

Mortality

ANNUAL REPORT

FY 2007

This is the sixth 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 Developmental Services. Reports focus on an analysis of mortality data and specific findings resulting from the Connecticut DDS mortality case review process. Reports are scheduled for publication March of each year.

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CT DDS Mortality Report

SECTION ONE OF THIS REPORT :

OVERVIEW OF CT DDS POPULATION

This section includes demographic information on the population served by the CT DDS

SECTION TWO OF THIS REPORT:

ANALYSIS OF ALL CT DDS MORTALITIES

This section includes information and data concerning all deaths of individuals served by DDS who were listed in the CT DDS data base and died during the 2007 fiscal year (July 1, 2006- June 30, 2007). Some of these deaths do not meet the CT DDS criteria for a formal mortality review by either the regional mortality review committees or state Independent Mortality Review Board.

SECTION THREE OF THIS REPORT:

CT DDS MORTALITY REVIEW

This section describes the various tiers of the CT DDS Mortality Review Process.

SECTION FOUR OF THIS REPORT:

ANALYSIS OF DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS

This section includes information and analysis of data generated for the 137 deaths reviewed by the DDS regional review committees and Independent Mortality Review Board (IMRB) for the period July 1, 2006 – June 30, 2007.

SECTION FIVE OF THIS REPORT:

MORTALITY TRENDS CT DDS

This section provides an analysis and synthesis of CT DDS mortality data over time.

SECTION SIX OF THIS REPORT:

LEADING CAUSES OF DEATH

This section presents CT DDS leading cause of death data in comparison with CT state and national leading cause of death data.

SECTION SEVEN OF THIS REPORT:

BENCHMARKS

This section presents mortality data submitted by the CT DDS and MA DMR mortality review systems for the purpose of comparison and identification of benchmark data.

SECTION EIGHT OF THIS REPORT:

SUMMARY MORTALITY CAE REVIEW FINDINGS AND QUALITY ENHANCEMENTS

This section includes information on the findings identified through the DDS mortality review process and quality initiatives implemented as a result of the regional committees and Independent Mortality Review Board case findings.

This report represents a review of the period between July 1, 2006 to June 30, 2007.
Data in this report was obtained from the CT DDS Database system.

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Highlights 2007 Report

Over a six year period mortality data collected, reviewed and analyzed by the CT DDS has revealed consistent trends in mortality and residence, mortality rate by age, gender and leading causes of death

The consistency of cumulative data from one year to the next seems to validate and support the trends and findings identified within the intellectual disability population group served by the State of Connecticut Department of Developmental Services.



- The strongest predictors of mortality are age, mobility status, the need for special assistance when eating, and the amount of supervision provided
- The “aging in place” phenomenon continues to be a leading risk factor as individuals served by DDS become older and more disabled over time
- Mortality is highly related to the level of intellectual disability, the greater the level of disability the higher the mortality rate
- Women served by DDS have a higher mortality rate



- Health care coordination by Registered Nurses played a key role in timely identification of change in condition of persons with ID and appropriate referral to medical practitioners.
- The decreased life span for people with ID is related to the onset of multiple chronic and acute co-morbidities at an earlier age than the general population
- The earlier age of onset of acute and chronic health issues in people with ID presents a unique challenge to caregivers who support people with ID
- The increasing age of death for people with ID is most likely related to improved knowledge, medical technology and support services
- Community based health care providers continue to lack training in the care of people with ID/DD
- The CT DDS process for reviewing withholding of cardiopulmonary resuscitation is timely and appropriate
- No fatalities were associated with the administration of medications
- Nursing supports were in place In all cases that were reviewed by the regional and/or Independent Mortality Review Board
- People supported by the CT DDS receive appropriate medical services, however, access to quality dental services was not always available especially in nursing facilities.
- For the majority of anticipated deaths hospice services are provided
- Most mortality cases referred to the Department of Public Health or the Office of Protection and advocacy for further investigation resulted in citations/violations or the substantiation of neglect
- When populations are adjusted for age and other variables mortality benchmarks for the CT DDS and MA DMR ID population demonstrate noticeable similarities and patterns
- The CT DDS mortality review process is a powerful quality assurance activity evidenced by the fact that over the years there has been a distinct and noticeable connection between mortality review recommendations and quality improvement initiatives in the CT DDS service system.

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Highlights 2007 Report (continued)

- 
- There were 199 deaths resulting in a crude mortality rate of 12.97/1000
 - The average life expectancy of people with ID rose to 57.93 years compared to the general CT State and US population (75 and 77.9 years respectively).^{2,11}
 - Heart disease continues to be the leading cause of death in the CT DDS population
 - Accidental deaths continue to occur at a rate below that of the general state and national population
 - Respiratory failure was the leading cause of death for people with Down syndrome
 - The average age of death for people with Down syndrome remained steady
 - Alzheimer's disease was present in 63% of people with Down Syndrome prior to their death
 - The incidence of cancer related deaths of men was twice that of women with ID.
 - Starting early in the fifth decade of life there is a progressive increase in the mortality rate for people with intellectual disabilities
 - Respiratory disease including aspiration pneumonia/ pneumonia accounted for 35% of all deaths

- 
- The CT DDS mortality data suggests that enteral feedings do not prolong survival in people with intellectual disabilities
 - 54% of people who required enteral feedings died within two years of tube placement usually due to aspiration pneumonia
 - The greatest number of DDS deaths occurred in licensed nursing facilities (33%)
 - The majority of deaths (81%) were pronounced outside of a DSS operated/licensed or funded residential setting
 - The average age of death for people living in ICF/MR facilities was 72.8 years
 - Sixty-nine percent (69%) of all deaths that occurred in FY 2007 were reviewed by CT DDS mortality review process
 - Forty-eight percent (48%) of all deaths were reviewed by the CT DDS Independent Mortality Review Board (IMRB)

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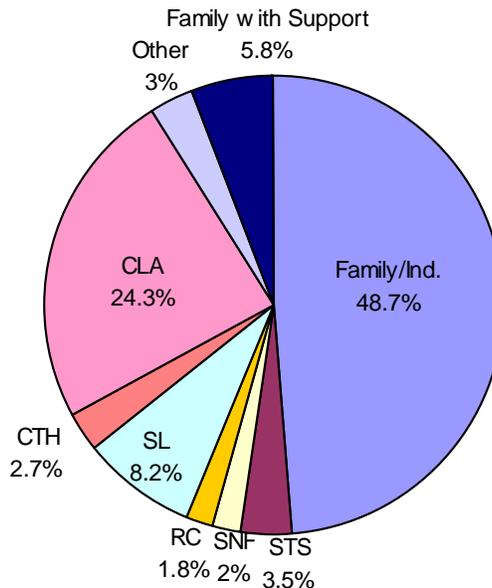
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SECTION ONE: Overview of DDS Population

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 DDS services they must have significant deficits in intellectual functioning and in adaptive behavior, both before the age of 18 yrs. As of June 30, 2007, **15,148** individuals with intellectual disability were being supported by the department.

Figure 1

Overview of DDS Population Percentage by Setting



Over half of the people served by CT DDS live at home with their family or independently without supports. The remainder of the people served by DDS (over 6,000) receive funded residential supports. The majority of these supports are traditional in nature, with support services provided in (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 licensed nursing facilities (SNF), the CT Department of Mental Health and Addiction Services, the CT Department of Children and Families, the CT Department of Corrections and residential schools.

NOTE: As of July 2007 the CT DDS redefined Supported Living (SL) services as people living in their own home or receiving individualized supports. This change will be reflected in the Mortality Annual Report FY 2008.

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Section One Continued

CT DDS Population Trends

Table 1
DDS CONSUMERS BY RESIDENTIAL SETTING
FY 2005 - FY 2007

Restype	2007		2006		2005		2006 - 2007
	TOTALS	Percent	TOTALS	Percent	TOTALS	Percent	% Pop Change
Family/Independent Living	7,369	48%	7,484	50%	7,750	52%	(-1.5%)
CLA (Group Home)	3,680	24%	3,609	24%	3,565	24%	2%
Supported Living	1,240	8%	1,264	8%	1,261	8%	(-2%)
Family with Individual Supports	866	6%	597	4%	305	2%	31%
Training School	526	4%	551	4%	572	4%	(-4.6%)
Other	443	3%	515	3%	514	3%	(-14%)
Community Training Home (CTH)	408	3%	412	3%	426	3%	(-1%)
SNF	348	2%	307	2%	280	2%	12%
Regional Center (RC)	268	2%	267	2%	267	2%	0.5%
TOTAL	15,148	100%	15,018	100%	14,943	100%	

RESIDENTIAL POPULATION TRENDS

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

Although the gross percentages of people served by CT DDS have increased by less than 1% over the past two fiscal years, there have been greater population shifts within program types as noted below.

