State of Connecticut

DMR

Mortality

ANNUAL REPORT

2006

This is the fifth of a series of annual reports on mortality, mortality trends and related information pertaining to the health and quality of care received by individuals served by the Connecticut State Department of Mental Retardation. Reports focus on an analysis of mortality data and specific findings resulting from the Connecticut DMR mortality case review process. Reports are scheduled for publication December of each year.

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SECTION EIGHT OF THIS REPORT:
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This section presents mortality data, findings and trends identified from CT DMR and MASS DMR mortality for the purpose of comparison and identification of benchmark data.

This report represents a review of the period between July 1, 2005 to June 30, 2006.
Data in this report was obtained from the CT DMR Database system.

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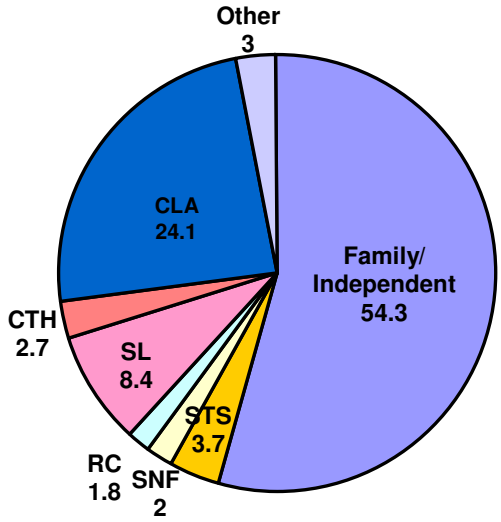
SECTION ONE: Overview of DMR Population

Intellectual Disability 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, 2006, **15,018** individuals with intellectual disability were being supported by the department.

Figure 1

Overview of DMR Population

Percentage by Program Type



Over half of the people served by CT DMR live at home with their family or in their own home. The remainder of the people served by DMR (over 6,000) receive funded residential supports. The majority of these supports are traditional in nature, with support services provided in supported living, group homes (CLA's), community training homes (CTH), regional centers (RC) and a campus program, Southbury Training School (STS) . The rest of the people are supported by other state or local government and/or private entities including skilled nursing facilities (SNF), the Department of Mental Health and Addiction Services, the Department of Children and Families, the Department of Correction and residential schools.

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CT DMR Population Trends

Table 1

DMR RESIDENCE BY TYPE OF PROGRAM
FY 2005 - FY 2006

	2006		2005	
Restype	TOTALS	Percent	TOTALS	Percent
Family/Independent	8,093	54%	8,058	54%
CLA (Group Home)	3,609	24%	3,565	24%
Supported Living (SL)	1,264	8%	1,261	8%
Training School (STS ICF campus)	551	4%	572	4%
Other	515	3%	514	3%
CTH (community training home)	412	3%	426	3%
SNF (skilled nursing facility)	307	2%	280	2%
Regional Center (RC)	267	2%	267	2%
TOTAL	**15,018**	**100%**	**14,943**	**100%**

RESIDENTIAL SETTING DEMOGRAPHICS

Table 1 represents the residential settings in which DMR provides supports and services and the number and percent of people served by DMR who live in each of the identified residential settings.

Although the gross percentages of people served by CT DMR have remained constant over the past two fiscal years, there have been population shifts within program types.

The number and percent (54%) of people served by CT DMR who live in independently or with their families is almost identical to the number of people living at home in FY 2005.

The number of people served who live at the training school campus decreased by 4%, the same decrease that occurred from FY 2004 to FY 2005 while the number of people served at regional centers (RC) was identical to the previous year.

The number of people served in community living arrangements (CLA) increased by less than 2% compared with a 4% increase the previous year. The number of people served by community training homes (CTH) continued a downward trend. This year the number served by CTH providers decreased by 3.5% The number of people served in skilled nursing facilities increased by almost 10% from FY 2005. The number of people served in the SL services remained static over the last two fiscal years.

Table 2

Resident Population By Age
2004 - 2006

	2004	2005	2006
Children (0-19)	3,815	3,766	3,663
Adults (20 - over)	11,121	11,177	11,355
TOTAL ALL AGES	**14,936**	**14,943**	**15,018**

Adults (55 - over)	**2,318**	**2,397**	**2,470**
Adults (65 - over)	**944**	**954**	**957**

Table 2 above illustrates the the number of children, and adults served by DMR from 2004 - 2006.

That data shows that between FY 2004 – 2006 the population served by CT DMR has increased by only ½% from 14,936 to 15,018.

However a more in depth analysis of this data is more revealing illustrating demographic changes that have been occurring within the population served by CT DMR system over time.

For example, the population data from FY 2004 – FY 2006 reveals that the DMR population is gradually aging with the number of children below the age of 19 years decreasing by 4% while the number of adults over the age of 20 years has increased by 2%.

Over the past three years this "aging phenomenon" is even more apparent for the DMR population at the other end of the age spectrum. The number of people served who are 55 years or older increased by 6.2% and those over 65 years of age by 1.5%. There was a corresponding 3.5% population decline for persons 75 years or older between 2004 - 2006.

This "aging phenomenon" within the CT DMR population has special significance from a service delivery standpoint given the fact that as the DMR population ages there are concomitant health issues and associated support needs which need to be addressed.

As expected this increase in the older adult DMR population parallels national trends, as well as other CT DMR population findings (State of CT DMR Aging Focus Team Report and Recommendations October 2003).[29]

Older adults (>55 years of age) now comprise over 16% of all people served by CT DMR. Excluding family homes from the equation the number of adults 55 years or older who are served in more traditional supports jumps to a surprising 33% of all people served by DMR.

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AGE DEMOGRAPHICS

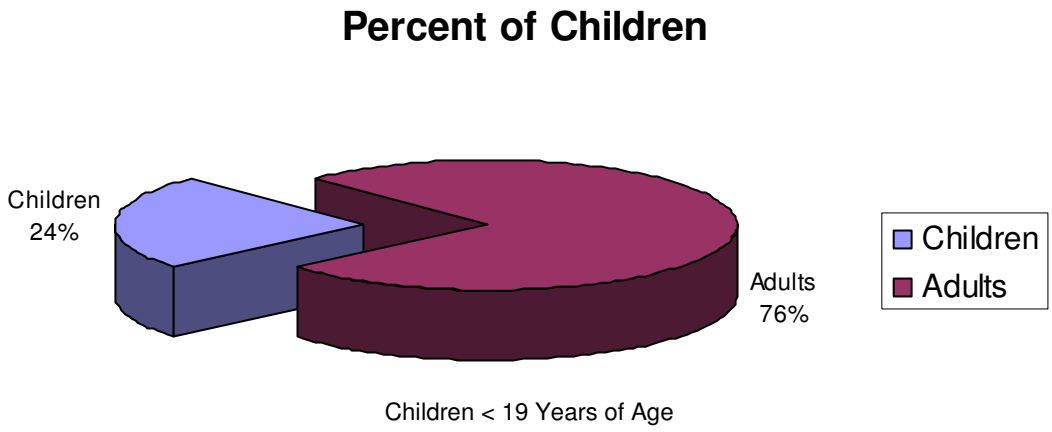
Table 3

Percent Population by Age Ranges
FY 2006

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,694	24.60%
Age 20-29	2,828	18.80%
Age 30-39	2,173	14.50%
Age 40-49	2,741	18.30%
Age 50-59	2,031	13.50%
Age 60-69	932	6.20%
Age 70-79	427	2.80%
Age 80+	192	1.30%
TOTAL	**15,018**	

Table 3 depicts the number and percentage of people served by CT DMR by various age ranges for FY 2006 in greater detail.

Figure 2



Children 19 years of age or younger represent 24 percent of the CT DMR population .

Table 4

AGE CATEGORY AND RESIDENCE
FY 2006

Restype	Children (0-18)	Adults (19-64)	Older Adults (65+)	TOTALS
CLA (Group Home)	84	3,139	391	3,614
CTH (Community Training Home)	11	354	47	412
Family Home	2,931	4,490	70	7,491
Independent Living	1	544	45	590
Regional Center	0	265	1	266
Supported Living	0	1,141	128	1,269
SNF	0	138	171	309
STS	0	397	153	550
Other	184	263	70	517
TOTAL	**3,211**	**10,731**	**1,076**	**15,018**
PERCENT	**21%**	**72%**	**7%**	**100%**

Table 4 above reveals that the greatest number of older adults (> 65 years of age) reside in community living arrangements followed by skilled nursing facilities, the campus program and supported living services. Ninety-eight percent (98%) of all children in the CT DMR services system live at home with their families.

AVERAGE AGE OF ALL PEOPLE SERVED BY CT DMR : 35.4 YEARS

Table 5

Consumers Age 19 - 64 Years By Program Type

RC	99%
SL	90%
CLA	87%
CTH	86%
STS	72%
Family/Independent	62%
SNF	45%

Table 6

Consumers over the Age of 65 By Program Type

SNF	55%
STS	28%
CTH	11%
CLA	11%
SL	10%
Family/Independent	1%
RC	<1%

Only 10% -11% of people who live in CTH, CLA, or SL services programs are over 65 years of age. It is interesting that less than 1% of people served in regional centers or who live at home with their families or independently are over the age of 65 years of age.

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CT DMR GENDER STATISTICS

Table 7

Gender by Age FY 2006

Gender	Children (0-18)	Adults (19-64)	Older Adults (65+)	TOTALS
Female	1,195	4,744	579	6,518
Male	2,017	5,995	488	8,500
TOTAL	3,212	10,739	1067	15,018

Historically the number of men served in the CT DMR system far exceeds the number of woman. FY 2006 was no different with males comprising 56.6% of the population versus 43.4% for women. In other words, CT DMR services 1.3 males for every female served. A similar male to female ratio is also reported in other states. One explanation for the greater proportion of males served by the CT DMR system is that families may find it more difficult to manage/support males at home. There is an inverse relationship between the number of males served by DMR and the general population for the State of Connecticut (2004). In CT females comprise 51.4% of the populations and males 48.6%.

However, as people served by DMR age (65 and over) the number of females far surpasses the number of males. 1.19 females for every male which is more in line with general population trends.

AVERAGE AGE OF MALES SERVED BY CT DMR: 34.1 YEARS

AVERAGE AGE OF FEMALES SERVED BY CT DMR: 37.2 YEARS

2004 CT Population Gender Statistics
Male 48.6%
Female 51.4%

Death Ratio CT 2004
1.4 Males - Females

Death Ratio CT DMR 2004
1.02 Males - Females

2006 CT DMR Population Gender Statistics

Male 56.6%
Female 43.4%

2005
Male 56%
Female 44%

2004
Male 56%
Female 44%

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SECTION TWO: ANALYSIS OF *ALL* CT DMR MORTALITIES (JULY 1, 2005 – JUNE 30, 2006) NUMBER OF DEATHS REPORTED = 202

This section summarizes **all deaths (202**) reported to CT DMR and provides a detailed analysis of these deaths.

Overall Mortality Rate

During the 12 month time period between July 1, 2005 and June 30, 2006 a **total of 202** individuals served by CT DMR passed away **resulting in a mortality rate of 13.27.** (Figure 3 & 4 below)

The same mortality rate seen in FY 05.

Figure 3

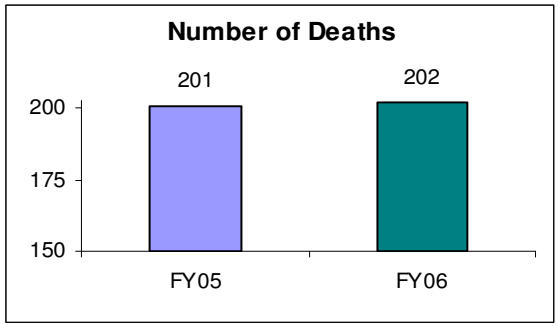
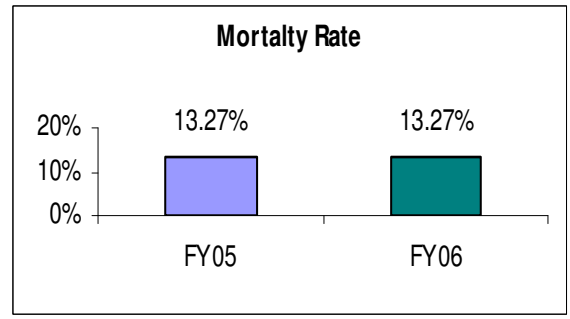


Figure 4



Mortality and Residence

As can be seen in Figure 5 (to the right) 48% of individuals served by CT DMR died while in a residential setting operated, funded or licensed by DMR. Deaths which occurred in family or own home or skilled nursing facility accounted for the remainder of the reported deaths.

