
- 95% of all the deaths reviewed were due to Natural causes.
- 7 deaths were classified as Accidental.
- 13 cases of Neglect were substantiated.

Investigations

ABUSE/NEGLECT

DMR reports all client deaths to the Office of Protection and Advocacy for Persons with Disabilities (OPA) on a weekly basis. All such deaths are subject to review/investigation by the OPA Fatality Review Board (FRB). In addition, DMR is required to make a referral to the OPA Abuse Investigation Division within 24 hours of the determination by the Commissioner (of DMR) that there is "reasonable cause to suspect or believe that [a] death may be due to abuse or neglect." For persons for whom the DMR Commissioner has "direct or oversight responsibility for medical care", OPA has jurisdiction for investigating all abuse/neglect referrals involving death.

Of the 152 cases reviewed by the regional mortality review committees and/or the Independent Mortality Review Board 18 cases were investigated by either the OPA or the Department of Mental Retardation through its Investigations Division. Seventeen of these cases were investigated by OPA and one by DMR.

<u>Disposition of the 17 cases reviewed by OPA</u>	
<i>Neglect substantiated</i>	12
<i>Neglect not substantiated</i>	1
<i>Investigation remains open</i>	4

<u>Disposition of the cases reviewed by CT DMR</u>	
<i>Neglect substantiated</i>	1

In **five** of the thirteen cases where neglect was substantiated the neglect directly resulted in injuries/incidents (see below) which directly contributed to the individual's death.

- asphyxia due to airway obstruction,
- severe burn,
- drowning,
- trauma

The remaining eight (8) cases for which neglect was substantiated were based on the following causes: lack of supervision by direct care staff, lack of coordination of medical services, lack of adequate nursing or health care supports, delay in treatment, delay in recognition of changing health condition, lack of programmatic safeguards and insufficient monitoring of an individual's health care status. These findings may well have contributed to a **chain of events** leading to an individual's death.

Investigations

DPH

During FY 2005 twelve mortality cases were referred to the **State of Connecticut Department of Public Health** (DPH) by the regional committees or IMRB due to concerns regarding the quality of health services provided by either a practitioner or health care facility (hospital, SNF, clinic etc.) After investigation by the Facilities and Licensing Section of DPH several of the cases were also referred to the Practitioner and Licensing Section of DPH for investigation of licensed health care professionals.

Summary of DPH Investigations

The 12 cases referred to DPH generated 20 investigations

<p><u>Practitioner Division Investigations</u></p> <p>10</p> <p>Number of investigations closed by dismissal no violations of statutes – 9</p> <p>Number of investigations closed by dismissal- letter of violation initiated – 1</p>

<p><u>Facility Division Investigations</u></p> <p>10</p> <p>Number of investigations closed by dismissal due to a lack of evidence or no violations found –4</p> <p>Number of investigations closed citations, violations or multiple violations found –5 (ER care, coordination or care on discharge from inpatient hospitalization, inpatient hospital care)</p> <p>Number of investigations that remain open - 1</p>