- The number of people served in community living arrangements (CLA) increased by 2%
- The number of people served by community training homes (CTH) continued a downward trend down another 1% over the past year.
- The number of people served in skilled nursing facilities increased by almost 12% from FY 2006 –2007 this increase is related to the aging DDS population, increased medical acuity level, the number of people placed in nursing facilities from home and the number of people requiring short term rehabilitation post hospital discharge. The population of DDS consumers in SNF's fluctuates (+)(-) 5% throughout the course of the year
- The number of people served in the SL services decreased by almost 2%
- The number and percent (54%) of people served by CT DDS who live in independently or with their families increased by 1.8% compared to the number of people living at home in FY 2006
- The number of people served who live at the training school decreased by 4.6%, the same decrease that occurred from FY 2005 to FY 2006
- The number of people served at regional centers (RC) was almost identical to the previous year

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Section One Continued

Table 2

DDS Population By Age 2004 - 2007

	2007	2006	2005	2004	2004 - 2007	
					Population Changes	Percent Change
Children (0-19)	3,625	3,663	3,766	3,815	-190	-5.0%
Adults (20 - over)	11,523	11,355	11,177	11,121	+402	3.5%
TOTAL ALL AGES	15,148	15,018	14,943	14,936	+212	1.4%

Adults (55 - over)	2,587	2,470	2,397	2,318	+261	10.4%
Adults (65 - over)	991	957	954	944	+47	4.8%

Table 2 above illustrates the the number of children, and adults served by DDS from 2004 - 2007.

That data shows that between FY 2004 – 2007 the population served by DDS has increased by only 1.4% from 14,936 to 15,148.

However an in-depth analysis of this data is more revealing illustrating demographic changes that have been occurring within the population served by DDS system during the same timeframe.

- The population data illustrates that the DDS population is gradually aging. The number of children below the age of 19 years has decreased by 5% while the number of adults over the age of 20 years has increased by 3.5%
- Over the past four years the “aging” of the DDS population is more pronounced. The number of people served who are 55 years or older increased by 10.4% and the number of people over 65 years of age has increased by 4.8%
- There was a corresponding 3.5% population decline for persons 75 years or older between 2004 - 2007
- Older adults (>55 years of age) now comprise over 17% of all people served by DDS. The number of adults 55 years or older who are served in traditional DDS supports (excluding family homes/IL) comprise close to 30% of all people served by DDS
- As expected, this aging phenomenon in the adult DDS population parallels national trends, and has previously been identified in other CT DDS population trend analyses (State of CT DDS Aging Focus Team Report and Recommendations October 2003).²⁹

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

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Section One Continued

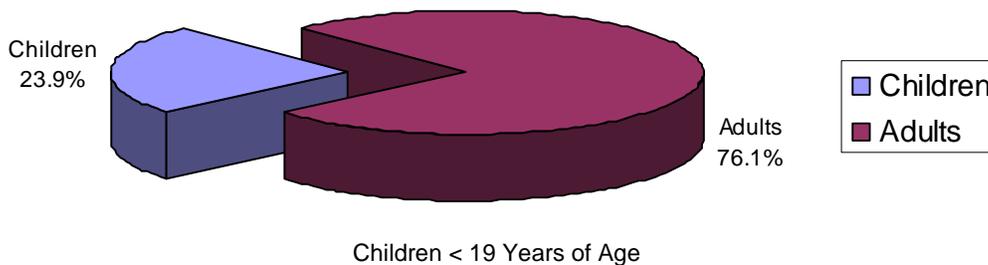
AGE DEMOGRAPHICS

Table 3
Percent Population by Age Ranges
FY 2007

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,625	23.9%
Age 20-29	3,002	19.8%
Age 30-39	2,082	13.8%
Age 40-49	2,701	17.8%
Age 50-59	2,075	13.7%
Age 60-69	1,064	7.0%
Age 70-79	411	2.7%
Age 80+	188	1.3%
TOTAL	15,148	100%

Table 3 depicts the number and percentage of people served by CT DDS by various age ranges for FY 2007. Approximately 25% of people are over 50 years of age.

Figure 2
Percent of Children



Children 19 years of age or younger represent 23.9% percent of the CT DDS population.

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Table 4
AGE CATEGORY AND RESIDENCE
FY 2007

Restype	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
CLA	125	3,194	362	3,681
SNF	0	142	160	302
STS	0	384	142	526
SL	5	1,121	113	1,239
Other	210	211	67	488
Family Home	3,259	4,248	60	7,567
Independent Living	11	613	45	669
CTH (Community Training Home)	13	352	43	408
Regional Center	2	265	1	268
TOTAL	3,625	10,530	993	15,148
PERCENT	24%	70%	6%	100%

Table 4 above reveals that the greatest number of older adults (> 65 years of age) reside in community living arrangements and in descending order skilled nursing facilities, STS and SL services. Ninety percent of all children served by the CT DDS service system live at home with their families.

AVERAGE AGE OF ALL PEOPLE SERVED BY CT DDS :

35.7 YEARS – 2007

35.4 YEARS - 2006

Table 5

Consumers Age 20 - 64 Years By Program Type

SNF	46%
STS	73%
CLA	86%
CTH	87%
SL	91%
Family/Independent	62%
RC	99%

Table 6

Consumers over the Age of 65 By Program Type

SNF	54%
STS	27%
CLA	11%
CTH	10%
SL	8.8%
Family/Independent	<1%
RC	<1%

On a percentage basis skilled nursing facilities (54%) and STS (27%) support the greatest number of people over the age of 65.

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Section One Continued

CT DDS GENDER STATISTICS

Table 7

CT DDS GENDER STATISTICS

Gender	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
Female	1,341	4,664	536	6,541
Male	2,284	5,866	457	8,607
TOTAL	3,625	10,530	993	15,148

Historically the number of men served in the CT DDS system far exceeds the number of woman. FY 2007 was no different with males comprising 56.8% of the population versus 43.2% for women. CT DDS supports 1.3 males for every female served. A similar male to female ratio is also reported in other state's DD service systems. One explanation for the greater proportion of males served by the CT DDS system is that families may find it more difficult to manage/support males at home. Due to survival rate dynamics the number of females over 65 years of age (536) surpasses the number of males (457).

AVERAGE AGE OF ALL CT DDS CONSUMERS:	35.7 YEARS
AVERAGE AGE OF MALES SERVED BY CT DDS:	34.1 YEARS
AVERAGE AGE OF FEMALES SERVED BY CT DDS:	37.2 YEARS

<p>2007 CT DDS Population Gender Statistics 2007</p> <p>Male 56.8% Female 43.2%</p>
<p>2006</p> <p>Male 56.6% Female 43.4%</p>
<p>2005</p> <p>Male 56% Female 44%</p>

<p>2005 CT Population Gender Statistics</p> <p>Male 48.6% Female 51.4%</p>

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**SECTION TWO: ANALYSIS OF ALL CT DDS MORTALITIES
(JULY 1, 2006 – JUNE 30, 2007)
NUMBER OF DEATHS REPORTED = 199**

This section summarizes **all deaths (199)** reported to CT DDS and provides a detailed analysis of these deaths.