SNF = skilled nursing facility, RC = regional center, STS = Southbury Training School
CLA = community living arrangement (group home), CTH = community training home, SL = supported living, Family = live independently or with family at home.

Shaded areas represent settings operated, funded or licensed by CT DMR.

Figure 5
Residence at Time of Death

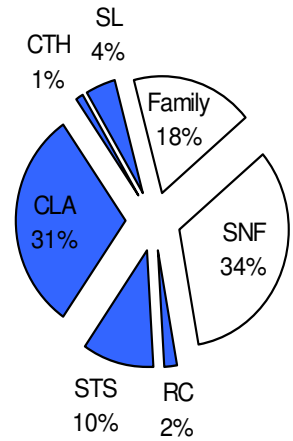


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Figure 6

Number of Deaths by Where People Live

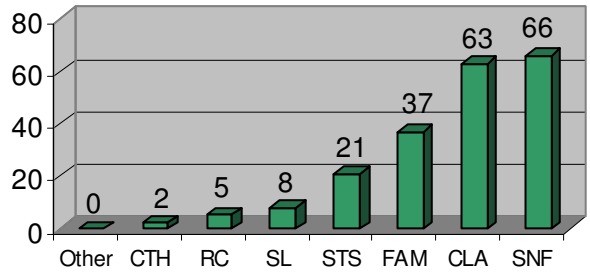

Figure 6 (above) depicts the actual number of deaths by where people live. In line with last year's data the greatest number of deaths occurred in skilled nursing facilities followed by CLA's, family homes and STS . Over 78% of the CT DMR population live in family/own home or CLA's.

Figure 7

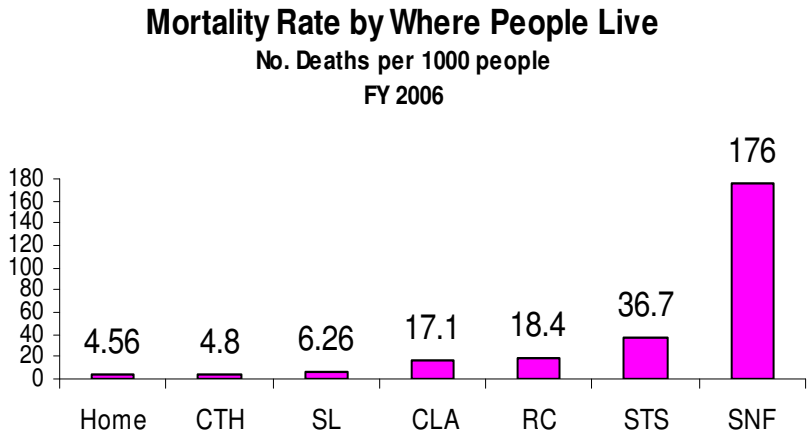

Figure 7 (graph on the left) shows the number of people who died for every 1000 people served in each type of residential setting. The average death rate* continues to show a predictable pattern.

Individuals living in skilled nursing facilities, regional centers and at STS tend to be older and have significant intellectual disabilities, functional impairments and health co-morbidities which require greater levels of supervision and health monitoring by licensed health professionals than individuals living in CLA's, supported living services, independently or with their families.

* 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 number of deaths by the EOY population + number deaths and multiplying by 1000 to generate a rate (number per thousand).

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Mortality and Residence

Family or Own Home: People who live with their family or own home represent 54% of the DMR population and 88% of these people are under the age of 21 years. Only 18% of all deaths in DMR occurred in the family/own home setting and had the lowest mortality rate 4.56. Forty four per cent of the people who died in there family or own home were under the age of 21.

CLA: Serves people with varying levels of intellectual disabilities who require 24 hour supervision for their health and direct care supports in group home settings. Health supports are generally less intensive than regional centers or campus settings which may explain a lower mortality rate for this type of residence. Mortality rate of 17.1 in FY 2006 accounting for 31% of all reported deaths

CTH: There were only two deaths in the CTH program and both were anticipated and related to an existing condition. The CTH mortality rate of 4.8 was similar to the mortality rate of people living in their own home or independently. People living in CTH programs represent only 1% of the DMR population and < than 1% of reported deaths.

SL: People living in supported services are generally younger and less medically involved than the other residential program types and need minimal hours of direct support to live in their own place and as such the death rate in SL services was only 6.26 representing only 4% of reported deaths.

STS: This larger campus setting serves a stable/fixed population of people with severe to profound intellectual disabilities who are older and have many health co-morbidities and care issues both chronic and acute. The higher mortality rate of 36.7 reflects this. Ten percent (10%) of all DMR deaths occurred on the campus.

RC: Similar to the campus settings the majority of people supported in regional centers have multiple co-morbidities and require 24 hour direct and nursing supervision. The mortality rate of 18.4 is higher than the overall CT DMR mortality rate of 13.27. Only 2% of all deaths in FY 2006 occurred at regional centers.

SNF: Only 2% of people served by CT DMR live in skilled nursing facilities yet they make up almost 16% of all DMR consumers over 65 years of age. In FY 2006 people living in skilled nursing facilities accounted for 34% of all reported deaths. As expected, this older and medically fragile population in need of nursing supports provided by nursing homes had the highest mortality rate of 176 per thousand. Less than 12% of all people served by CT DMR who are over the age of 75 reside in skilled nursing facilities.

CLA: 24 hour support is provided with staff in group home settings 2-6 people share an apartment or house

CTH: Live in a family setting that is not within their own family. CTH family has received training and are licensed by DMR.

RC: Residential centers are facilities for over 16 people that provide 24 hour staffing.

SL: Minimal hours of support to live in their own place. Staff support may be from a few hours a day to only a few hours a month depending on the support needs of the person.

SNF: Skilled nursing facility for people requiring skilled nursing level of care not licensed or funded by DMR.

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Mortality and Gender

Table 8

Mortality Rate by Gender - 2006

GENDER	All Individuals Served by DMR	No. Deaths	Percentage of Deaths	Rate (No. Deaths Per 1000)	Average Age of Death
Men	56%	102	51%	11.86	56.8
Women	44%	100	49%	15.11	58.3
Total	**100%**	**202**	**100%**	**13.27**	**57.5**

As can be seen in Table 8, during Fiscal Year 06, more men died than women. However, as in FY 05 **women had a greater mortality rate 15.11 – than men 11.86**. This is due to the fact that far fewer women are served by CT DMR. The percentage of men (56%) and women (44%) served by the CT DMR system was identical to last fiscal year's numbers. Men accounted for 51% of all deaths in FY 2006.

As in the general population women supported in the CT DMR system are older than the men and as noted in Table 8 live longer than their male counterparts (58.3 years vs. 56.8 years).

Figure 8

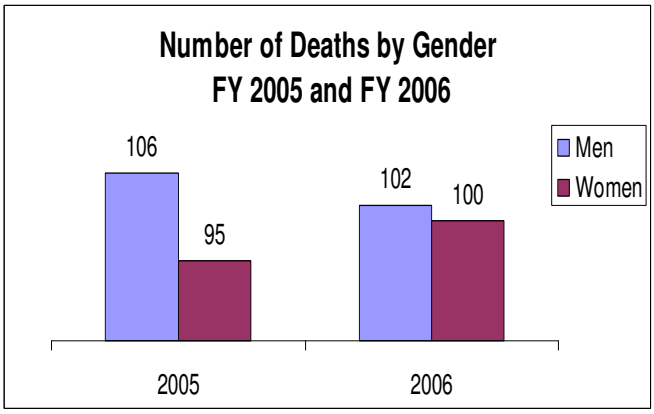
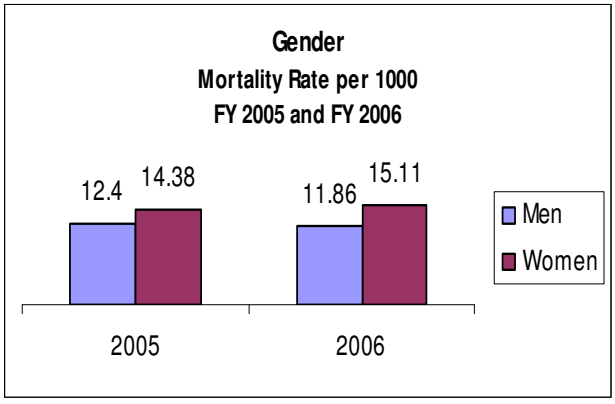


Figure 9



During FY 2006, an almost equal number of men and women died (102 men and 100 women). However, the mortality rate once again was greater for women (15.11) as noted in Figure 8 and Figure 9 above.

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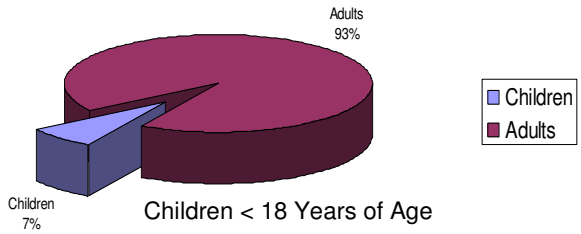
Mortality and Age

Average Age of Death (total population)	**– 57.53**

Figure 10

Deaths of Children and Adults Total Reported Deaths FY 06 = 202



Children < 18 Years of Age

Table 9

Age of Death

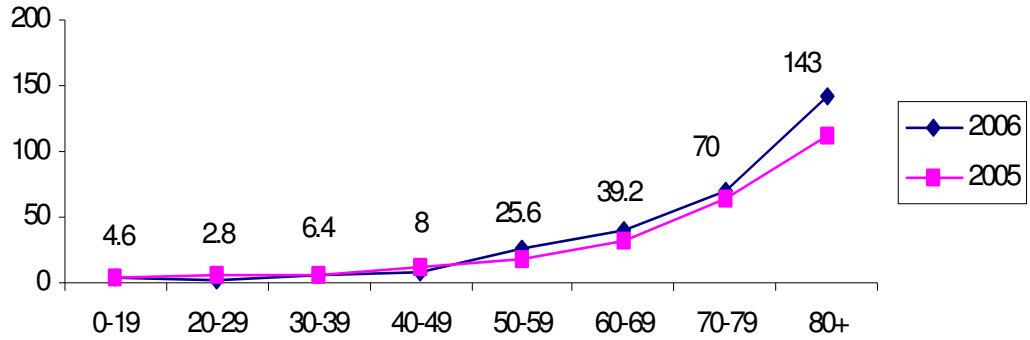
Report Year	Men	Women	Average
CT DMR FY 2006	56.8	58.3	57.5
CT 2004	75	81	78
US 2004	75.2	80.4	77.8

As mentioned earlier in this report, children served by DMR represent 20% of the CT DMR population. 91% of children served by DMR live at home but accounted for only 7% of deaths reported in FY 06.

Life expectancy at birth for the total CT DMR population for FY 06 reached close to a record high of 57.53 years. The average age of death in FY 2006 represents an increase of over three years compared to the average age of death in FY 2005.

Figure 11

Mortality Rates by Age Range
No. Death per 1000 People
Served FY 2005 and FY 2006



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 11, 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 CT DMR mortality data and is in line with aging trends observed in the general population. There is not a pronounced difference between the mortality rates for the younger age groups. Death rates for those individuals below 60 years of age declined or remained stable. Some variability in death rates occur in the older age groups > 60 years of age compared to FY 2005.