Percentages of Mortality Cases Investigated by DPH

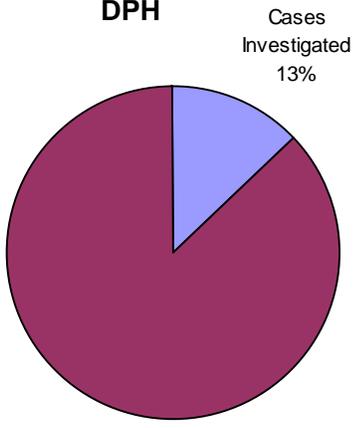
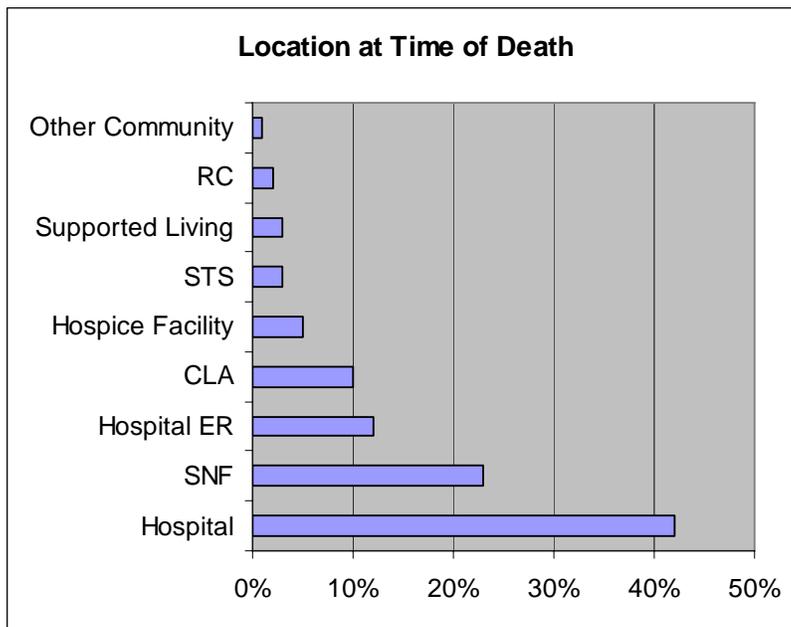


Figure 13

Location at Time of Death

Figure 14 below shows both the number of individuals who died and where death was pronounced

Figure 14



KEY: Location of Death

RC = Regional Center

STS = Training School

Hospital = Admission to the Hospital (inpatient admission) death occurred in the hospital.

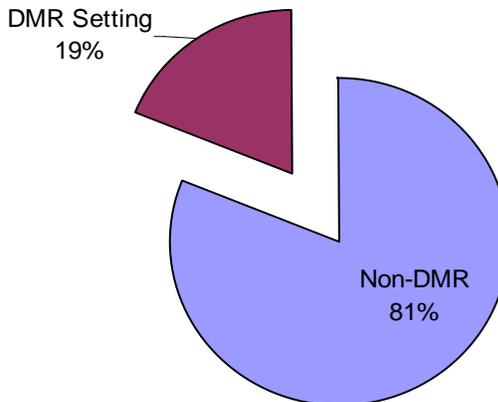
Hospital ER = Evaluated/treated in hospital ER, died in ER, while receiving treatment, not admitted to the hospital.

All Other = Died at home (death pronounced in the individual's home) or other community setting such as a day program.

Figure 15

As can be seen in Figure 15 to the right **81%** of all deaths reviewed by the mortality review committees during FY 05 occurred outside of a DMR operated, licensed or funded residential setting, an increase in the proportion of individuals dying outside of a DMR setting compared to FY 04 (69%)

**Where People Died
FY 2005 Mortality Reviews**



SECTION III

Leading Causes of Death

IMPORTANT NOTE: The following section presents information about the causes of death for individuals served by CT DMR. Similar to other mortality reports cause of death focuses on the underlying cause of death. 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 (2005) basis. This will allow more direct comparison to Connecticut and national mortality benchmarks developed for the general population.

A review of **Connecticut DMR leading causes of death data for Calendar Year 2005** illustrates that heart disease was the leading cause of death followed by respiratory diseases. More specifically, during 2005:

35% of deaths were due to	Heart Disease	<i>including</i>	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
24% of deaths were due to	Respiratory Disease	<i>including</i>	Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma
12% of deaths were due to	Pneumonia/Aspiration	<i>including</i>	Aspiration Pneumonia, Pneumonia
8% of deaths were due to	Cancer	<i>including</i>	Wide variety of primary origin sites
6% of deaths were due to	Sepsis	<i>including</i>	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
4% of deaths were due to	Accident/Trauma	<i>including</i>	Drowning, Falls, Asphyxia, Choking
4% of deaths were due to	CVA/Stroke	<i>including</i>	Intercerebral Hemorrhage
3% of deaths were due to	Nervous System Disorders	<i>including</i>	Alzheimers, Encephalopathy, Epilepsy
1% of deaths were due to	Digestive Disorders	<i>including</i>	Intestinal Obstruction, Liver Disease
>1% of deaths were due to	Renal/Kidney Disorders	<i>including</i>	Renal Failure

For the remaining 3% of deaths there were a variety of causes or undetermined none of which individually exceeded more than 1-2% of the deaths reviewed during 2005.