Overall Mortality Rate

During the 12 month time period between July 1, 2006 and June 30, 2007 a **total of 199** individuals served by CT DDS passed away **resulting in a mortality rate of 12.97**. (Figure 3 & 4 below)

Figure 3

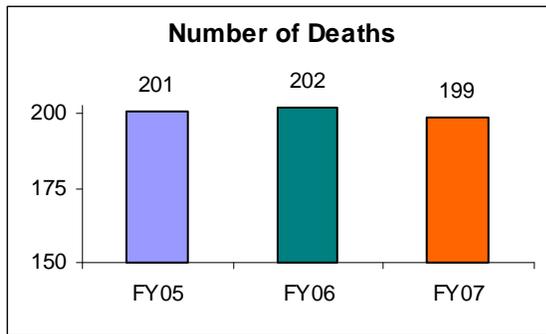
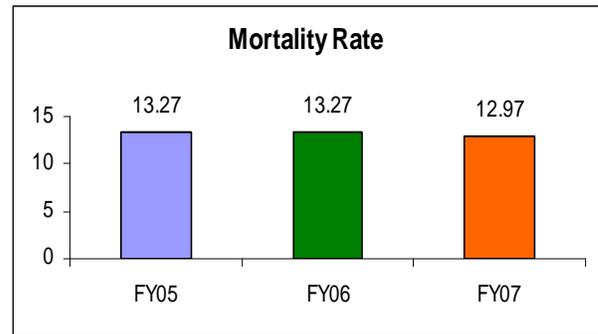


Figure 4



Mortality and Residence

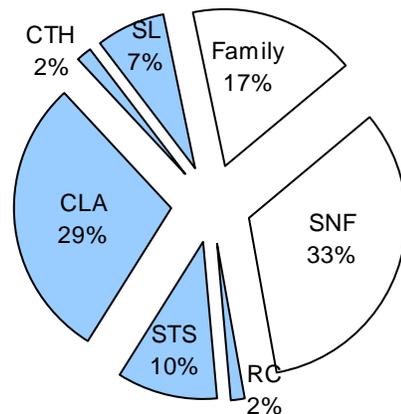
As can be seen in Figure 5 (to the right) 50% of individuals served by CT DDS died while in a residential setting operated, funded or licensed by DDS. Deaths which occurred in family or IL or skilled nursing facility accounted for the remainder of the reported deaths.

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 DDS.

Figure 5

Residence at Time of Death



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Figure 6

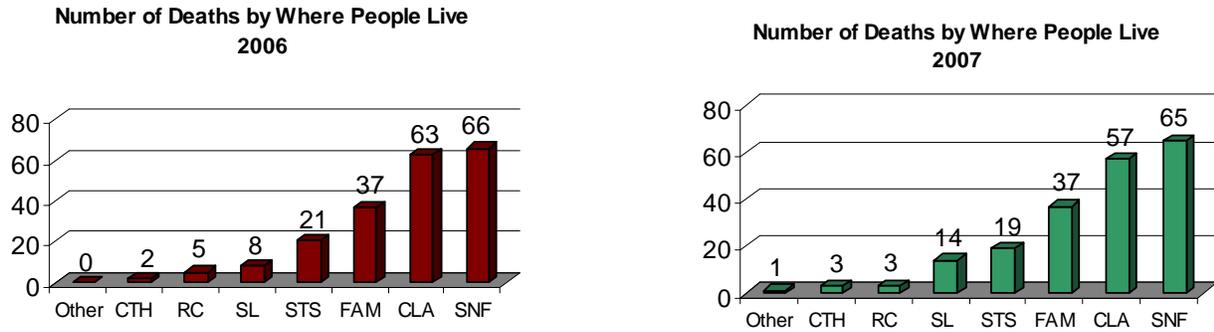


Figure 6 (above) depicts the actual number of deaths by where people live. In line with last year's data the greatest number of deaths occurred in skilled nursing facilities followed by CLA's, family homes and STS. Fifty-four (54%) of the people DDS supports live in family homes/independently, 24% in group homes (CLA's) and only 2% in skilled nursing facilities.

Figure 7

Mortality Rate by Where People Live

No. Deaths per 1000 people
FY 2007

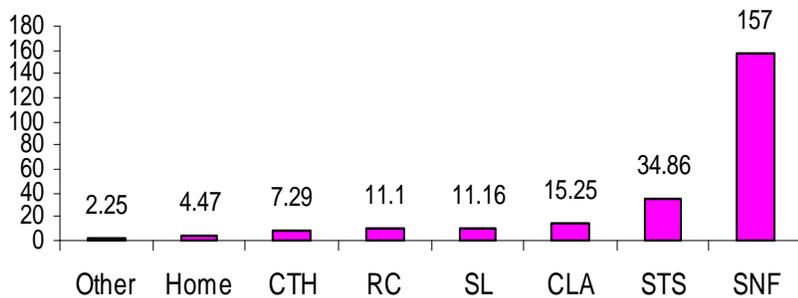


Figure 7 (on the left) shows the number of people who died for every 1000 people served in each type of residence.

Individuals living in skilled nursing facilities, and at STS tend to be older than people living in other residences or at home. They also have greater intellectual impairment, functional impairments and health related co-morbidities which require greater levels of supervision and health monitoring by licensed health professionals.

* 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/Independent: People who live with their family or independently without DDS supports represent 54% of the DDS population. In FY 2007 only 17% of all deaths in DDS occurred in the family/independent home settings with an associated mortality rate of 4.47. Thirty-five percent of the people who died in this sub-population were under the age of 20.

CLA: These settings serve people with varying levels of intellectual disabilities who require 24 hour supervision for their health and direct care supports. Health supports are generally less intensive than licensed nursing homes (SNF) or campus settings which may explain a lower mortality rate of (15.25) for this type of residence. In FY 2007 28.6% of all deaths occurred in CLA's.

CTH: There were only three deaths in the CTH program. They were anticipated and related to an existing condition. The CTH mortality rate of 7.29 was greater than the mortality rate for people living with their family or independently (4.47) but less than other types of residences. People living in CTH's represent only 1% of the DDS population and accounted for less than 1.5% of reported deaths.

SL: People receiving intermittent individualized supports in their own homes are less medically involved than people in other residential program types and, therefore, require less than 24 hour direct supports. Seven percent (7%) of reported deaths occurred in SL with a mortality rate of 11.16.

STS: This larger campus setting serves a stable population of older people (27.7% are 65 years of age or older) with severe to profound intellectual disabilities and have many co-morbidities. The higher mortality rate of 35 is not surprising in this medically fragile population. Nineteen people who resided at STS died this past fiscal year or 9.5% of all deaths of DDS consumers.

RC: Similar to the STS campus the majority of people supported in have multiple co-morbidities and require 24 hour direct support and nursing supervision. However, in contrast to previous years' data this year's mortality rate of 11.1 was lower than the overall CT DDS mortality rate of 12.97. Only three (3) deaths occurred at regional centers accounting for only 1.5% of all DDS deaths in FY 2007.

SNF: Only 1.8% of people served by CT DDS live in skilled nursing facilities and 54% of these people are over the age of 65. In FY 2007 people living in skilled nursing facilities accounted for 33% of all deaths. As expected, licensed nursing facilities had the highest mortality rate 157 per thousand. This older and medically fragile population requires a high level of nursing supports. Sixteen percent (16%) of all DDS consumers over 65 years of age live in SNFs.

- Community Living arrangement (CLA): 24 hour support is provided with staff in group home settings 2-6 people share an apartment or house also known as a group home
- Community Training Home (CTH): A family setting that is not within their own family. CTH family has received training and are licensed by DDS to provide services
- Regional Center (RC): Residential centers are facilities for over 16 people that provide 24 hour staffing
- Supported Living (SL): Minimal hours of support to live in their own home. 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
- Skilled Nursing Facility (SNF): Skilled nursing facility for people requiring skilled nursing level of care not licensed or funded by DDS also known as nursing home

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Mortality and Gender

Table 8

Mortality Rate by Gender - 2007

GENDER	All Individuals Served by DDS	No. Deaths	Percentage of Deaths	Rate (No. Deaths Per 1000)	Average Age of Death
Men	56.7%	100	50.3%	11.49	56.89
Women	43.3%	99	49.7%	14.89	58.98
Total	100%	199	100%	12.97	57.93

Consistent with the general population women supported in the CT DDS system are older than the men (average age 37.2 vs.34.1 years) and live longer (58.98 years vs. 56.89 years).

During Fiscal Year 07, (Table 8 above) slightly more men died than women. However, **women had a greater mortality rate than men (14.89 vs. 11.49)**. This is due to the fact that women live longer than men and far fewer women are served by CT DDS. The percentage of men (56.7%) and women (43.3%) served by the CT DDS system has remained consistent over the past three fiscal years.