Table 10

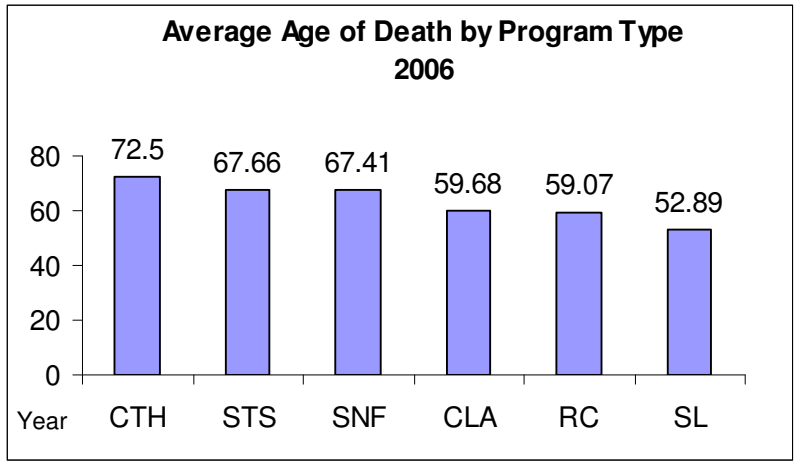
Mortality Age Range Data

FY 2006

AGE RANGE	TOTAL	% OF TOTAL	# OF DEATHS	% OF DEATHS	MORTALITY RATE
Age 0-19	3,694	24.6%	17	8.4%	4.6
Age 20-29	2,828	18.8%	8	4.0%	2.8
Age 30-39	2,173	14.5%	14	6.9%	6.4
Age 40-49	2,741	18.3%	22	10.9%	8.0
Age 50-59	2,031	13.5%	39	19.4%	25.6
Age 60-69	932	6.2%	38	18.8%	39.2
Age 70-79	427	2.8%	32	15.8%	70
Age 80+	192	1.3%	32	15.8%	143
TOTAL	**15,018**	**100%**	**202**	**100%**	**13.27**

As depicted in the previous graph, mortality rates within CT DMR population increase dramatically in the fifth decade of life and again between the sixth and seventh decade. People over the age of 70 accounted for 64 deaths or 32% of all deaths. As mentioned earlier in this report, the average age of people served by CT DMR = **35.4 years of age** with an average age of death of 57.5 years.

Figure 12



Because of the small number of deaths in some of the residential program types such as CTH (only two reported deaths) the average age of death data for those programs may be misleading. However, in the programs where the the number of deaths is greater, the reader can see a more accurate relationship between program type and age of death.

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SECTION THREE: DMR MORTALITY REVIEW

THE MORTALITY REVIEW PROCESS

Connecticut law (which comprises statutes and executive order) currently requires CT 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. CT DMR has established a two tier mortality review process as part of its quality assurance system to trigger corrective action and reduce future risk for people. The two tier system includes a regional mortality review committee and Independent Mortality Review Board.

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 consumers?

Regional Mortality Review Committee

Criteria for Review

Any death where the department bears direct or oversight responsibility for medical care.

Independent Mortality Review Board

Criteria for Review

Determined necessary by the regional mortality committee

Medical, health or residential care concerns

Post mortem examination

Suspicion of abuse/neglect etc.

Ongoing abuse/neglect investigation

Assume immediate jurisdiction and conduct an expedited review when determined necessary by the Commissioner or the OPA Executive Director if it is likely that the death occurred because of abuse or neglect or on the request of the Director of Quality Assurance and/or the Director of Health and Clinical Services.

NURSE INVESTIGATORS MEDICAL DESK REVIEW

In addition to the regional mortality review committees and the Independent Mortality Review Committee the DMR death reporting and mortality review process requires that all deaths are reported to a **Nurse Investigator** (NI) who is assigned to the DMR Investigations Division. The Nurse Investigator conducts a **Medical Desk Review** (an abbreviated mortality review) to determine the need for an expedited comprehensive review by a Regional Mortality Committee and/or the Independent Mortality Review Board or if an immediate investigation of the death by another state agency is warranted.

ROLE OF THE NURSE INVESTIGATORS

If an immediate mortality review is indicated, the Nurse Investigator will forward the Medical Desk Review and associated documents to the DMR Director of Investigations, DMR Director of Health Services who chairs each respective Regional Mortality Review Committee and the DMR Director of Health and Clinical Services who chairs the Independent Mortality Review Committee if:

- Abuse or neglect is suspected according to DMR abuse/neglect policies and procedures
- Systems deficiencies are identified or suspected
- For routine mortality review as defined in DMR procedure

Independent Mortality Review Board Membership

Members of the Independent Mortality Review Board (IMRB) are appointed by the CT DMR Commissioner and Executive Director of the CT Office of Protection and Advocacy for DD and include:

- DMR Director of Health and Clinical Services (Chair)
- DMR Director Division of Investigations
- DMR Director Division of Quality Management
- Assoc Medical Examiner (State Office of the Chief Medical Examiner)
- Community based physician
- State Office of Protection and Advocacy
- State Department of Public Health
- Executive Director private provider agency
- Parent representative

Regional Mortality Committee Membership

Members of the Regional Mortality Review Committees are appointed by the regional or training school (STS) Director and include:

- DMR Regional Health Services Director (Chair)
- Medical Director (for STS campus)
- DMR Quality Improvement Director
- Non-DMR registered nurse
- Non DMR consumer advocate
- DMR residential manager
- DMR Assistant Regional Director
- DMR abuse/neglect liaison
- Family representative

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SECTION FOUR: ANALYSIS OF DATA GENERATED BY THE CT DMR MORTALITY REVIEW PROCESS

IMPORTANT NOTE: THE INFORMATION PRESENTED IN THIS SECTION SUMMARIZES **ONLY THOSE DEATHS THAT WERE REVIEWED BY THE REGIONALCOMMITTEE AND /OR STATE MORTALITY BOARD AND THEREFORE THE DATA AND DATA ANALYSIS WILL DIFFER IN SOME RESPECTS FROM THE INFORMATION PRESENTED AND DISCUSSED IN SECTION II OF THIS REPORT**

The DMR Mortality Review Committees/Board reviewed 145 cases during FY 2006 (July 1, 2006- June 30, 2007)

Community Hospice Support

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 who live in all settings, including regional centers, campus, community living arrangements, community training homes, supported living services and family/own homes. This includes state of the art palliative and hospice care provide end of life support, hope and comfort to individuals either in the home or in a hospital setting. Once again in FY 2006 the DMR system was able to serve people through the final stages of terminal illness in their own residence.

- **Hospice supports were provided for 59 consumers or 41% of individuals prior to their death**
- **86 deaths that were anticipated as a result of a known condition/diagnosis: 61% of these individuals received hospice support services prior to their death**
- **Provision of hospice supports for FY 2006 (41%) compares favorably with last year's 34%.**

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 based pathology departments when DMR requests and the family consents to the autopsy. CT DMR continues to encourage autopsies as noted below.

GUIDELINES FOR REQUESTING AUTOPSIES

- certain sudden or unexpected deaths in which the cause of death is not due to a previously diagnosed condition or disease
- deaths involving an earlier accident or trauma
- deaths involving questionable contributing factors
- cases involving an allegation of abuse or neglect

Total number of post mortem examinations performed:	**17**	**(12% of all deaths)**
Number of post mortem examination performed by CT OCME:	**8**	**(5% of all deaths)**
Percentage of the post mortem examinations performed by CT OCME:		**(47%)**

Post mortem examinations by the OCME and private pathologists have been a valuable tool in identifying or confirming the cause and manner of death in many cases. Once again the post mortem rate for CT DMR (12%) exceeds the national average autopsy rate of 11.7% reported in 2002 by the Columbus Organization following a survey of selected ID/DD state agencies across the country.

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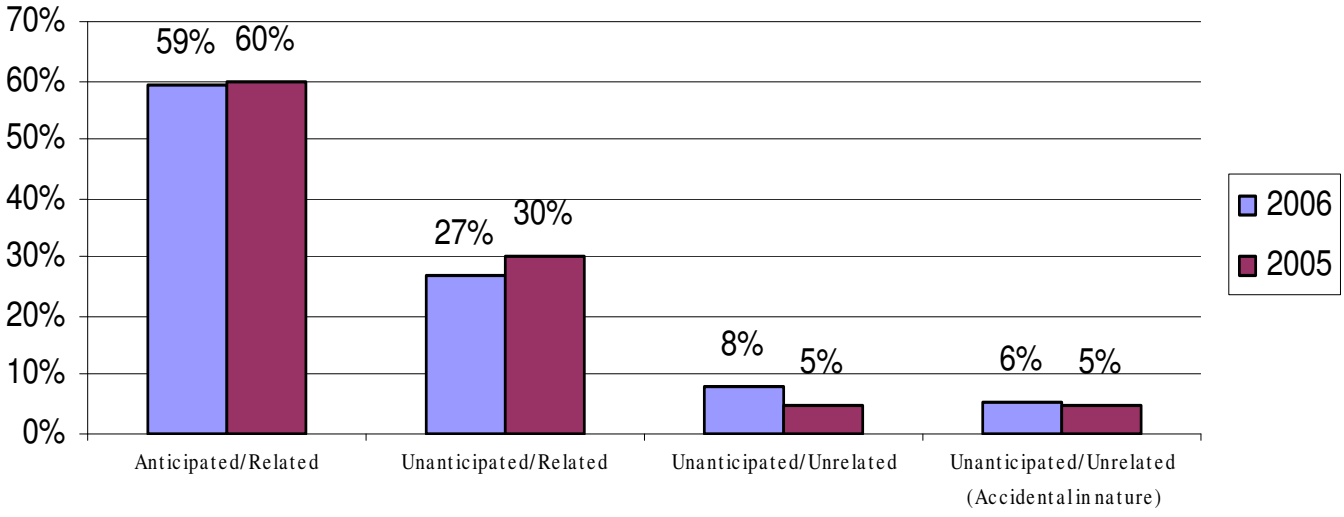
Predictability

Analysis of the mortality review data indicates a relationship between previously diagnosed medical conditions and the cause of an individual's death. In fact in 86% of all cases individuals died as a result of a known or previously diagnosed medical condition/disease (see Figure 13 below).

- **Death was anticipated and related to a preexisting diagnosis: 59%**
- **Death was unanticipated but related to a preexisting diagnosis: 27%**
- **Death was unanticipated and unrelated to a preexisting diagnosis: 14% (includes accidental deaths)**

Figure 13

Predictability of Death



Death was anticipated and related (the result of a known condition) in 72% of those individuals over the age of 65 compared to only 53% of individuals < 65 years of age.

Figure 13 also reveals that 87% (40/46) of individuals > 65 years of age had a condition related to their cause of death although their death was unexpected compared to 59% of individuals < than 65. This data supports the fact that in the vast majority of cases consumers' underlying medical conditions were identified prior to their death per routine or specialty medical examination(s)/consultations or both.

Seventy-two percent (72%) of individuals living in skilled nursing facilities deaths were anticipated as a result of a known condition compared to only fifty-three percent (53%) for the CT DMR population living in other program types. In contrast for unanticipated deaths of people with a known related medical condition only 15% lived in skilled nursing facilities while 32% lived in other settings. Advanced age was the strongest predictor of death within the CT DMR system.

Ninety-five (95%) of individuals who lived in a SNF died as a result of a medical condition that was diagnosed prior to their death.

UNANTICIPATED/UNRELATED DEATHS:

Of the 20 deaths that were unanticipated and not related to a known condition 7 were accidental in nature and 13 were due to natural causes. The causes of mortality for these natural unanticipated deaths were: Cardiac arrest (4) Sepsis (3) Sepsis due to bowel ischemia (1) Respiratory failure (1) Pneumonia (1) Aspiration pneumonia (1) Pneumonitis (1) Hypoxic encephalopathy (1).

ACCIDENTAL DEATHS

In almost every case of accidental death, the accident which directly contributed to the individual's death was the result of a brief period of inattention, poor judgment on the part of support staff or a failure of staff responsible for supervising the individual to follow prescribed programs. The accidental deaths **were not** due to a failure on the part of the individual's support team to identify risk factors or the absence of a plan/program to ensure the individual's health and safety.

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. Documentation regarding end of life planning and withholding of cardiopulmonary resuscitation continues to be excellent.