As in past years heart disease due to various cardiac diagnoses continued to be the leading cause of death for individuals in the CT DMR system. The percentage of individuals who died as a result of heart disease this year (35%) was identical to last years data. Respiratory disease as a cause of death increased 41% from last year(2004) while deaths due to pneumonia and aspiration pneumonia decreased slightly.

Cancer replaced sepsis as the fourth leading cause of death. However, the continued presence of sepsis as a prominent cause of death resulting from a variety of causes demands further scrutiny and future investigation to determine the causative factors leading to sepsis which may be preventable. In addition the incidence of deaths associated with aspiration pneumonia warrants further investigation.

It is *noteworthy* that although accidents as a cause of death increased from 2% to 4% **accidental deaths appear to play less of a role** as a cause of death in individuals supported by DMR than for the general population living in Connecticut (4.5%). Accidental deaths are the fourth leading cause of death in CT, but only the sixth leading cause for CT DMR.

Causes of death were taken from death certificates, however in selected cases the underlying cause of death was amended based on the recommendations of the IMRB after completion of the mortality review process.

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 statistically significant.

The table below compares the top four leading causes of death for individuals served by CT DMR from previous years with three benchmarks for the general population from state and national data. As can be seen, heart disease is the no. 1 cause of death for all three reference groups with CT DMR reporting the greatest number of cardiac related deaths. As reported last year respiratory disorders were the 2nd leading cause of death within the CT DMR population, while for all other reference groups cancer was the 2nd leading cause of death.

Table 3
Comparison Leading Causes of Death

Rank	U.S. 2003	CT 2003 (State)	MA 2003 (State)	CT DMR 2003	CT DMR 2004	CT DMR 2005	MA DMR 2003	MA DMR 2004
1	Heart Disease 28 %	Heart Disease 28%	Heart Disease 26%	Heart Disease 29%	Heart Disease 35%	Heart Disease 35%	Heart Disease 22.3%	Heart Disease 18.5%
2	Cancer 23%	Cancer 24%	Cancer 24%	Pneumonia/ Aspiration 19%	Respiratory Disease 17%	Respiratory Disease 24%	Cancer 13.5%	Cancer 12.5%
3	Stroke 6%	Stroke 6%	Stroke 6%	Nervous System Diseases* 16%	Pneumonia/ Aspiration 14%	Pneumonia/ Aspiration 12%	Pneumonia/ Aspiration 12.3%	Aspiration Pneumonia 11.2%
4	Respiratory Disease 5%	Respiratory Disease 5%	Respiratory Disease 4.9%	Cancer 15%	Sepsis 6%	Cancer 8%	Sepsis 9%	Influenza and Pneumonia 10.9%
5	Accidents 4.5%	Accidents 4%	Influenza and Pneumonia 3.6%	Digestive System Diseases 4%	Cancer 6%	Sepsis 5.6%	CP arrest/ Seizure 7.2%	Alzheimer's 7.5%

* Nervous System – includes Alzheimer's Disease, Epilepsy, and Other

A review of the data from CT DMR and MASS DMR continues to suggest that the leading causes of death for individuals with mental retardation/developmental disabilities is different than for the general population. This data demonstrates the continued role played by respiratory disorders, pneumonia and pneumonia associated with aspiration as a major causes of death for people with MR/DD when compared to the general population. This finding is most likely influenced by the risk indicators discussed earlier in this report and the prevalence of mobility and eating impairments and the significant risk of aspiration pneumonia secondary to Alzheimer's disease in persons with Down Syndrome.