Figure 8

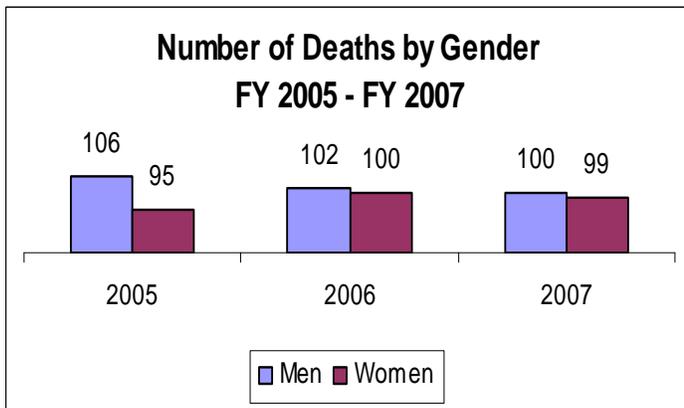
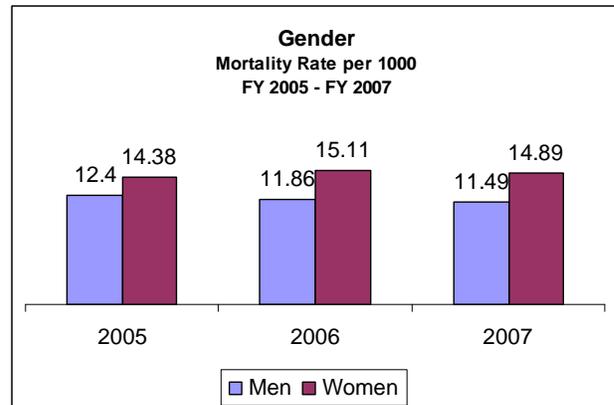


Figure 9



As noted in past years, during FY 2007, the number of deaths for males exceeded that of females. However, the mortality rate continued to be greater for women (as noted in Figure 8 and Figure 9 above).

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Mortality and Age

Average Age of Death (total population)	57.93
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Figure 10

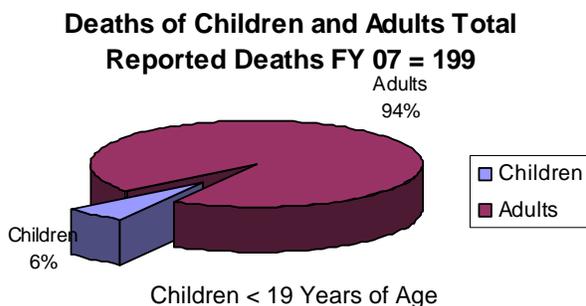


Table 9
Age of Death

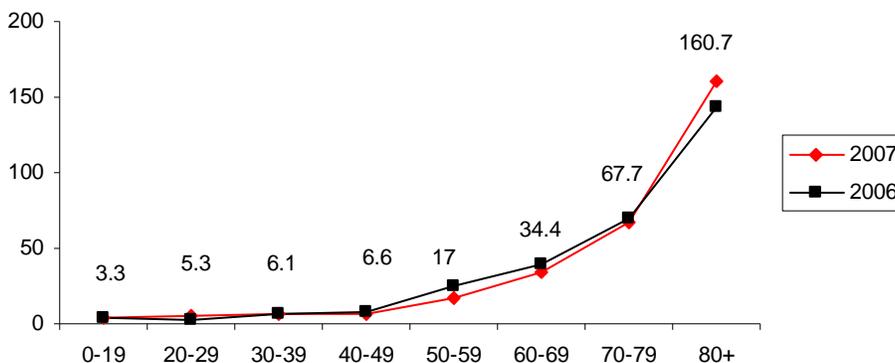
Report Year	Men	Women	Average
CT DDS FY 2007	56.9	58.9	57.9
CT DDS FY 2006	56.8	58.3	57.5
CT 2005	71	79	75
CT 2004	75	81	78
US 2005	75.2	80.4	77.9
US 2004	75.2	80.4	77.8

As mentioned earlier in this report, children served by DDS represent 23.6% of the CT DDS population. Children served by DDS accounted for only 6% of deaths reported in FY 07.

Life expectancy at birth for the total CT DDS population for FY 07 increased to 57.93 years. This average age of death represents an increase of almost ½ year compared to the average age of death in FY 2006.

Figure 11

Mortality Rates by Age Range
 No. Death per 1000 People
 Served FY 2006 and FY 2007



The relationship between **age** and **mortality** demonstrates the expected trend, with the mortality rate increasing as people served by DDS get older. As seen in Figure 11, by early in the fifth decade of life there is progressive increase in the mortality rate for people with intellectual disabilities served by DDS. This finding is consistent with previous CT DDS mortality rate data. For example in FY 2006 mortality rates were less than 10 per thousand for people under the age of 50 and then as in FY 2007 increased more dramatically with each successive decade.

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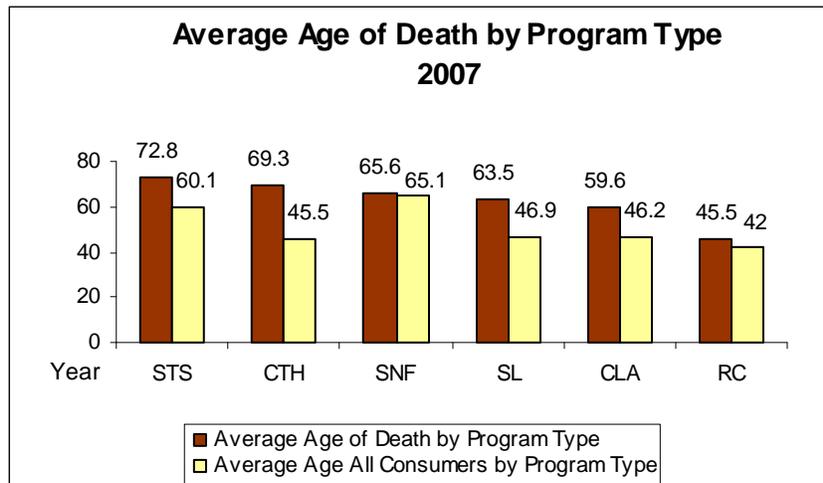
Section Two Continued

Table 10
Mortality Age Range Data
FY 2007

AGE RANGE	# OF DEATHS	% OF DEATHS	MORTALITY RATE
Age 0-19	12	6.0%	3.3
Age 20-29	16	8.0%	5.3
Age 30-39	13	6.5%	6.1
Age 40-49	18	9.1%	6.6
Age 50-59	36	18.1%	17
Age 60-69	38	19.1%	34.4
Age 70-79	30	15.1%	67.7
Age 80+	36	18.1%	160.7
TOTAL	199	100%	12.97%

As depicted in the previous graph, mortality rates within CT DDS population increase dramatically beginning in the fifth decade of life. People over the age of 70 accounted for 66 deaths or 33% of all deaths.

Figure 12



OF NOTE: There are certain types of residential support services such as CTH's where the average age of death may vary a great deal from one year to the next. This variability is related to the small number of deaths that occur in that type of support service. For example in FY 2007 there were only (3) deaths in CTH's. The same can be said for RC deaths (3). However, in other services such as CLA's or SNF where the annual number of deaths is much greater, the mortality data demonstrates a more consistent and accurate relationship between support type and the average age of death.

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SECTION THREE: DDS MORTALITY REVIEW

THE MORTALITY REVIEW PROCESS

Connecticut law (which comprises statutes and executive order) currently requires CT DDS 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 DDS 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. As noted below the two tier system includes a regional mortality review committee and Independent Mortality Review Board. In addition, the mortality process includes a Medical Desk Review by trained Nurse Investigators and finally the DDS Commissioner and Director of Health and Clinical Services review all cases that were referred to the 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 DDS 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.

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NURSE INVESTIGATORS MEDICAL DESK REVIEW

In addition to the regional mortality review committees and the Independent Mortality Review Board the DDS death reporting and mortality review process requires that all deaths are reported to a **Nurse Investigator** (NI) who is assigned to the DDS 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 DDS Director of Investigations, DDS Director of Health Services who chairs each respective Regional Mortality Review Committee and the DDS Director of Health and Clinical Services who chairs the Independent Mortality Review Board if:

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

Independent Mortality Review Board Membership

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

- DDS Director of Health and Clinical Services (Chair)
- DDS Director Division of Investigations
- DDS 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:

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

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SECTION FOUR: DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS

IMPORTANT NOTE:

THE INFORMATION PRESENTED IN THIS SECTION SUMMARIZES ONLY THOSE DEATHS THAT WERE REVIEWED BY THE REGIONAL COMMITTEE AND /OR STATE MORTALITY BOARD

THEREFORE THE MORTALITY DATA WILL DIFFER FROM THE INFORMATION PRESENTED AND DISCUSSED IN SECTION II OF THIS REPORT (ALL DDS MORTALITIES)

The DDS Mortality Review Committees/Board reviewed 137 cases during FY 2007 (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 DDS and is routinely requested and provided for individuals served by DDS who live in all settings, including regional centers, campus, community living arrangements, community training homes, supported living services and family 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 2007 through the use of hospice services DDS was able to support people through the final stages of a terminal illness in their own residence. Additionally the use of hospice services for people supported by DDS exceeds that of the general population

- Hospice supports were provided for 57 consumers or 42% of individuals prior to their death
- 63% of individuals who died as a result of an anticipated or known condition/diagnosis received hospice support services prior to their death
- Provision of hospice supports for FY 2007 (42%) compares favorably with last year's 41%

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 DDS requests and the family consents to the autopsy. CT DDS continues to encourage consideration of post mortem examinations.