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 145 mortality cases reviewed:

67% of all reviewed deaths (145) had a DNR order in place

95% of all DNR orders were formally reviewed by DMR

100% of DNR orders met the established DMR review criteria

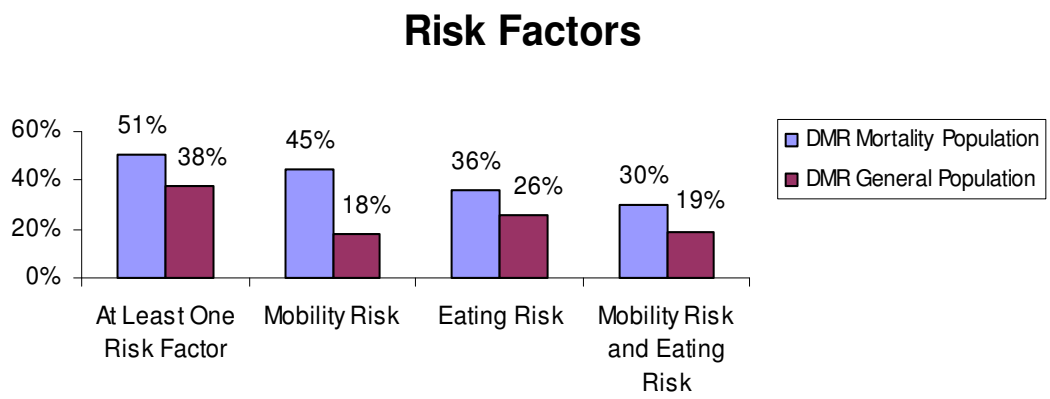
DMR was not notified prior to the implementation of the DNR orders in 5 cases or (5%). In all of these non-reported cases the individuals resided in skilled nursing facilities or had been admitted to acute care hospitals. **However during the mortality review process it was determined that in all cases (reported and not reported) the established DMR criteria was met.** 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 CT DMR was provided.

Eighty-seven (87%) of people residing in skilled nursing facilities had a DNR in force at the time of their death.

Risk Factors

Mobility impairments and dysphagia and swallowing risks requiring the need for special assistance when eating are well known risk indicators that place individuals at significantly higher risk of morbidity and mortality. Therefore, during the mortality review process the presence or absence of these two risk indicators are carefully analyzed. The FY 2006 data revealed, as in past years, that there is a relationship between these risk factors and mortality rates (see Figure 14 below).

Figure 14



Of the 145 cases that were reviewed 51% of people had risk factors identified pre-mortem.

MORTALITY POPULATION	* GENERAL DMR POPULATION
* 45% were not able to ambulate independently 36% were not able to eat independently * Excludes Family Homes	18% were not able to ambulate independently 26% were not able to eat independently *Excludes Family Homes

- **30% or 45 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 05 the majority of people who died had one or more of these identified risk factors present at the time of their death.

It is well documented in the literature that the more compromised an individual's level of mobility, the greater the likelihood of death.[5,7,31,34] This continues to be true based on the analysis of the mortality cases reviewed by the CT DMR regional and statewide committees/board.

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.

Table 11

	FY 06 % of All Deaths	FY 06 Death Rate	FY 05 % of All Deaths	FY 05 Death Rate
24 HOUR SKILLED NURSING SERVICES:	45.5%	76.4	50%	75.4
24 HOUR SUPERVISION LIMITED NURSING:	32.7%	17.1	24%	30
LESS THAN 24 HOUR SUPERVISION (HOME ETC):	23.3%	4.8	26%	5.2

As noted in the chart above, the death rate for individuals requiring 24 hour skilled nursing services (76.4) far exceeded the death rate for individuals needing limited nursing services (17.1) and also for individuals requiring less than 24 hour supervision (4.8). Therefore, placement of a person in a community residence instead of a larger regional center or campus facility were not the determining factor in the death rate, but the level of supervision/supports needed and specific risk factors for each individual was related to the mortality rate.

Table 12

Level of Intellectual Disability and Mortality Rate

	Mild	Moderate	Severe	Profound
2006	5.48	9.36	12	27.6
2004	10.75	6.38	14.45	22.86
2003	8.69	7.69	12.26	25.21
2002	8.78	8.51	19.95	26.04

The level of intellectual disability is related to the mortality rate as noted in Table 12 above.

Individuals with severe or profound intellectual disabilities have a higher mortality rate. This trend has held steady over five year period noted above.

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Context: Manner of Death for Cases Reviewed.

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 145 cases reviewed during FY 06, 138, (95%) were classified as due to natural causes. The other cases were determined to be the result of an accident.

Table 13

FY06 Manner of Death

Manner of Death	No.	Percent
Natural	138	**95%**
Accident	7	**5%**
Homicide	0	0%
Suicide	0	0%
Undetermined	0	0%
Total	145	100%

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

Choking (4) :	**airway obstruction/asphyxia due to a foreign body/food bolus**
Fall (2):	**fracture secondary to a fall resulting in sepsis/embolism** **blunt trauma secondary to fall**
Car Accident (1):	**subdural hematoma secondary to trauma**

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Investigations

ABUSE/NEGLECT-OPA/AID

CT DMR must report all deaths to the Office of Protection and Advocacy for Persons with Disabilities (OPA/AID) which determines if abuse or neglect was involved.

Of the 145 mortality cases reviewed by DMR, 13 cases were investigated by either the OPA/AID or the DMR through its Investigations Division where abuse or neglect is suspected to have contributed to a person's death. In most cases deaths that were investigated by the Office of Protection and Advocacy were also referred and investigated by the CT Department of Public Health.

Disposition of OPA/AID Cases	
Neglect substantiated	***10***
Neglect not substantiated	***1***

Disposition of CT DMR Cases	
Neglect substantiated	***2***

In 7 of the 12 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,

trauma

injury secondary to a fall

In the other five cases of substantiated neglect: lack of supervision by direct care staff, delay in treatment, delay in recognition of changing health condition, lack of programmatic safeguards and monitoring of an individual's health care status led to a ***chain of events*** that may well have contributed to the individual's death.

Department of Public Health

The CT Department of Public Health investigates the quality of care/practice by licensed practitioners and licensed healthcare facilities that include hospitals, rehabilitation hospitals, end stage renal dialysis units, outpatient surgical centers, laboratories and Medicaid certified physical therapy units.

During FY 2006 four (4) mortality cases were referred to the **State of Connecticut Department of Public Health** (DPH) by the regional committee or IMRB. After investigation by the Facilities and Licensing Section of DPH several of the cases were also referred to the Practitioner and Licensing Section for investigation of licensed health care professionals.

Disposition of DPH Investigations

The 4 cases referred to DPH generated 4 investigations

Practitioner Division Investigations – (2)
closed by dismissal no violations of statutes – 1
resulting outcome of discipline/actions – 1

Facility Division Investigations – (2)
closed lack of evidence or no violations found – 0
resulted citations, violations found – 2

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SUMMARY OF FINDINGS

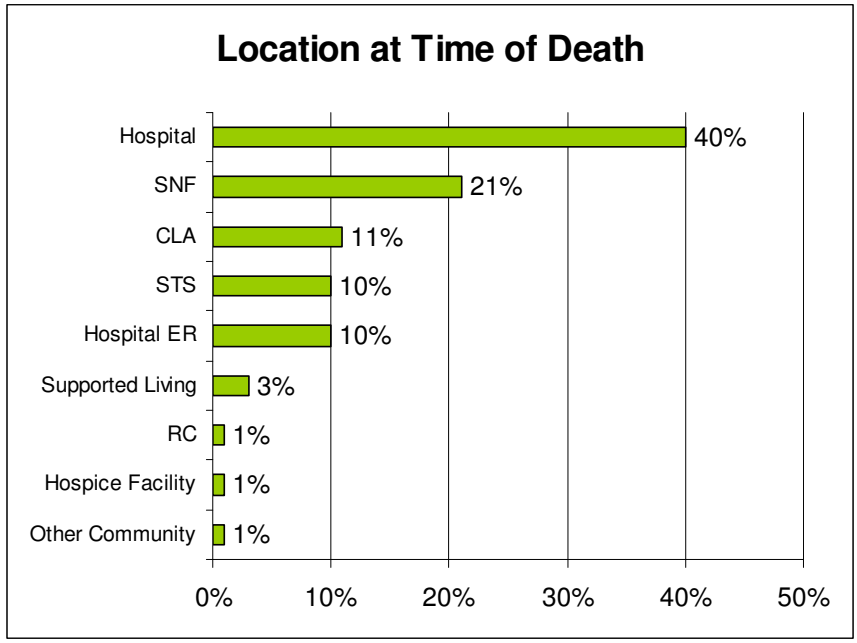
for the 145 deaths that were reviewed in FY06

- **57.5** years is the **average age at death**
- **41%** of the individuals received **Hospice** supports prior to their deaths.
- **12%** of the individuals had **Autopsies** performed.
- **86%** of all deaths were **Related** to an existing diagnosis.
- **67%** of the individuals had a **DNR** order in place at the time of death.
- **51%** of the individuals had at least one **Risk Factor** (could not ambulate independently or could not eat without assistance).
- **30%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance.
- **94%** of the deaths reviewed were due to **Natural** causes.
- **33%** died in **Skilled Nursing Facilities**
- **7** number of deaths were classified as **Accidental**.
- **4** number of referrals to **DPH**
- **13** number of referrals to **OPA/AID**
- **12** number of cases **Neglect** was substantiated by OPA or DMR

Pronouncement of Death (Location Time of Death)

Figure 15 below depicts the location where death was pronounced.

Figure 15



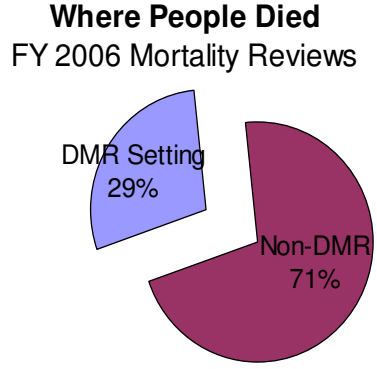
Hospital = Admission to the Hospital as an inpatient, death occurred in the hospital.

Hospital ER = Evaluated in hospital ER, died in ER, while receiving treatment, 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. RC- regional center, STS- training school.

As can be seen in Figure 16 to the right, 71% of all deaths reviewed by the mortality review committees during FY 06 occurred outside of a DMR operated, licensed or funded residential setting, this represents a decrease in the number of people dying outside of a DMR setting compared to FY 05 (81%). The increased use of **in home hospice** services accounts for most of this change.

Figure 16



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Leading cause of death data (based on 145 reviewed cases) FY 2006

For the purposes of this report only an analysis of the cause of death data for 145 mortality cases reviewed during FY 06 are presented below. The leading cause of death in this section cannot be used for comparison to State or national benchmarks as it is not calendar year data and may include deaths that occurred in the previous (2005) fiscal year. Comparative leading cause of death data for CT DMR in calendar year 2006 is compared with other benchmark data in **Table 19 page 36**. As one would expect, the CT DMR FY 2006 and calendar year 2006 leading cause of death data do not necessarily correlate in sequence (rank or percentages) to the data described below.

IMPORTANT NOTE: The information below represents 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.

A review of **Connecticut DMR leading causes of death data for FY 2006 review period** illustrates that once again heart disease was the leading cause of death followed by respiratory diseases.

29%	*of deaths were due to*	**Heart Disease**	*including*	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
16.5%	*of deaths were due to*	**Respiratory Disease**	*including*	Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma
16.5%	*of deaths were due to*	**Cancer**	*including*	Wide variety of primary origin sites
11.7%	*of deaths were due to*	**Aspiration Pneumonia**		Aspiration Pneumonia
6.9%	*of deaths were due to*	**Sepsis**	*including*	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
5.5%	*of deaths were due to*	**Pneumonia**		Pneumonia
4.8%	*of deaths were due to*	**Accident/Trauma**	*including*	Falls, Asphyxia, Choking, Trauma
2.8%	*of deaths were due to*	**Nervous System Disorders**	*including*	Encephalopathy, Epilepsy
2.8%	*of deaths were due to*	**Digestive System**	*including*	Intestinal Obstruction, Liver Disease
2%	*of deaths were due to*	**CVA/Stroke**	*including*	Intercerebral Hemorrhage
<1%	*of deaths were due to*	**Renal/Kidney**	*including*	Renal Failure chronic and acute

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Leading Causes of Death for People with DOWN SYNDROME

Between 300,000 and 350,000 people living in the United States have Down Syndrome. It is estimated that in the State of Connecticut 2,400 people have Down Syndrome most of whom are served by the CT DMR. Therefore, people with Down Syndrome represent almost 16% of the population supported by DMR.