The IMRB closely tracks all cases related to choking and aspiration in order to identify additional training needs. The CT DMR has developed comprehensive tools and protocols to address dysphagia and swallowing risks that require assessment by allied health professionals (OTR/SLP).

SUMMARY

QUALITY OF CARE ISSUES FINDINGS AND TRENDS

Professional Nursing Care and Coordination

In the majority of cases reviewed the need for skilled nursing services was accurately identified by the interdisciplinary team and appropriate nursing supports were provided.

The IMRB noted the following concerns regarding nursing support services in a limited number of cases

- Scope of nursing practice – Licensed practical nurses practiced outside of their scope of practice as defined by the state of Connecticut Nurse Practice Act

Through various regional systemic and individual training initiatives the department has reinforced the nursing practice standards required by state statute (Nurse Practice Act)(supervision of an LPN by a registered nurse)

- In general there is a relationship between enhanced registered nursing supports for medically fragile individuals and improved the coordination of care and competency of non-licensed staff.
- Orientation and comprehensive training for licensed nurses practicing in the field of developmental disabilities/MR is essential due to the dearth of registered nurses trained in this special area of nursing practice.

Notification /Communication

*In all cases reviewed residential service providers have achieved best practice and statutory requirements by establishing nursing on call systems**

- In a few cases residential provider agencies internal nursing on call procedure resulted in a delay in treatment or nursing assessment.
- In some cases the registered nurses and/or primary care physicians were not immediately notified of an individual's signs and symptoms of illness which resulted in a delay in evaluation/treatment (e.g. diagnostic testing) which may have contributed to the individual's death.
- Case reviews revealed that in almost every case there was ongoing communication between primary care physicians and specialty physicians
- When individual's require ongoing health care monitoring residential and day service providers need to establish a system to ensure the continuity of care between programs

Placement of individuals into skilled nursing facilities

- Prior to their death several individuals who could have been supported in at home were permanently transferred to a skilled nursing facility.

* A twenty four hour nursing on call system is required by the State Of Connecticut Board of Examiners for Nursing and the CT State Nursing Practice Act

➤ **This summary is based on the 152 cases reviewed by the regional mortality review committees and the 78 cases reviewed**

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Health care planning/ coordination of care

- In some cases the mortality review committees/board found that referrals for specialty medical evaluations were not initiated or followed up on, because a specific staff person was not assigned to assume the responsibility to ensure that medical/health recommendations were completed.

Inpatient hospital care

- In all of the cases reviewed inpatient hospital care and services were appropriate although the quality of care provided to persons with special needs was not always optimal due to the hospital staff's limited experience in caring for individual's with special needs.
- The knowledge base of medical, nursing and ancillary support staff regarding the special needs of individuals with MR/DD revealed a deficit in their professional education and training.
- There were several cases of hospital acquired infections

Emergency department services

- In several cases ED medical staff did not fully evaluate or accurately diagnose an individual's medical condition due to their lack of knowledge/expertise in treating individuals with MR/DD
- It is evident that some medical practitioners have difficulty in assessing/diagnosing MR/DD individuals who are dually diagnosed or have challenging behaviors.
- Direct care staff do not always convey significant clinical information to ED medical practitioners
- Emergency Department's may need to develop additional criteria/protocols for evaluating individual's with MR/DD who are not able to communicate symptoms of illness.

Hospital discharge planning/coordination

- Several deaths revealed that premature discharge and the lack of coordination/planning during the hospital discharge process might have contributed to morbidity or mortality.

For example

- confusing discharge orders written by the practitioner
- lack of coordination of support services in the individual's residence post discharge
- lack of a nursing assessment pre-discharge or in the home post-discharge
- premature discharge
- insufficient training pre- discharge at the home and/or inadequate supervision at home post discharge

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Accidental death

Accidents, which directly contributed to an individual's death, were the result of brief periods of inattention or poor judgment on the part of staff or a failure on the part of staff responsible for supervising the individual to follow prescribed programs. The accidental deaths reviewed were not due to a failure to identify risk factors or the absence of a plan/program in place to ensure the individual's health and safety.