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:	11 (8% of all deaths)
Number of post mortem examination performed by CT OCME:	5 (4% of all deaths)
Percentage of the post mortem examinations performed by CT OCME:	(45%)

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.

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Section Four Continued

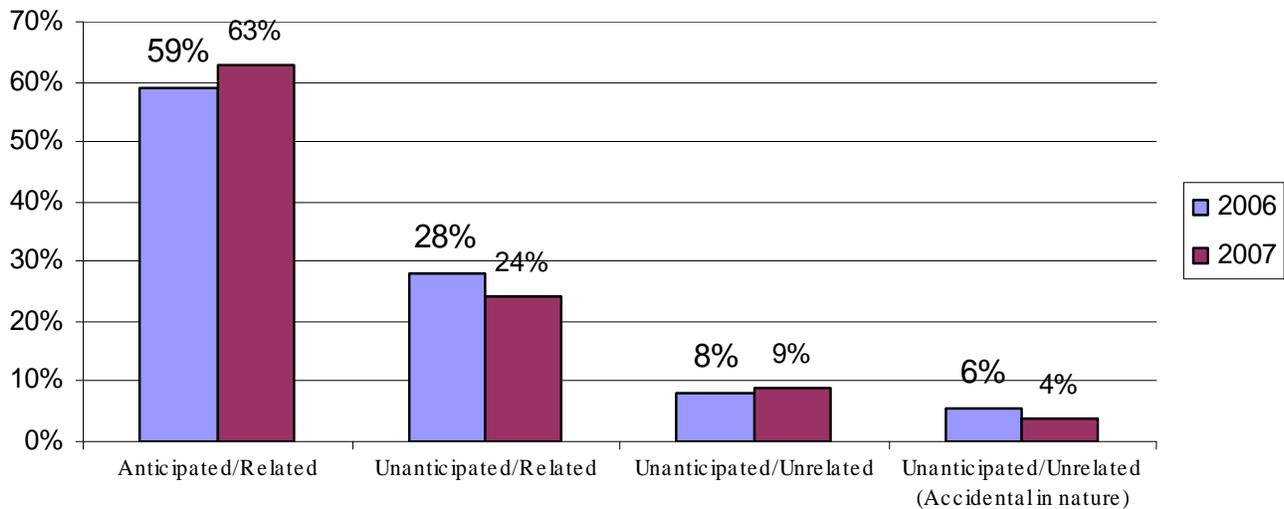
Predictability

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 87% 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: 63%
- Death was unanticipated but related to a preexisting diagnosis: 24%
- Death was unanticipated and unrelated to a preexisting diagnosis: 13% (includes accidental deaths)

Figure 13

Predictability of Death



- Death was anticipated and related (the result of a known medical condition) in 55% of those individuals over the age of 65
- 96% (45/47) of individuals > 65 years of age had a known medical condition related to their cause of death
- Seventy-five (75%) of individuals living in skilled nursing facilities deaths were anticipated as a result of a known condition
- (97%) of individuals who lived in a SNF died as a result of a medical condition that was diagnosed prior to their death

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

Advanced age was the strongest predictor of death within the CT DDS system.

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UNANTICIPATED/UNRELATED DEATHS:

Of the 15 deaths that were unanticipated and not related to a known condition 5 were accidental in nature and 10 were due to natural causes. The causes of mortality for the (10) unanticipated deaths due to natural causes were: Cardiac arrest (5) Respiratory Failure (2) Sepsis (1) Pancreatitis (1) Coronary Atherosclerosis (1).

ACCIDENTAL DEATHS

In (3) of the 5 accidental deaths: 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. The Medical Examiner could not determine the exact time or event which caused the other (2) deaths that were determined to be accidental in nature.

DNR

Per Connecticut State Statute, CT DDS 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 DDS. Documentation regarding end of life planning and withholding of cardiopulmonary resuscitation is required per CT DDS policy.

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 DDS medical staff (Health Services Directors and in some cases Director of Health & Clinical Services).

For the 137 mortality cases reviewed in FY 2007

103 of all reviewed deaths (137) had a DNR order in place

89% of all DNR orders were formally reviewed by DDS

100 % of DNR orders met the established DDS review criteria

DDS was not notified prior to the implementation of the DNR orders in (11%) of all DNR cases. **However during the mortality review process it was determined that in all cases (reported and not reported) the established DDS criteria was met.** In every non-reported case the individuals resided in skilled nursing facilities or had been admitted to an acute care hospital prior to their death. 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 DDS was provided.

OF NOTE: Seventy-two (72%) of DDS consumers residing in skilled nursing facilities had a DNR in place at the time of their death.

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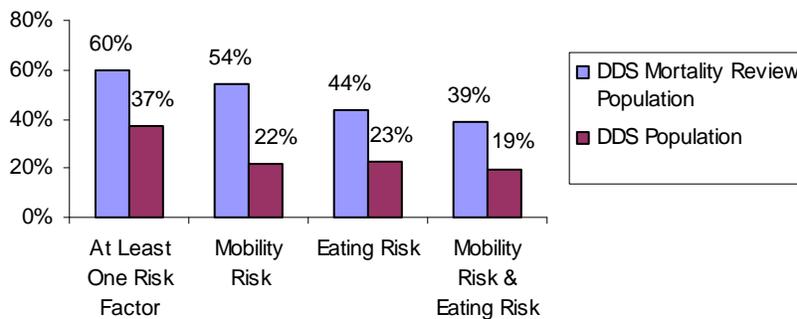
Section Four Continued

Risk Factors

Mobility impairments and dysphagia/swallowing risks are well known risk indicators that place individuals at significantly higher risk of morbidity and mortality. CT DDS mortality data has consistently demonstrated that people who require the need for special assistance when eating and those who cannot ambulate without assistance have a greater mortality rate. Therefore the CT DDS mortality review process carefully analyzes the presence or absence of these two risk indicators. Once again the FY 2007 data illustrates the relationship between these risk factors and mortality rates (see Figure 14 below).

Figure 14

Risk Factors 2007



As in FY 06 the majority (60%) of people in FY 07 had one or more of these identified risk factors present at the time of their death.

MORTALITY REVIEW POPULATION ONLY

54% did not ambulate independently
44% did not eat independently

* DDS POPULATION

22% do not ambulate independently
23% do not eat independently
*Excluding Family Homes

- **39 % of people who died required assistance in the functional areas of eating and ambulation.**

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 DDS regional and statewide committees and review boards.

At the time of this report 30% of all DDS consumers who live in traditional DDS residential settings have maladaptive behaviors or dysfunction in swallowing (dysphagia) which put them at risk.

* Of note: The presence and/or risk of silent aspiration is not included in the risk factor data.

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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, eating dysfunction, and/or enteral feedings had a higher mortality rate (70.8) than individuals who had fewer health concerns.

Table 11

	FY 07 % of All Deaths	FY 07 Death Rate	FY 06 % of All Deaths	FY 06 Death Rate
24 HOUR SKILLED NURSING SUPPORTS:	44%	70.8	45.5%	73.6
24 HOUR SUPERVISION NURSING COORD:	37%	13.8	32.7%	17.1
24 HOUR SUPERVISION LIMITED NURSING:	19%	4.5	23.3%	4.8

As noted in the table above, the death rate for individuals requiring 24 hour skilled nursing services (70.8) far exceeded the death rate for individuals needing limited nursing services (13.8) and for individuals requiring less than 24 hour supervision (4.5). These findings are consistent with the FY 2006 mortality data which also illustrates a direct relationship between the level of nursing/medical supervision/supports an individual requires and death rate.