The CT DMR case data derived from the mortality review system provides some additional insight into causes of death for persons with Down Syndrome. People with Down Syndrome accounted for 18% of all deaths reviewed in FY 2006.

Cardiac arrest (35%) was the leading cause of death for persons with Down Syndrome followed by aspiration pneumonia (30%) and respiratory failure secondary to pneumonia (15%). In half of the cardiac related deaths the contributing cause of death was pneumonia.

Seventy-three percent (73%) of people with Down Syndrome who died also had a diagnosis of Alzheimer's Disease at the time of their death. These figures support the literature that people with Down Syndrome develop Alzheimer's Disease at a far younger age.[8,10,14] Symptoms of early onset Alzheimer's Disease are typically observed in individuals with Down Syndrome by the age of 40 years. Other research studies have also found that the average age of death for person's with Down Syndrome and Alzheimer's Disease is approximately 50 years of age while the life expectancy among adults with Down Syndrome is about 55 years of age.[15,16,19,20]

For FY 2006 the average age of death for people with Down Syndrome and Alzheimer's Disease was actually greater (57.3 years) than for people with only Down Syndrome (56.4 years).

It is very encouraging to report that people with Down Syndrome in the CT DMR system are living almost as long (56.4 years) as the general DMR population (57.5 years). This encouraging increase in life expectancy for people with Down Syndrome is probably due to earlier and more comprehensive medical evaluation, treatment and supports that have occurred over the past 20 years.

Primary Causes of Death/Down Syndrome

Cardiac Arrest	9
Aspiration pneumonia	8
Respiratory failure	4
Gastrointestinal hemorrhage	2
Subdural hematoma	1
Renal Failure	1
Sepsis	1
Total	**26**

Percent of Down Syndrome with a diagnosis of Alzheimer's Disease at the time of death - 73%

Down Syndrome

Average Age of death:	56.4
Average Age of death men:	56.4
Average Age of death women:	56.5

Down Syndrome and Alzheimer's	**Avg. Age Death**
Down & Alzheimer's:	57.3
Down without Alzheimer's:	53.67
Men with Alzheimer's:	58.3
Men without Alzheimer's:	50
Women with Alzheimer's:	56.2
Women without Alzheimer's:	57.3

Analysis of Cancer Deaths

Cancer death represented 14.5% of all deaths reviewed by the Mortality Review Committee FY 06.

Cancer was determined to be the cause of death in 21 or 14.5% of the 145 cases reviewed - the third leading cause of death in the CT DMR system. An analysis of the specific cancers diagnosed reveals that bladder, breast and colon cancer were the most prevalent types of cancers in FY 2006.

The rate of death due to cancer in the CT DMR population (1.4/1000) was lower than the rate of 2.0/1000 in the state of CT and 1.9/1000 nationally.[2,11]

Women in the CT DMR system accounted for 11 of the 21 cancer related deaths with breast and stomach cancer occurring more frequently. The highest incidence of cancer in women was breast cancer (30% of all cases) and the average age of onset of the cancer was 62 years. Approximately 1/26 women develop breast cancer at the age of 60.

Nationally the highest incidence of cancer diagnosed in women is breast cancer, representing 1/3 of all cancer cases in women. The median age at diagnosis for breast cancer from 1998 - 2002 was 61 years old. The average of age of women who died as a result of breast cancer in the CT DMR system in FY 2006 was 62 years of age in line with the general population.[27,35]

In addition to breast cancer, stomach (2), colon (2), lung, bladder, liver and oral/pharynx resulted in the cancer related deaths for women.

Women with cancer lived longer than men.The average age of death for women was 66 years and 64.1 years for men. Both of these survival rates exceeded the average age of death of the total CT DMR population (57.5) as well as the age adjusted CT DMR population (people in the DMR system 18 years of age 61.5).

In the male population there was an equal distribution of stomach, colon, lung, bladder, prostate, pancreatic, endocrine, tracheal, esophageal and lymphatic cancers.

As noted in the table below people diagnosed with bladder, lung and liver cancer died at a younger age.

Table 14

Cancer Death Analysis

Primary Site	Number of Deaths	Average Age at Death
Stomach	3	67
Colorectal	3	71
Breast	3	62
Lung	2	59
Bladder	2	48
Liver	1	53
Pancreas	1	67
Prostate	1	73
Endocrine/ Adrenal gland	1	61
Trachea/ Bronchus	1	81
Oral/pharynx Carcinoma in situ	1	68
Lymphatic/	1	73
Hematopoietic	1	73
Esophagus	1	74
TOTAL	**21**	**68.4**

Alzheimer's Disease

It is important to mention that Alzheimer's Disease was not indicated as a leading cause of death in Table 19 and 22 due to the fact that many of the certificates of death did not indicate Alzheimer's as the immediate cause of death. There is a great deal of variability in how physicians document the immediate cause of death for an individual with Alzheimer's Disease. For example, they may document the immediate cause of death for a person with Alzheimer's Disease as respiratory failure, end stage respiratory disease, aspiration pneumonia, pneumonia, pneumonia secondary to sepsis, cachexia, failure to thrive, multi-system organ failure, or Down syndrome, etc. rather than Alzheimer's Disease.

Therefore, in order to accurately reflect the prevalence of Alzheimer's Disease it is important to note that in 41% of all deaths due to respiratory failure, pneumonia or sepsis the underlying cause of death was documented to be Alzheimer's Disease.In fact, the conditions noted above are in many cases co-morbidities which develop as a natural course of Alzheimer's Disease.

As mentioned previously 73% of the individuals with Down syndrome had a diagnosis of Alzheimer's Disease at the time of their death.

Of the 145 mortality cases reviewed in FY 2006, twenty-eight or 19% of individuals were diagnosed with having Alzheimer's Disease at the time of their death.

Alzheimer's Disease would have accounted for 13.9% (28) of all deaths reported in FY 2006. If Alzheimer's Disease was consistently documented on certificates of death as the immediate cause of death,

Cerebral Palsy

It is of some importance to report that 25% of individuals who died in FY 2006 had a diagnosis of Cerebral Palsy at the time of their death. In most cases this condition and its associated sequellae contributed to the deaths of these individuals.

Aspiration Pneumonia

Only 5.5% of reported deaths indicated on the certificate of death that aspiration pneumonia was the immediate cause of death, However, in 41% of all deaths in which respiratory disease/failure, pneumonia and sepsis were documented as the immediate cause of death,aspiration pneumonia was noted an underlying cause of death or active diagnosis.

The role of aspiration pneumonia is even more striking in the Down syndrome population where 62% of people with Down Syndrome died as a result of pneumonia, aspiration pneumonia, respiratory failure or sepsis related aspiration as either a primary or secondary cause of death.

There is a dearth of research regarding the prevalence, best standard of treatment and prognosis for people with ID/DD who have a diagnosis of aspiration pneumonia. The research which is available most is not age specific or defined by level of intellectual disability. Literature related to the effectiveness of various interventions such as fundolplication or placement of gastrostomy or jejunostomy tubes is also scarce.

In our experience improved prognosis and quality of life as well as decreased mortality and morbidity may be related to early diagnosis and intervention such as of placement of a feeding tube. However,most treatment decisions occur toward the end of a cycle of aspiration/pneumonia which usually affects the success rate of the procedure and ultimately the survival rate of the person.

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SECTION FIVE: MORTALITY TRENDS CT DMR

Figure 17

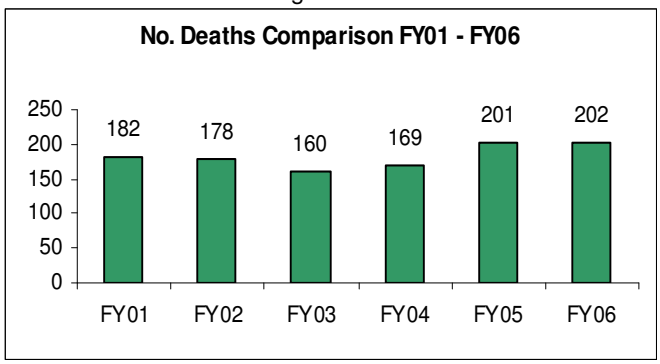
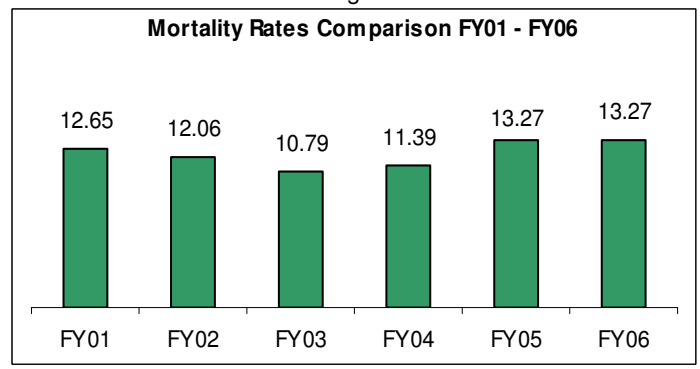


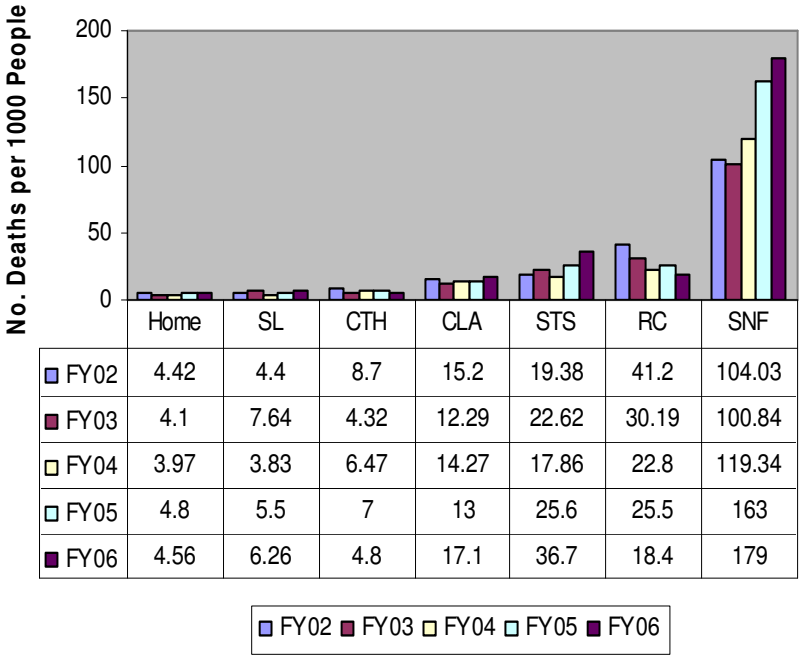
Figure 18



Figures 17 and 18 compare the number of deaths for FY 2001 - 2006 within the population served by DMR and the average death rate during these years. Over this 6 year period of time there has been only slight variations in the number of deaths and mortality rate with the death rate averaging 12.2/1000. Since FY 03 the mortality rate and number of deaths has increased. This trend is most likely due to the increasing age and medical complexity of the individuals served by the CT DMR.

Figure 19

Mortality Rate by Where People Live
5 Year Trend



	Home	SL	CTH	CLA	STS	RC	SNF
FY02	4.42	4.4	8.7	15.2	19.38	41.2	104.03
FY03	4.1	7.64	4.32	12.29	22.62	30.19	100.84
FY04	3.97	3.83	6.47	14.27	17.86	22.8	119.34
FY05	4.8	5.5	7	13	25.6	25.5	163
FY06	4.56	6.26	4.8	17.1	36.7	18.4	179

Figure 19 (graph to the left) compares the death rate (the number deaths per 1000 persons served) for the past five (5) fiscal years by type of residential setting.