Documentation (professional/non-professional staff)

- Documentation submitted by professional, direct care residential and day services staff in most cases verifies the ongoing monitoring and assessment of identified medical/health care concerns.
- Critical health information/documentation for individual's who live independently with less intensive support services is not always in place.
- Medical information (allergies, diagnoses, health and risk factors) are consistently documented.
- More comprehensive documentation standards for direct care staff need to be established for noting signs symptoms of illness or a change in a individual's condition.

End of Life planning and care

- Where appropriate end of life planning and support services were provided prior to death with the individual's team involved in the planning process.
- Documentation regarding end of life planning and with holding of cardiopulmonary resuscitation (DNR orders) continues to be excellent.

Timeliness of death reporting/investigations

- Deaths have been reported and investigations initiated per department policy

Medication Administration

- Non-licensed certified personnel administer medications for the majority of individual's (>6,000) residing in DMR funded and operated residential and day services.
- During FY 05 as in previous years no mortalities have been associated with the administration of medication by licensed or non-licensed certified personnel or as a result of errors in the administration of medication. This is commendable given the number of medications administered by licensed and non licensed certified staff in the private and public sector and may be due in part to the CT DMR's comprehensive medication certification program which requires that licensed registered nurse's manage and supervise medication administration by certified non-licensed personnel.

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Post mortem examinations

- Post mortem examinations by the CT OCME and private pathologists have been valuable in determining or confirming the cause and manner of death.
- Post mortem examinations were instrumental in diagnosing previously unknown conditions

Training

- As a result of the mortality review process and findings the department has instituted numerous training initiatives for professional clinicians and direct service staff and developed best practice standards to ensure the health and safety of individuals served by the CT DMR service system

General medical /health care

Case reviews revealed the following:

- access to appropriate primary and specialty medical and nursing services was readily available and the quality of these services met established standards of medical/nursing care.
- There was routine monitoring of individual's on polypharmacy and psychotropic medications.
- The Board noted that the identification of adverse or side effects of psychotropic medications needs to be fully assessed and monitored as these medications may affect the functional ability of an individual (e.g. dysphagia, lethargy, loss of ambulation).
- Occasionally medications have been prescribed without a comprehensive evaluation and documentation of the risks vs. benefits of the treatment (e.g. use of hormonal therapy)
- Progressive or sudden weight loss was not always evaluated or treated.
- Pain management was consistently provided when identified as a support need.
- Coordination of community based health supports requires special attention.
- Specific monitoring and plans of care need to be put in place for recognizing symptoms of gastrointestinal dysfunction.
- Access to oral health care services

SECTION IV

Benchmarks

Benchmarks are standards by which similar items can be compared and allow the reader to place findings in context. As mentioned in the 2004 MASS DMR Mortality Report there is a dearth of relative benchmarks for use in comparing mortality data for individuals with MR/DD.

Use of benchmarks including comparative data from other populations and/or from other state disability departments is an important mechanism for helping to understand analytical findings such as those presented in this report

In 2002 The Connecticut DMR retained the services of two outside consultants to conduct a comprehensive Independent Study/Analysis on mortality and basic demographic trends from 1996 to 2002 within the population of individuals served by DMR. ⁷

The study authors found that:

- *Changes in mortality rates over time are not significant*
- *As expected, mortality is highly related to client age*
- *Women served by DMR are older than men, and hence have a higher mortality rate*
- *Increased levels of disability are inter-related and correlated with higher risk of mortality*
- *The strongest predictors of mortality are age, mobility status, and amount of supervision provided*
- *The "aging in place" phenomenon is leading to increased risk of mortality since individuals served by DMR are becoming older and more disabled over time*

The trends identified in this year's Health and Mortality Annual Report (July 1, 2004-June 30, 2005) were consistent with the findings and basic demographic trends found in the 2002 Independent Study.