Table 12

Level of Intellectual Disability and Mortality Rate

	Mild	Moderate	Severe	Profound
2007	3.6	8	14.5	22.5
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 the past five years.

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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 137 cases reviewed during FY 07, 132, (96%) were classified as due to natural causes. The other (5) cases were determined to be the result of an accident.

Table 13

FY 07 Manner of Death

<i>Manner of Death</i>	<i>No.</i>	<i>Percent</i>
<i>Natural</i>	<i>132</i>	<i>96%</i>
<i>Accident</i>	<i>5</i>	<i>4%</i>
<i>Homicide</i>	<i>0</i>	<i>0%</i>
<i>Suicide</i>	<i>0</i>	<i>0%</i>
<i>Undetermined</i>	<i>0</i>	<i>0%</i>
<i>Total</i>	<i>137</i>	<i>100%</i>

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

Choking (3) :	airway obstruction/asphyxia due to a foreign body/food bolus
Fall (2):	subdural hematoma secondary to a fall

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Investigations

Office of Protection & Advocacy / Abuse Investigations Division

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

Of the 137 mortality cases reviewed by DDS, 10 cases were investigated by either the OPA/AID or the DDS 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 to and investigated by the CT Department of Public Health.

<u>Disposition of OPA/AID Cases</u>	
<i>Neglect substantiated</i>	5
<i>Neglect not substantiated</i>	2
<i>Cases still pending</i>	3

In (3) of the cases where neglect was substantiated, the neglect directly resulted in injuries/incidents such as asphyxia due to airway obstruction which directly contributed to the individual's death.

In the other (2) 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 2007 six (6) mortality cases were referred by the regional mortality committee or IMRB to the **State of Connecticut Department of Public Health** (DPH) Health Systems Regulation Division where these cases were investigated by the Facilities and/or the Practitioner and Licensing Section.

Disposition of DPH Investigations

The 6 cases referred to DPH generated 6 investigations

<u>Practitioner Division Investigations – (2)</u> cases pending – 2

<u>Facility Division Investigations – (4)</u> cases pending – 1 resulted citations, violations found – 3

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SUMMARY OF FINDINGS

for the 137 deaths that were reviewed in FY07

- **48%** of all cases were reviewed by the **IMRB**
- **42%** of the individuals received **Hospice** supports prior to their deaths.
- **8%** of the individuals had **Autopsies** performed.
- **87%** of all deaths were **Related** to an existing medical diagnosis.
- **75%** of the individuals had a **DNR** order in place at the time of death.
- **60%** of the individuals had at least one **Risk Factor** (e.g. could not ambulate independently or could not eat without assistance).
- **39%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance).
- **96%** of the deaths reviewed were due to **Natural** causes.
- **20%** lived in **Skilled Nursing Facilities**
- **5** number of deaths that were classified as **Accidental**.
- **6** number of referrals to **Department of Public Health**
- **10** number of referrals to **Office of Protection & Advocacy Abuse Investigation Division**
- **5** number of cases **Neglect** was substantiated by OPA or DDS

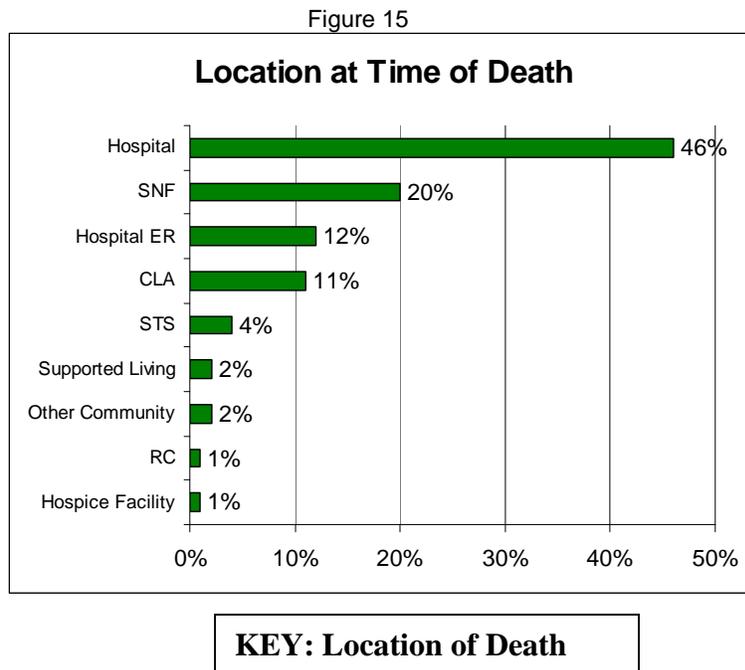
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Pronouncement of Death (Location at Time of Death)

Figure 15 below depicts the location where death was pronounced.



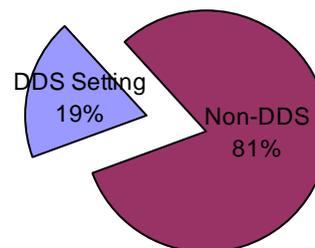
Hospital = Admission to the Hospital as an inpatient, death occurred in the hospital.

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, 81% of all deaths reviewed by the mortality review committees during FY 07 occurred outside of a DDS operated, licensed or funded residential setting, this represents a increase in the number of people dying outside of a DDS setting compared to FY 06 (71%).

Figure 16
Where People Died
FY 2007 Mortality Reviews



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SECTION FIVE: MORTALITY TRENDS CT DDS

Figure 17

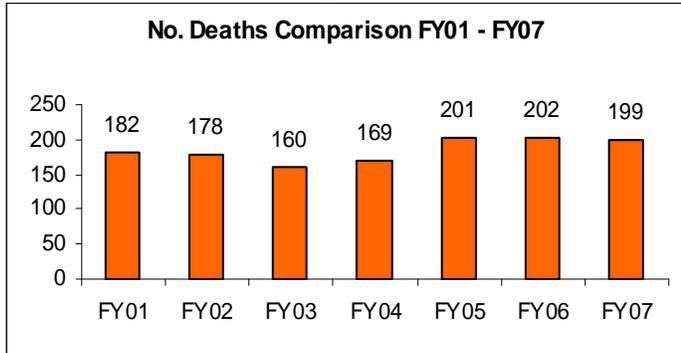
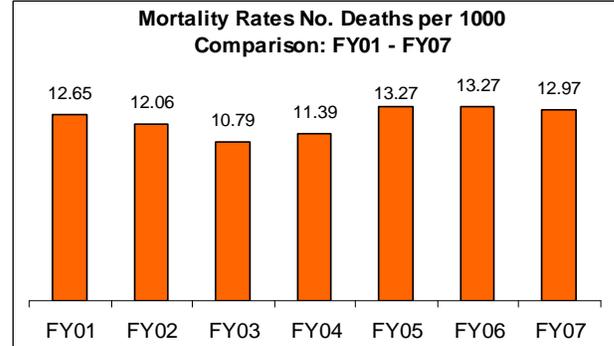


Figure 18



Figures 17 and 18 depict on an annual basis the number of deaths and the average death rate for FY's 2001 - 2007 within the population served by DDS. Over the past three years there has been minimal variations in the number of deaths and mortality rate. The death rate average over the seven year period of time is 12.34/1000 people.

Figure 19

Mortality Rate by Where People Live
6 Year Trend

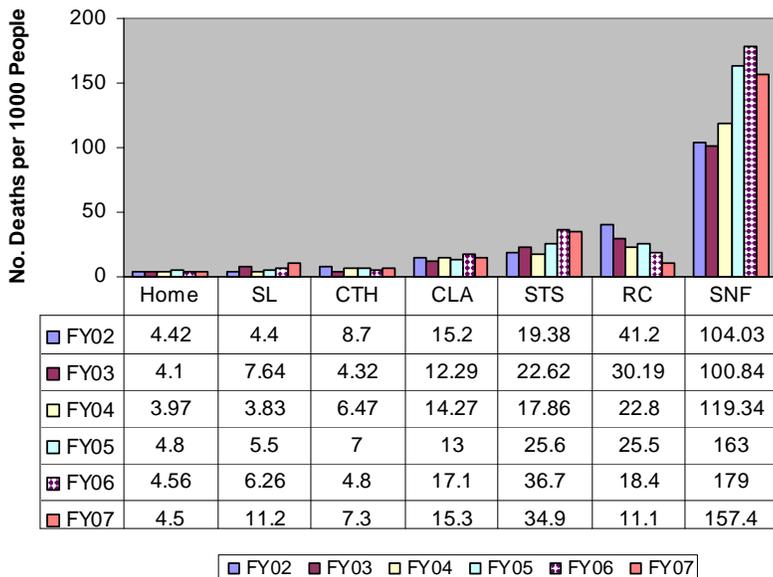


Figure 19 (to the left) compares the death rate (the number deaths per 1000 persons served) for the past six (6) fiscal years by type of residential setting.