The death rate for individuals residing in larger programs (SNF, RC, Campus) who require more intensive nursing supports and medical oversight due to their compromised health status is greater than in other program types.

*In contrast to other research findings the mortality rates for persons living in CT DMR community settings have consistently been lower that mortality rates for people living in congregate (institutional like) settings.[21,33]

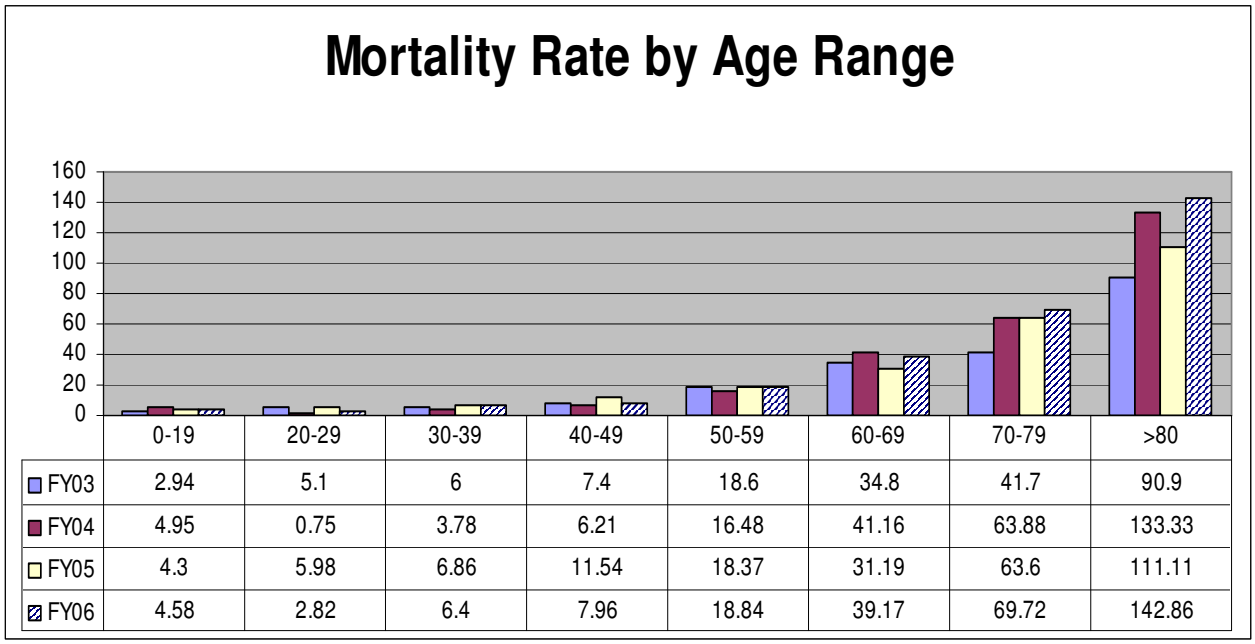
Caution must be exercised in reviewing this data since the actual number of deaths in some of these settings was relatively small.

Table 15
Mortality and Gender
(2002 - 2006)

Year	# Deaths Men	# Deaths Women	Percent Men	Percent Women	Mortality Rate Men	Mortality Rate Women
2002	92	86	52%	48%	11.14	13.23
2003	96	64	60%	40%	11.54	9.84
2004	87	82	56%	44%	10.47	12.57
2005	106	95	56%	44%	12.40	14.38
2006	102	100	50.5%	49.5%	11.86	15.11

For the five year period noted above more men died annually than women. However, except for FY 2003 the mortality rate for women exceeded the mortality rate for men. Last fiscal year the mortality rate for women reached 15.11 the highest level since data collection began.

Figure 20

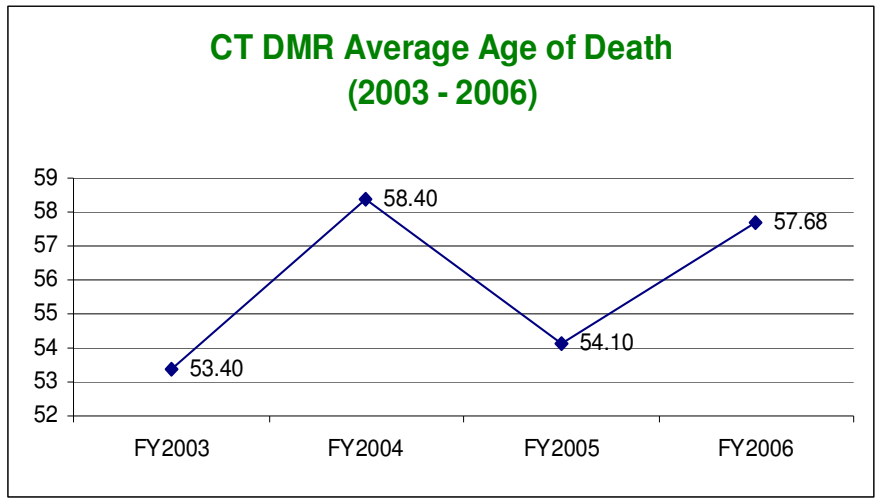


	0-19	20-29	30-39	40-49	50-59	60-69	70-79	>80
FY03	2.94	5.1	6	7.4	18.6	34.8	41.7	90.9
FY04	4.95	0.75	3.78	6.21	16.48	41.16	63.88	133.33
FY05	4.3	5.98	6.86	11.54	18.37	31.19	63.6	111.11
FY06	4.58	2.82	6.4	7.96	18.84	39.17	69.72	142.86

Figure 20 (above) illustrates mortality rate by age range.

The data over the past four fiscal years reveals a consistent pattern of increasing mortality rates with each successive decade of life. The mortality rates increases markedly for older adults starting in the fifth decade of life. Some fluctuation occurs in mortality rates from year to year within each of the age ranges.

Figure 21



For the last four fiscal years the average age of death has fluctuated between the low to upper 50's and demonstrates a gradual increase in the life expectancy at birth for people with intellectual disabilities served by CT DMR. As a point of reference average age of death data since 1989 reveals that in only two years has the average age of death exceeded 55 years of age FY 2004 and FY 2006.

Table 16

RESIDENCE AT TIME OF DEATH
TRENDS
(2002 - 2006)

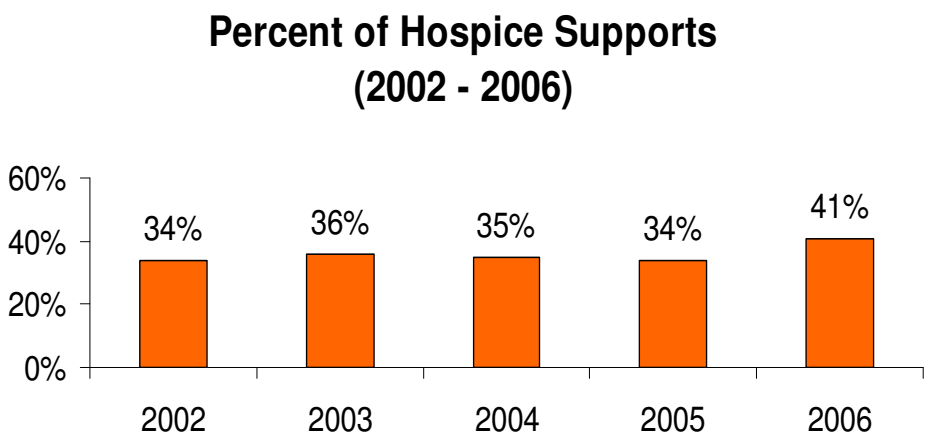
	2002	2003	2004	2005	2006
SNF	28%	30%	35%	40%	34%
CLA	30%	27%	31%	23%	31%
Family	19%	20%	15%	19%	18%
STS	*	9%	7%	7%	10%
RC	*	5%	4%	4%	2%
SL	3%	6%	3%	4%	4%
CTH	3%	1%	2%	1%	1%
Other	2%	2%	0%	2%	0%
	100%	100%	100%	100%	100%

* Data not available

Table 16 depicts the percentage of deaths within various program types over a five year period of time.

Although there is some variability, the percentage of DMR deaths in a given year that occur in SNF's and CLA's is greater than other residential settings and for people who live with their family or in their own home.

Figure 22



End of life planning and hospice care has been a hallmark of the CT DMR system as noted above. In fact the acceptance/embracing of hospice supports increased in FY 2006 to an all time high. Where appropriate end of life planning and support services were provided prior to death with the individual's team involved in the planning process. The increase in hospice supports can be attributed to mortality review findings and recommendations.

Table 17

Location Where Death Pronounced
(FY 2002 - 2006)

Location	2002	2003	2004	2005	2006	5 Year Total
Hospital	41	34	35	64	58	**232**
SNF	13	22	26	35	30	**126**
Hospital ER	10	9	4	18	14	**55**
CLA	17	16	18	16	17	**84**
Hosice	2	1	3	7	2	**15**
STS	4	1	5	4	14	**28**
SL	4	4	3	4	5	**20**
RC	7	11	5	3	2	**28**
Other	1	1	0	1	3	**6**

Over the past two years there has been an increase in the number of people who die in an acute care hospital setting or emergency department versus in their own home/residence. Reasons for this may include more timely treatment, earlier recognition of signs and symptoms of illness by staff, enhanced training of direct care staff, nursing on call system, aging of people and increased use of the health care unit at the training school campus.

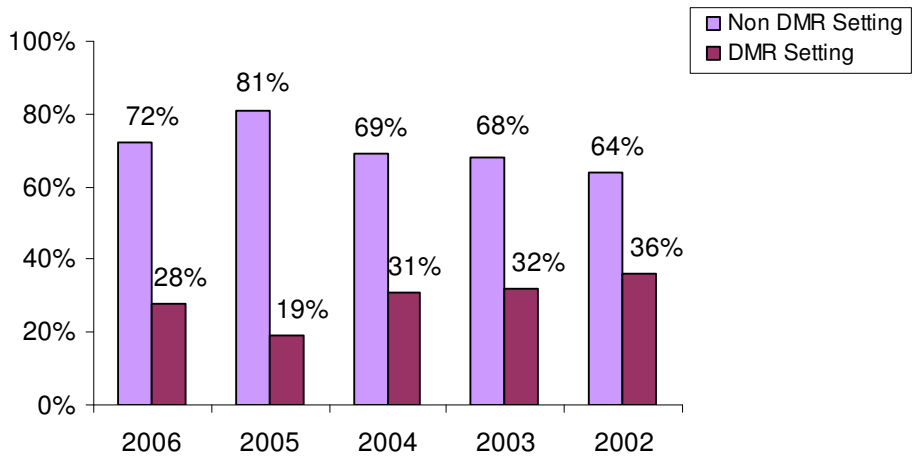
Table 18

NUMBER OF AUTOPSIES (FY 2003 – FY 2006)		
FY 03	28	**21%**
FY 04	16	**16%**
FY 05	20	**13%**
FY 06	**17**	**12%**

As noted in Table 18 above the number of autopsies have fluctuated from one year to the next. Although the number of deaths has increased over the past four years the percentage of autopsies performed has declined slightly. This reduction in post mortem examinations may be associated with a decline in the number of sudden unexpected/unanticipated deaths in the CT DMR system.

Figure 23

Where People Died
2002-2006



The number of people served by DMR who expired in non-DMR funded settings has increased from 2002 – 2005 with a decease noted in 2006 (72%). As mentioned earlier the overall increase in the number of individuals who expire in non-DMR settings may be due to the earlier recognition of signs and symptoms of an individual's acute or chronic illness by direct support staff. This timely reporting of changes in health condition by staff may be a result of training which has occurred due to IMRB findings and recommendations. In addition, formalized training for registered nurses who are on call after hours in the CT DMR system has led to more timely recognition, intervention and referrals to hospitals (hospital inpatient or hospital emergency departments).