- *Mortality is highly related to client age*
- *Women served by DMR are older than men, and hence have a higher mortality rate*
- *The strongest predictors of mortality are age, mobility status, the amount of supervision provided and the need for special assistance when eating*
- *The "aging in place" phenomenon continues to be a leading risk factor since individuals served by DMR become older and more disabled over time*

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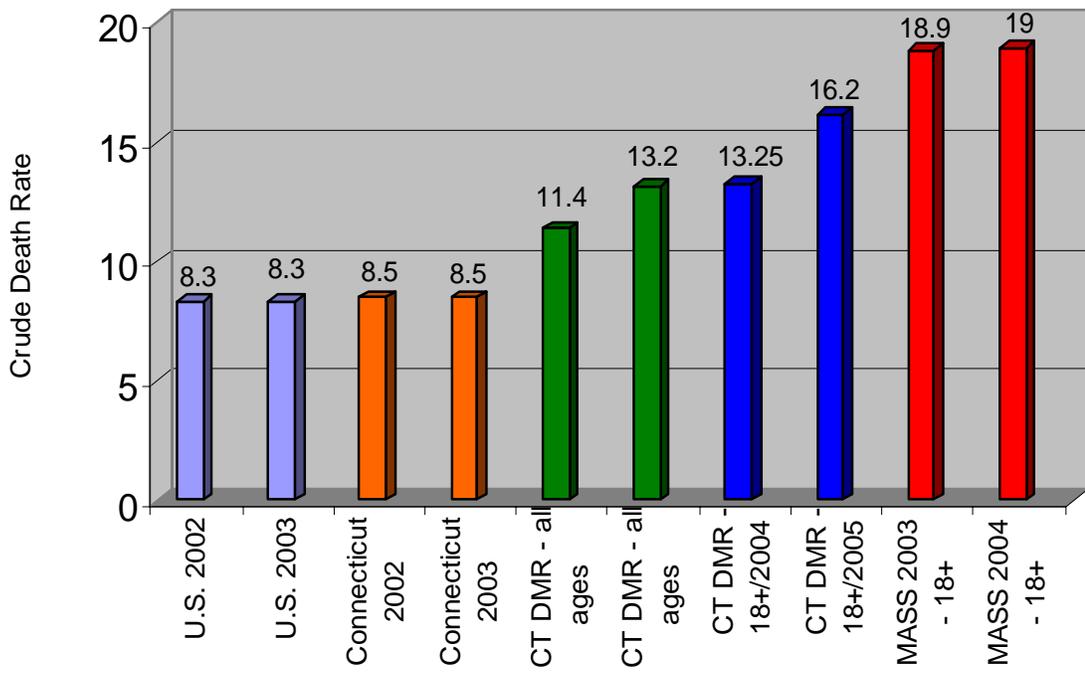
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Massachusetts DMR

The Massachusetts Department of Mental Retardation continues to enhance and expand its mortality reporting requirements for its annual report. The 2003/2004 Mortality Reports were prepared by the University of Massachusetts Medical School/Shriver Center for Developmental Disabilities Evaluation and Research¹. The Massachusetts reporting period covers the calendar year January 1 through December 31. Massachusetts Mortality statistics pertain only to persons 18-years and older served by DMR and were analyzed according to a number of variables which are similar to those included in this report. Consequently, it is possible to use some of the Massachusetts data for comparative purposes. It should be noted that the Massachusetts DMR system, although larger, is very similar to Connecticut's (e.g., population served, type of services and supports, organization). However, there are differences in reporting requirements, age limits, and categorization of service types. It is therefore important that readers exercise caution when reviewing comparative information. The use of general population benchmarks provides a baseline by which to understand the unique characteristics of the MR/DD population.