Historically, individuals residing in programs (SNF, Campus) that require more intensive nursing supports and medical oversight due to their compromised health status have a greater death rate than people living in other residential settings. This data is in contrast to other research studies which found that mortality rates are higher for people living in community based settings and lower for people with intellectual disabilities who live in congregate institutional like settings.^{21,33}

*Of note: Over the past three years the mortality rate for people living in RC's has progressively declined.

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

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Table 14
Mortality and Gender
(2002 - 2007)

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
2007	100	99	50.3%	49.7%	11.49	14.89

For the six year period noted above more men died annually than women. Except for FY 2003 the mortality rate for women exceeded the mortality rate for men. Last fiscal year the mortality rate for men and women decreased slightly.

Figure 20

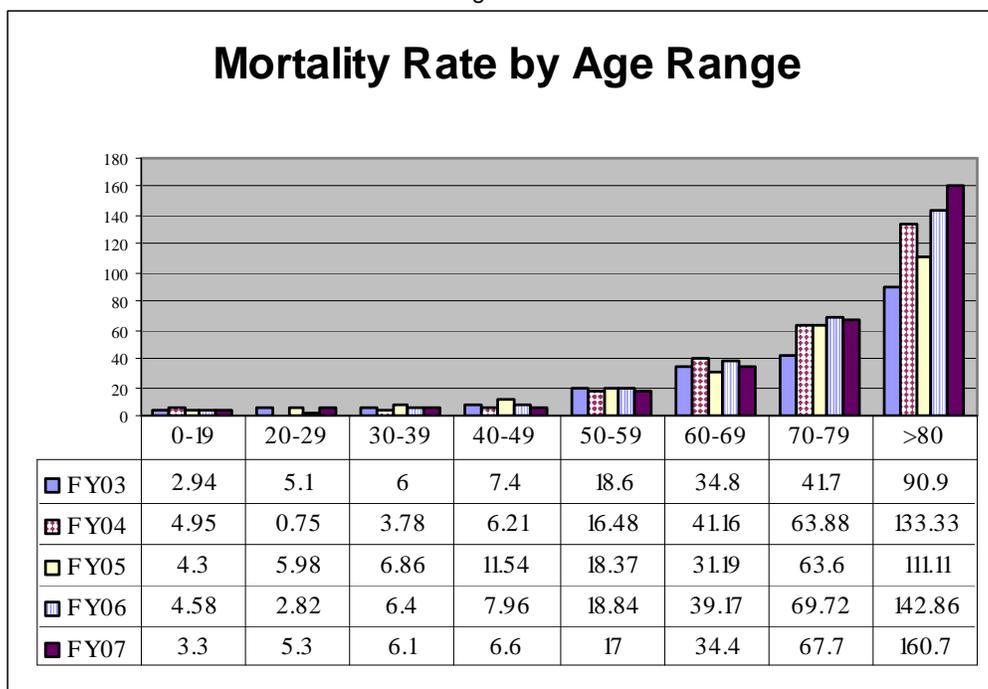


Figure 20 (above) illustrates mortality rate by age range.

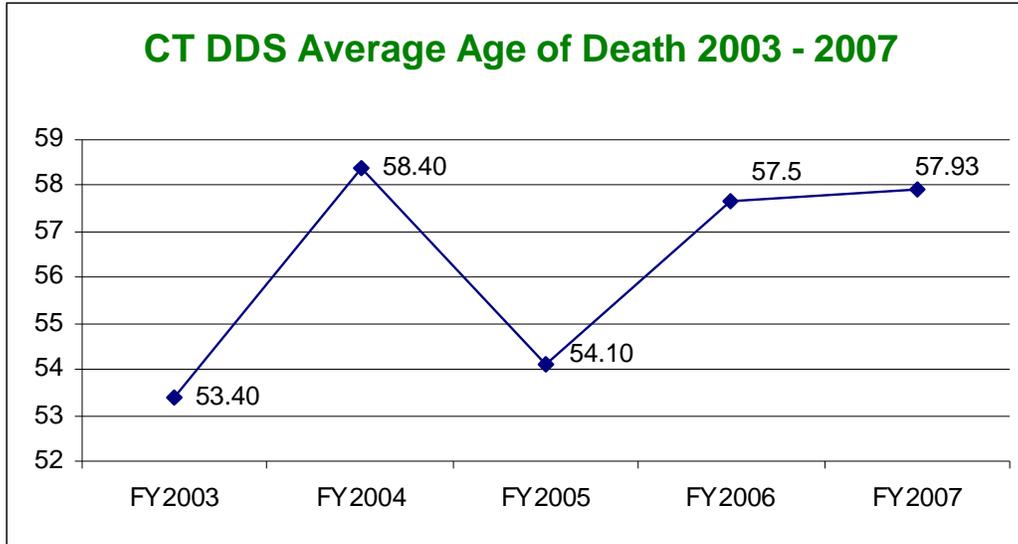
The data over the past five fiscal years reveals a consistent pattern of increasing mortality rates with each successive decade of life. The mortality rates increases markedly for older adults starting in the fifth decade of life. Some fluctuation occurs in mortality rates from year to year within each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

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Figure 21



For the last five fiscal years the average age of death has fluctuated between the low to upper 50's and in general depicts a gradual increase in the life expectancy at birth for people served by CT DDS. As a point of reference since 1989 when DDS began to collect mortality data on only three occasions has the average age of death exceeded 55 years of age (2004, 2006 and again in 2007).

Table 15

RESIDENCE AT TIME OF DEATH TRENDS (2002 - 2007)

	2002	2003	2004	2005	2006	2007
SNF	28%	30%	35%	40%	33%	33%
CLA	30%	27%	31%	23%	31%	29%
Family	19%	20%	15%	19%	18%	17%
STS	*	9%	7%	7%	10%	10%
SL	3%	6%	3%	4%	4%	7%
RC	*	5%	4%	4%	2%	2%
CTH	3%	1%	2%	1%	1%	1%
Other	2%	2%	0%	2%	0%	1%
	100%	100%	100%	100%	100%	100%

* Data not available

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

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

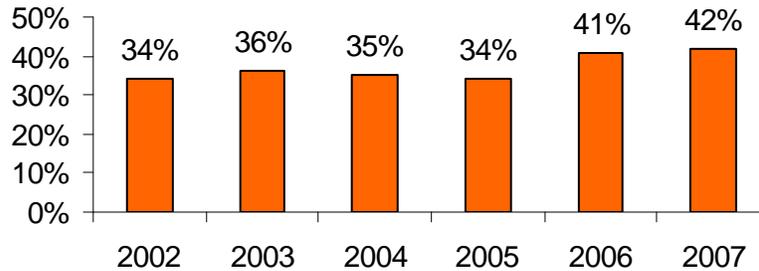
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Figure 22

Percent of Hospice Supports (2002 - 2007)



End of life planning and hospice care has been a hallmark of the CT DDS system as noted above. In fact the acceptance/embracing of hospice supports increased in FY 2007 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 increased use of hospice supports can be partly attributed to mortality review findings and recommendations. Case managers, nurses and other team members actively seek out hospice services in cases where death is anticipated as a result of a terminal illness.

Table 16

Location Where Death Pronounced (FY 2002 - 2007)

Location	2002	2003	2004	2005	2006	2007	6 Year Total
Hospital	41	34	35	64	58	63	295
SNF	13	22	26	35	30	28	154
CLA	17	16	18	16	17	15	99
Hospital ER	10	9	4	18	14	16	71
STS	4	1	5	4	14	6	34
RC	7	11	5	3	2	1	29
SL	4	4	3	4	5	3	23
Hospice	2	1	3	7	2	2	17
Other	1	1	0	1	3	3	9

Over the past three years there has been an increase in the number of people who die in an acute care hospital setting, SNF's and emergency departments. In fact over the past six years 40% of deaths have occurred in hospitals, 21% in SNF's and 10% in Emergency Departments. Reasons for this may include more timely treatment, earlier recognition of signs and symptoms of illness by staff, enhanced training of direct support staff, nursing on call system, and the general aging of the CT DDS population.