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SECTION SIX: LEADING CAUSES OF DEATH NATIONAL, STATE OF CT AND CT DMR

Table 19

Comparison Leading Causes of Death National, State of CT and CT DMR

Rank	US 2004	US 2003	CT 2004	CT 2003	CT DMR 2006	CT DMR 2005	CT DMR 2004	CT DMR 2003	CT DMR 2002
1	Heart Disease 27.2%	Heart Disease 28%	Heart Disease 26.8%	Heart Disease 28.3%	**Heart Disease 25.4%**	Heart Disease 35%	Heart Disease 35%	Heart Disease 29%	Heart Disease 22%
2	Cancer 23.1%	Cancer 23%	Cancer 24.4%	Cancer 24%	**Respiratory Disease 18.2%**	Respiratory Disease 24%	Respiratory Disease 17%	Pneumonia Aspiration 19%	Respiratory/ Lung 22%
3	Stroke 6.3%	Stroke 6%	Stroke 5.6%	Stroke 6.2%	**Pneumonia 14.4%**	Pneumonia Aspiration 12%	Pneumonia Aspiration 14%	Nervous System 16%	Nervous System 14%
4	Respiratory Disease 5.1%	Respiratory Disease 5%	Respiratory Disease 4.9%	Respiratory Disease 4.9%	**Cancer 11%**	Cancer 8%	Septicemia 6%	Cancer 15%	Cancer 10%
5	Accidents 4.7%	Accidents 4.5%	Accidents 4.3%	Accidents 3.7%	**Septicemia 7.8%**	Septicemia 5.6%	Cancer 6%	Digestive System 4%	Renal Failure 5%
6	Diabetes 3.1%	Diabetes 3%	Pneumonia/ Influenza 2.9%	X	**Pneumonia Aspiration 5.5%**	CVA 3.7%	Nervous System 4%	Renal Failure 2%	Digestive System 4%
7	Alzheimer's Disease 2.8%	Influenza/ Pneumonia 2.7%	X	X	**Kidney/ Renal 4.4%**	Accident 3.7%	CVA 3.7%	X	Septicemia 2%
8	Influenza/ Pneumonia 1.8%	Alzheimer's Disease 2.6%	X	X	**Accident 2.7%**	Nervous System 3.3%	Accident 2%	X	Diabetes 2%
9	Renal/ Kidney 1.4%	Nephritis/ Kidney 1.7%	X	X	**CVA Stroke 2.2%**	Digestive System 1.4%	Digestive System 1.6%	X	X
10	Septicemia 1.4%	Septicemia 1.4%	X	X	**Nervous System 2.2%**	Kidney Renal <1%	Kidney Renal 1.6%	X	X

The previous Table (19) compares the leading cause of death for people served by CT DMR from previous years with benchmarks for the State of Connecticut general population and national data. As in past years, heart disease (due to various cardiac diagnoses) is the number one cause of death for all three reference groups with CT DMR reporting a slightly lower percent of cardiac related deaths (25.4%).

As reported last year, respiratory diseases were the second leading cause of death within the CT DMR population (18.2%) while for the other reference groups cancer was the second leading cause of death.

The 2006 cause of death data demonstrates the continued role played by pneumonia and aspiration pneumonia as major causes (3rd and 6th) for people with ID/DD when compared to the general population. Pneumonia and influenza related deaths accounted for less than 3% of deaths in the general population versus 14.4% in the CT DMR system. In fact, while aspiration pneumonia was a cause of death in 5.5% of DMR deaths it was not cited as a leading cause of death in state or national vital statistics.

Respiratory disease (specifically pneumonia and aspiration pneumonia seem to be closely related to the risk factors of immobility and dysphagia/swallowing dysfunction which are prevalent in the population served by CT DMR. Furthermore, the large number of people with Down Syndrome who ultimately develop Alzheimer's disease and its concomitant sequellae (pneumonia/aspiration pneumonia) magnify the significance of respiratory disease in the ID/DD population.

Cancer remained the fourth leading cause of death in the CT ID/DD population (see page 27), while cancer related deaths rank second in the general CT and US populations.

Septicemia due to various etiologies was the fifth (5'th) leading cause of death in the CT DMR population (7.8%), the infection's process originating from various sites. Only 1.4% of death in the US population and less than 2% of deaths in the CT population were a result of sepsis/septicemia.

The five leading causes of death in Table 19 remained the same as in FY 05. There was a decline in the prevalence of heart disease in the CT DMR population in FY 06 which corresponded with a decline in heart disease nationally and in the CT State general population. The prevalence of heart disease also fell more in line with national and state leading cause of death statistics.

In FY 06 the percent of accidents as a cause of death in the CT DMR system (eighth leading cause of death) was once again lower (2.7%) that that reported in the 2004 US population (4.3%) and the CT population (4.7%) (fifth leading cause of death).

The continued presence of sepsis in the ID population as a cause of death reflects a year over year increase from 5.6% in 2005 to 7.8% in 2006 bears careful monitoring as community and hospital acquired infections and antibiotic resistant infections put older and immuno-suppressed people with ID at greater risk for mortality and morbidity.

Although heart disease and cancer continue to be prominent causes of death in the US, general Connecticut and CT DMR populations, there is a dramatic difference in the average life expectance of people with ID (57.5) compared to the general CT State and US population (78 and 77.8 years respectively).[2,11] Though the survival rate of people with ID rose to 57.5, people in the CT State and US general populations without ID/MR lived another two decades (78 years) or 25% longer. This decreased life span is due to the earlier age of onset of multiple chronic and acute co-morbidities associated with ID/DD. This earlier age of onset of severe health issues in people with ID (early in the fourth decade of life) and presents a unique challenge to public and private providers in the State of Connecticut who support people with ID.

The increasing age of death for people with ID reflects gains in lifespan over the past decade related to improved knowledge, medical technology and supports, but even with these gains the reality of a survival rate 25% lower than the general population cannot be ignored. The lower average of death may be due to a combination of factors co-morbidities, syndromes.

Seasonal variations in mortality require consistency when conducting comparative analysis and, therefore, the previous data regarding leading causes of death is based on the calendar year 2006. This will allow for more direct comparison to Connecticut and national mortality benchmarks developed for the general population (2004) calendar year.

Cause of death data included in this report is based on all certificates of death of the CT DM mortality reported in calendar year 2006.

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) in certain residential types and causes of death. Differences that occur year to year may not be statistically significant.

SECTION SEVEN: SUMMARY MORTALITY CASE REVIEWS FINDINGS AND TRENDS

- An important component of the quality and 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 systems enhancements. Consequently CT DMR continues to embrace a planned systems organization wide approach to design, performance measurement analysis and improvement by collect information pertaining to the death of all individuals served by the department. The CT DMR mortality review system has proven to be a quality assurance mechanism providing information driven quality to trigger corrective action and reduce future risk.

The CT DMR mortality review process provides a retrospective analysis

THAT

- assures compliance with standards
- reduces adverse events,
- leads to ongoing improvement
- crosses all waiver programs

AND GENERATES

- changes in policy
- protocol development
- practice standards
- focused training

Table 20

Mortality Case Summary FY 2006

Death Reviewed By Regional Committees	*Cases Closed at Regional Level*	*Cases Referred and Reviewed By IMRB*	*QA Cases Closed by region IMRB Review*
145	101 (70%)	44 (30%)	32 (32%)

Cases Referred to IMRB (44)	
Post Mortem Examination	17
Medical/Health Care Issues	14
Pending Abuse/Neglect Investigations	13

Of the 101 cases closed at the regional committee level, medical and other aspects of care was determined to be appropriate.

Per the CT DMR Mortality Review Policy and Procedure for quality assurance purposes, at least 10% of all mortality cases closed by the Regional Mortality Review Committee are also reviewed by the Independent Mortality Review Board (IMRB). In FY 06 the IMRB exceeded this number with 32 of all closed cases at the regional level reviewed by the IMRB. Quality assurance checks which equated to almost 32% of all cases closed at the regional mortality committee level.

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Summary of General Findings/Systems Enhancements

Findings/Recommendations	Actions/Enhancements
Professional nursing care and coordination. Compliance with CT Nurse Practice Act	DPH investigation recommendations regarding scope of practice implemented. Protocols regarding scope of practice as it relates to CT DMR system were established. Nursing delegation procedure in place.Training program developed for nursing delegation and on call nursing system. Best Practice standards for nursing established in various areas of practice
Emergency Department and hospital based evaluation and treatment.	Improvement was seen in the timely evaluation and treatment by ER practitioners as a result of DPH investigations, collaboration with DMR nursing staff for ER managers and physicians. Primary contacts established documentation forms.
Documentation standards	Documentation was present and verified delivery of support services in the majority of cases. Additional training and standards for documenting vital medical information, rational for treatment and communicating of diagnostic testing or physical examination were developed by CT DMR Health Services staff. System of documenting communication between CT DMR and community based nursing agencies (e.g. VNA) was initiated.
Accidental Deaths	CT DMR Safety Campaign initiated. Regional identification of risk and potential risk factors.
Reporting of Death and Abuse/Neglect Investigations	All deaths were reported to CT DMR per critical incident reporting procedure. Investigations were initiated in a timely manner. Families/guardians notified and involved in the process
Hospital Discharge Planning	Continued improvement in this complex area which in several cases led to mortality and/or morbidity. Special emphasis and training for RN and direct care staff. Standards for pre/post discharge assessment by RN regarding discharge orders, coordination of post discharge services and related training. Noticeable improvement in discharge planning with acute care hospitals. The increased focus on hospital and nursing home discharge planning for people with ID/DD has resulted in a noticeable improvement in coordination of supports post discharge.
Professional Nursing Services Coordination	Increased role and impact of nursing coordinating heath care. Development of health and nursing best practice standards/procedures.
Nursing Shortage in ID/DD Field	CT DMR established clinical internships with several schools of nursing BSN and LPN technical programs. Orientation for technical expertise and consultation for recruitment of nurses (RN/LPN) for both the public and private sector. CT DMR established a strong relationship with the state Developmental Nurses Association (DDNA.). Agency network collaboration with nurses specializing in ID/DD. Network collaboration with community base nursing agencies VNA and hospice.
Registered Nursing On Call System	Timely notification of change in condition and onsite assessment as determined by the registered nurse.

Summary of General Findings/Systems Enhancements (continued)

Recommendations/Findings	Actions/Enhancements
Training **Need for enhanced or refresher training for clinical and non-clinical staff. (e.g. dysphagia, documentation, signs and symptoms of illness)**	DMR staff development Department revised New Employee Training. E Learning Standards of Care.
Health and Wellness **Analysis of cases revealed need to manage chronic health issues that effect people with ID at earlier ages.**	Health and Wellness Pilot Program Emphasis Oral Health Care Coordinator Managed care evaluation – plan Standards to improve quality of life Non-crisis, preventative approach to risk management QI
Coordination of Care **Individuals living in less traditional programs with fewer supports require on going monitoring and coordination of health care.**	Managed Health Care Pilot Program initiated
Medication Administration	No reported mortalities or serious morbidity associated with errors in the administration of medications by licensed nursing staff or medication certified staff. Quality oversight by CT DMR comprehensive medication certification program and regulations regarding the administrations of medications to people served by CT DMR. Network established to communicate health and case specific findings and recommendations which impact on the health and safety. Guidelines, standard of care technical assistance to mitigate risk and resolve agency specific health support needs. Meeting with the Commissioner to review mortality findings and recommendations.
Standardization of nursing practice for both the public and private sector	Bimonthly meetings with public sector and private provider Registered Nurses for the purpose of reviewing IMRB/Regional mortality review findings and recommendations and clinical/health practices to improve health care services. Chaired by regional Directors of Health Services.

Systemic Findings	Actions
Use of bisphosphonates in non-ambulatory Individuals with developmental disabilities	Health Standard regarding osteoporosis Use of bisphosphonates
Rational for treatment For example: Decisions regarding hormone therapy	Communication to Registered Nurses regarding detailed documentation regarding risks and benefits of treatment.
Frequent falls resulting in injury risk for falls. Ongoing monitoring of falls.	DMR Safety Campaign identification of people at monitoring by Team and nursing staff.
Dysphagia/swallowing risks (choking incidents)	DMR Safety Campaign identification of people at for dysphagia. Development of dysphagia guidelines best practice standards and related training.
Parameters for considerable weight loss	Development of health standards.
Gastrointestinal Dysfunction Abdominal Emergencies (e.g. pancreatitis)	Development of health standards.
Pain management	Was consistently identified and provided.
Nursing home placement	Placement into nursing homes was appropriate. OBRA process implemented per regulations

The CT DMR mortality review process has evolved into a powerful quality assurance system for ensuring the delivery of optimal health care oversight and services in all DMR programs. The Regional and State recommendations regarding health care oversight and standardization of health care practices for professional and non-professional staff have improved basic health care services and mitigated health related risk. The impact of mortality findings and recommendations has been felt (observed) in all areas of service delivery from the public and private provider agencies supporting people in traditional community based programs to services with less support as well as skilled nursing facilities and acute care hospitals.