Figure 16
Overall Death Rate

Comparison of Average Death Rates



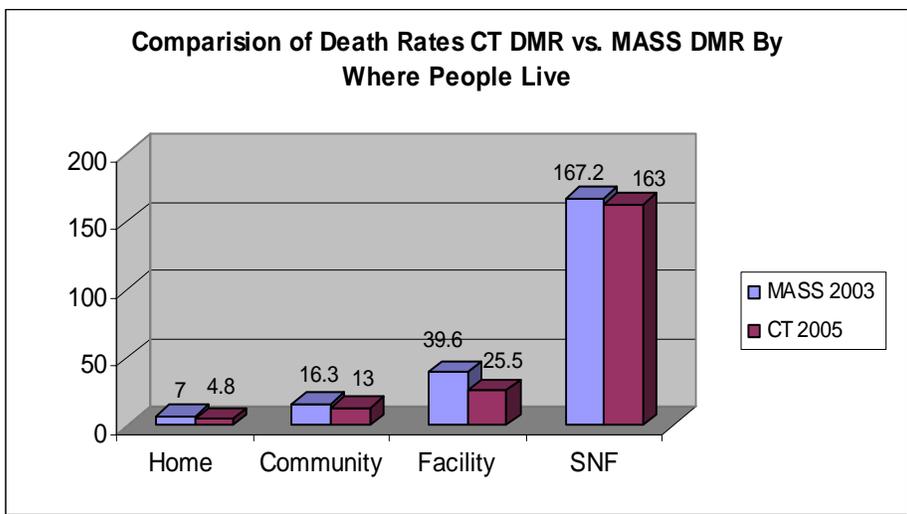
A comparison of the overall death rate for persons served by the Connecticut DMR with similar rates for the general population in Connecticut, the U.S. and the DMR population in Massachusetts are presented in this graph.

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(See Fig 16) The overall Connecticut DMR death rate (2005 data) of 13.2 is once again higher than the rate of 8.5 in Connecticut (2003) and the rate of 8.3 in the general population (United States 2003). This would be expected due to the many health and functional complications associated with disability and mental retardation. A comparison of Connecticut DMR with Massachusetts DMR illustrates a higher death rate in Massachusetts (18.9) for the adult population than Connecticut's rate of 16.3 deaths per thousand people (for individuals older than 18 years of age). This difference is similar to last year and may be a reflection of the aforementioned differences in the populations being served. CT DMR death rate in 2005 for individuals of all ages was 13.25 and rose to 16.2 for the sub group of CT DMR individuals over the age of 18 years. During this reporting year the CT DMR has adapted aspects of its mortality data and analysis to enable more direct comparisons to be made between CT DMR and Mass DMR possible.

Figure 17



Residential Analysis

« « « « « « « « « « A comparison of death rates by where people live is presented here. The general pattern for rates by type of setting is quite similar across the two states despite minor variations from year to year.

Death rates in CT DMR for comparable residential service settings would appear to be very consistent with an available benchmark as reported in Massachusetts DMR. Although CT rates are lower for all residential categories

Table 4

Leading Causes of Death CT and MASS

Rank	CT DMR 2005	CT DMR 2004	CT DMR 2003	CT DMR 2002	MASS DMR 2004	MASS DMR 2003	MASS DMR 2002
1	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease
2	Respiratory Disease	Respiratory Disease	Pneumonia Aspiration	Respiratory Disease/ pneumonia	Cancer	Cancer	Pneumonia Aspiration
3	Pneumonia Aspiration	Pneumonia Aspiration	Nervous System	Nervous System	Pneumonia	Pneumonia Aspiration	Cancer
4	Cancer	Sepsis	Cancer	Cancer	Influenza Pneumonia	Sepsis	Sepsis

The table above reveals that heart disease and respiratory disease (including aspiration pneumonia) continue to be the leading causes of death in the MR population.

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The next Health and Mortality Report UPDATE (2006) will be issued

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