The number of negative health outcomes that have been avoided as a result of the implementation of mortality review recommendations but the number has been impressive. Future data collection in this regard may be of great value.

One direct example of actions that have taken place within the CT DMR system as a result of mortality review recommendations improving the coordination and oversight of health care has been the increase in the number of registered nurses with specialized experience and training in the field of ID and DD nursing that have been hired in both the public and private sector. This has resulted in better coordination, direct clinical supports and healthcare oversight within these agencies. In addition, the competency of direct service staff in the area of health care monitoring have improved a great deal. Furthermore, when mortality review recommendations have been shared with community based healthcare practitioners their future healthcare encounters reflect a newfound sensitivity toward people with ID/DD.

Recommendations generated by the mortality review process have served to maintain the focus on the importance of health related supports for people with ID/DD.

Over the past several years there has been a distinct and noticeable connection between mortality review recommendations and quality improvement initiatives in the CT DMR service system.

SECTION EIGHT: BENCHMARKS

Benchmarks are standards by which similar items can be compared and allow the reader to place findings in context. As mentioned in the 2005 MASS DMR Mortality Report there are few relative benchmarks for use in comparing mortality data for persons with ID/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*

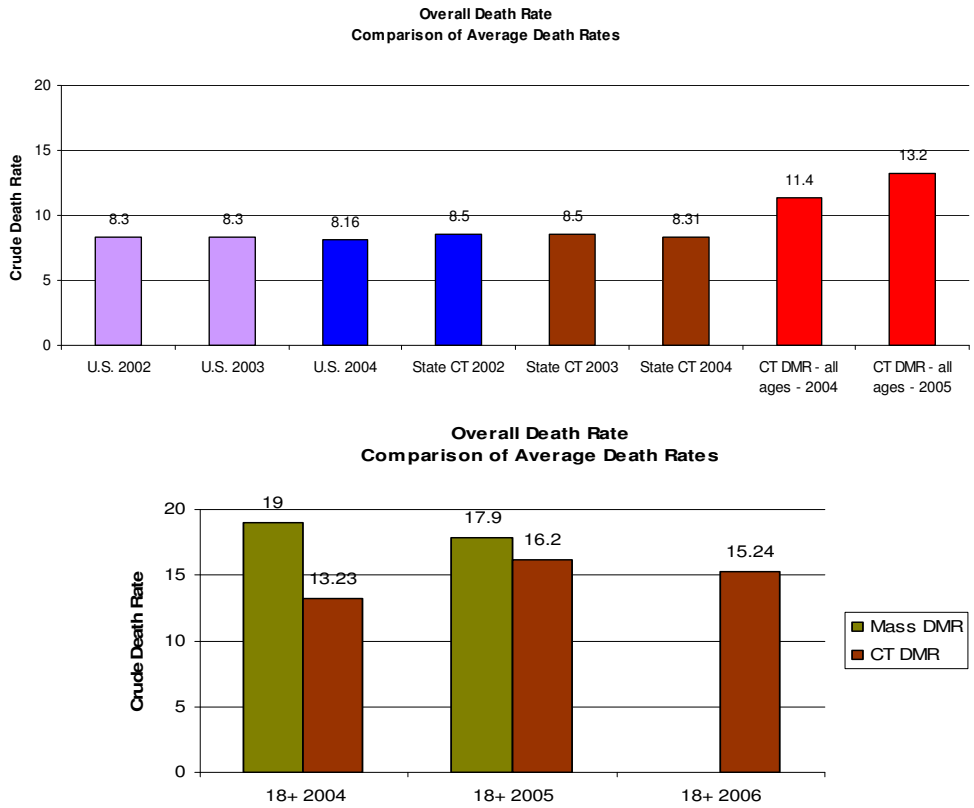
The trends identified in this year's (2006) Health and Mortality Annual Report (July 1, 2005-June 30, 2006) were consistent with the findings and basic demographic trends found in the 2002 Independent Study.

- *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*

Massachusetts DMR

The Massachusetts Department of Mental Retardation continues to enhance and expand its mortality reporting requirements for its annual report. The 2004/2005 Mortality Reports were prepared by the University of Massachusetts Medical School/Shriver Center for Developmental Disabilities Evaluation and Research[17]. 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 ID/DD population.

Figure 24

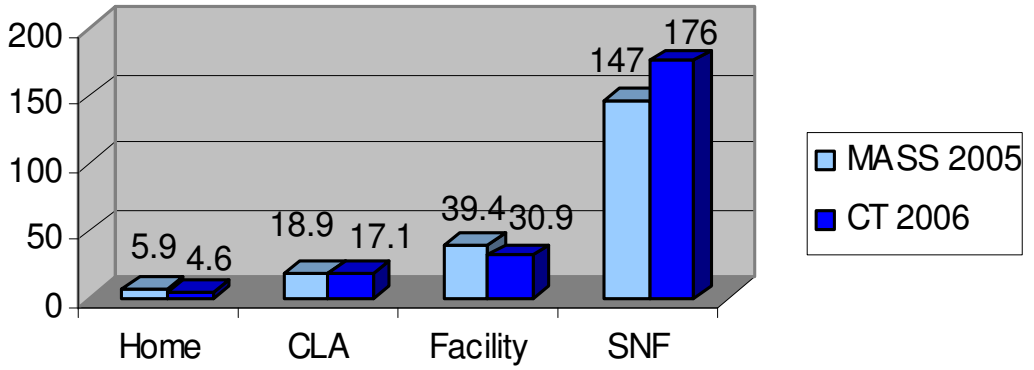


A comparison of the overall death rate for persons served by the Connecticut DMR with similar rates for the general population in Connecticut, the U.S. and the DMR population in Massachusetts are presented in the above histogram (Figure24)

(See Figure 24) 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.

Figure 25

Comparison of Death Rates CT DMR vs. MASS DMR by Where People Live



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.

CT DMR data is based on all people served by the CT DMR. Mass data is for the adult population only (Figure 25)

Average age of death MASS DMR 2005 was 60.8 years compared to CT DMR 57.5 However age adjusted for individuals over the age of 18 years or older the average age at death in CT DMR of 61.5 is almost identical to the MASS DMR average age of 60.8 (2005 data)

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Table 21

Leading Causes of Death CT and MASS

Rank	CT DMR 2006	CT DMR 2005	CT DMR 2004	CT DMR 2003	CT DMR 2002	MASS DMR 2005	MASS DMR 2004	MASS DMR 2003	MASS DMR 2002
1	Heart Disease 25.4%	Heart Disease 35%	Heart Disease 35%	Heart Disease 29%	Heart Disease 22%	Heart Disease 16.4%	Heart Disease 18.5%	Heart Disease 22.3%	Heart Disease 21.2%
2	Respiratory Disease 18.2%	Respiratory Disease 24%	Respiratory Disease 17%	Aspiration Pneumonia 19%	Respiratory/ Lung 22%	Cancer 12%	Cancer 12.5%	Cancer 13.5%	Aspiration Pneumonia 12.3%
3	Pneumonia 14.4%	Pneumonia Aspiration 12%	Pneumonia Aspiration 14%	Nervous System 16%	Nervous System 14%	Influenza/ Pneumonia 10.8%	Aspiration Pneumonia 11.2%	Aspiration Pneumonia 12.3%	Cancer Septicemia 10.1%
4	Cancer 11%	Cancer 8%	Sepis 6%	Cancer 15%	Cancer 10%	C-P Arrest Seizure 10.8%	Influenza Pneumonia 10.9%	Septicemia 9%	C-P Arrest/ Seizure 9.4%
5	Sepsis 7.8%	Sepsis 5.6%	Cancer 6%	Digestive System 4%	Renal Failure 5%	Aspiration Pneumonia 9.3%	Alzheimer's Disease 7.5%	C-P Arrest/ Seizure 7.2%	Alzheimer's Disease 7.2%
6	Pneumonia Aspiration 5.5%	CVA 3.7%	Nervous System 4%	Renal Failure 2%	Digestive System 4%	Alzheimer's Disease 8.60%	C-P Arrest/ Seizure 6.8%	CLRD 6%	CLRD 6.2%
7	Kidney/ Renal 4.4%	Accident 3.7%	CVA 3.7%	Diabetes 1.5%	Septicemia 2%	Septicemia 5.9%	Septicemia 6.6%	Alzheimer's Disease 5.3%	Influenza Pneumonia 4.7%
8	Accident 2.7%	Nervous System 3.3%	Accident 2%	X	Diabetes 2%	CLRD 4.6%	CLRD 5.7%	Influenza Pneumonia 4.6%	Nephritis 4.0%
9	CVA Stroke 2.2%	Digestive System 1.4%	Digestive System 1.6%	X	X	Stroke 4.2%	Nephritis 3.6%	Stroke 4.2%	Stroke 3.5%
10	Nervous System 2.2%	Kidney Renal <1%	Kidney Renal 1.6%	X	X	Unintentional Injuries 3.4%	Stroke 3.6%	Nephritis 2.6%	Congenital Defects 2.5%

A review of the data from CT DMR and MASS DMR continues to suggest that the leading causes of death for people with ID/DD is different than the general population.The table above reveals that heart disease and respiratory disease (including aspiration pneumonia) continue to be the leading causes of death in the ID population and continues to demonstrate the **role played by respiratory disorders** in this population group. Differences in causes of death and ranking may be due to the differences in the population analyzed (age range) and variations in cause of death documentation by practitioners.

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Addendum

Summary of IMRB Case Specific Findings and Actions

IMRB Case Specific Findings/Recommendations	Actions/Enhancements
Issues regarding standards and quality of care and provision of health care.	Referral to CT State Department of Public Health Facility Division
Issues with monitoring and provision of health care services in community based programs.	Private and public administrative staff to meet with representatives of CT DMR.
Community based practitioner standards of care were not comprehensive.	Letter to practitioner regarding medical treatment practice
Evaluation of dyphagia for individuals in CTH program was not provided.	Case presented to DMR Program Managers (CTH) - implemented dysphagia standards and guidelines
Identification of medication related death.	Case report to FDA Med Watch.
Issue regarding quality of health care monitoring by nonprofessional and professional staff	Quarterly monitoring of provider agencies by DMR QI monitoring.
Issue regarding post mortem findings.	Letter to CT OCME pathologist.
Issue regarding documentation by provider agency staff.	Letter to provider regarding documentation standards for licensed nursing and direct support staff.
Issue regarding scope of practice of licensed nursing staff	Letter to provider regarding scope of practice and monitoring by DMR Quality Management Division.
Issue regarding post discharge care.	Letter to provider regarding agency system for post discharge planning.
Issue regarding death certificate.	Letter to practitioner to amend death certificate.

Quality Assurance Case Specific Findings/Recommendations	Actions/Enhancements
Cases closed appropriate care.	No further findings or recommendations.
Issue regarding death certificate.	Letter to practitioner to amend death certificate.
Issue regarding lack of documentation (2), protocol for falls (1), monitor weight loss (1)	Letter to provider agency protocol for fall and weight loss.
Issue regarding physician/practitioner regarding standard of care.	Letter to provider regarding hormonal therapy, health screening, follow up of adrenal mass, colonoscopy.
Letter of commendation to facility/provider.	Letter to practitioner regarding excellend practice.
Letter regarding of systems issue risk/benefit of treatment (documentation).	Rational for hormone therapy treatment – document benefits vs. risks
Issues regarding standards and quality of care and provision of health care.	Referral to CT State Department of Public Health Facility Division

All aspects of care were found to be appropriate in 108 of the 145 cases reviewed or 74% of all cases

List of Tables and Figures