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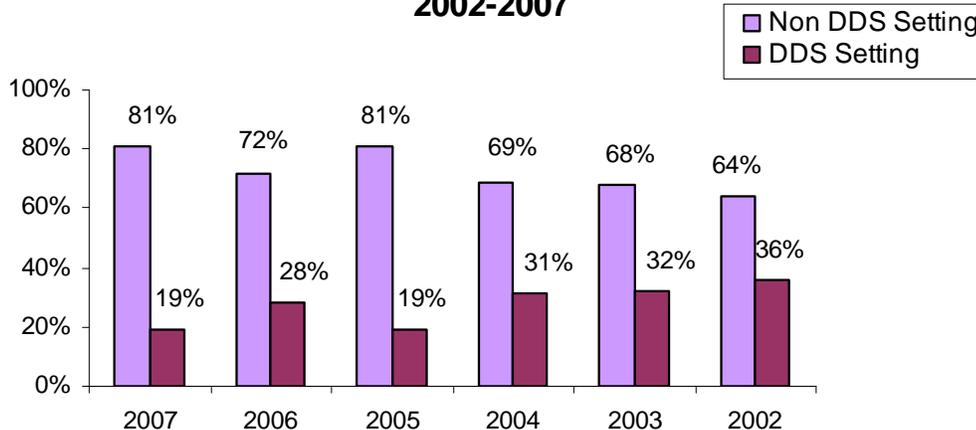
Table 17

NUMBER OF AUTOPSIES (FY 2003 – FY 2007)		
FY 03	28	21%
FY 04	16	16%
FY 05	20	13%
FY 06	17	12%
FY 07	11	8%

As noted in Table 18 above the number of autopsies performed has fluctuated from one review year to the next. Although the number of deaths has increased over the past four years the percentage of autopsies performed has continued to decline. This reduction in post mortem examinations for FY 2007 may be associated with a decline in the number of sudden unexpected/unanticipated deaths in the CT DDS system during this past year.

Figure 23

Where People Died 2002-2007



The number of people served by DDS who expired in non-DDS funded settings has increased in FY 2007 (81% compared to 72% in 2006). As mentioned earlier the overall increase in the number of individuals who expire in non-DDS 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 DDS 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 DDS

This section discusses cause of death data for people served by the CT DDS in calendar year 2007. The information used to determine the cause of death for each individual was gathered from the DDS Death Report Form and/or the Certificate of Death. In some cases the cause of death was confirmed after review by the regional mortality committee or Independent Mortality Review Board.

Table (22) compares the top ten leading causes of death for people served by CT DDS with data from the previous five 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 DDS reporting a slightly higher percent of cardiac related deaths (29.1%) than the general population.^{2,11}

As reported last year, respiratory diseases remained second leading cause of death within the CT DDS population (18%) occurring on a percentage basis more than 3 fold the percentage of deaths in the general population (5%).²

While deaths due to cancer remained at 11%, cancer related deaths changed position with pneumonia becoming the third leading cause of death. Cancer related deaths rank second in the general CT and US populations at more than twice the rate (22%) observed in the CT DDS population in 2007.^{2,11}

Pneumonia and influenza related deaths were the fourth leading cause of death and accounted for 8.5% of CT DDS deaths compared to <3% in the general population.^{2,11}

Aspiration pneumonia was the fifth leading cause of death and also accounted for 8.5% of the CT DDS deaths. Aspiration pneumonia was not cited as a leading cause of death in either the state or national mortality statistics.

Septicemia originating from various sites dropped to the sixth (6'th) leading cause of death from 5'th in the CT DDS population with a year over year decrease from 7.8% to 6% in 2007, Only 1.4% and less than 2% of deaths in the US and CT general population respectively are caused by sepsis.^{2,11}

The 2007 leading cause of death data demonstrates the continued role played by pneumonia and aspiration pneumonia as major causes of death for people with ID/DD.

In FY 07 the percent of deaths resulting from accidents (1%) in the CT DDS system did not make the top 10 leading causes of death and once again was lower than the number of accidental deaths reported in the 2005 US population (4.7%) and the CT population (3.8%).²



Caution: while comparison of CT DDS mortality data with benchmarks from the general population (state and national) are of interest, they are not very practical for direct comparison purposes due to differences in population characteristics, adjusted age and statistical methods etc. For example the special health concerns (co-morbidities) inherent in people with intellectual disabilities are related to a greater mortality rate. For example greater than 25% of the individuals who died in the CT DDS service system during FY 2007 had a diagnosis of cerebral palsy at the time of their death compared to less than 1% in the general population ⁵⁶ . In addition, a significant number of individuals in the CT DDS system had a diagnosis of dysphagia and or gastroesophageal reflux disease (GERD) (40%) at the time of their death. Both dysphagia and GERD has been implicated as a major cause of aspiration pneumonia leading to respiratory failure, sepsis and death in the ID/MR population.^{6,31,44,45,47,49,50}

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 2007. Leading cause of death data for the calendar year will allow benchmark data from CT DDS to be consistent with Connecticut and national mortality benchmarks developed for the general population (2005) calendar year and other MR/DD state agencies such as MA DMR.

* CT DDS receives certificates of death and death reports for all deaths reviewed.

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HEART DISEASE

Heart Disease/cardiovascular disease) remains the leading cause of death for the CT DDS population (29.1%). Cardiovascular disease is an umbrella term to describe any abnormal condition characterized by the dysfunction of the heart or blood vessels. Examples of diseases that fall within this category are congestive heart failure, cardiac arrhythmia, arteriosclerosis, ischemic heart disease, coronary artery disease, heart valve disease, hypertension, endocarditis, myocardial infarction, myocarditis, disease of the aorta, peripheral vascular disease and others.

As in the general population many of the consumers who died as a result of cardiovascular disease had identified risk factors prior to their death such as high blood cholesterol, high blood pressure, physical inactivity, obesity and diabetes mellitus.

In the general population over 83% of people who die of coronary heart disease are 65 or older.⁵⁸ In the DDS population only 58% who died as a result of coronary heart disease were over the age of 65. In DDS sixteen percent of cardiac deaths occurred before the age of 50, eleven percent in the 50-60 year age range and twenty-four percent in the 60-70 age range.

Men comprised 58% of all deaths due to heart disease in DDS with an average age of death of 60 years while the average age of death for women was 77.6 years. The overall average age of death due to cardiac disease was 67 years.

In the DDS population one factor which may explain the higher percentage of deaths that are due to cardiovascular disease is the significant number of people with Down syndrome who are supported by DDS. It is well known that Down Syndrome is a major cause of congenital heart disease and the most frequent cause of atrioventricular septal defects.⁶⁰

RESPIRATORY DISEASE

The 2007 leading cause of death data demonstrates the continued role played by respiratory diseases as a major cause of death for people with ID/DD in the CT DDS population.

In fact all diseases of the lung/respiratory system due to an identified respiratory disease process such as acute bronchitis, emphysema, asthma, pulmonary embolism, respiratory failure, COPD, ARDS pneumonia and aspiration pneumonia were responsible for more deaths 35% than deaths cause by heart disease 29.1%. The incidence of mortalities related to respiratory diseases is even more striking in the DDS Down syndrome population illustrated by the fact that 68% of people with Down Syndrome died as a result of pneumonia, aspiration pneumonia respiratory or generalized sepsis related to a respiratory infections.

Women accounted for 58% of all deaths due to respiratory disease with an average age of 69.7 while men with respiratory disease as an immediate cause of death (42%) succumbed at a younger age 60.3 years.

The frequency of respiratory disease (specifically pneumonia and aspiration pneumonia) and high mortality rate seem to be closely related to the risk factors of immobility and dysphagia or swallowing dysfunction, restrictive pulmonary function due to curvature of the spine, hiatal hernia and other anatomical anomalies which are prevalent in the population served by DDS. The extraordinary relationship between respiratory disease, aspiration pneumonia and morbidity and mortality in population of people with intellectual disabilities has also been identified and reported by other state ID/DD agencies.^{44,51,52,53,54,55}

IMPORTANT: The CT DDS mortality data suggests that enteral feedings (percutaneous endoscopic gastrostomy and jejunostomy tubes) do not seem to prolong survival in the population served by DDS. DDS mortality review data found that 30% of the people who died in FY 07 were fed enterally at the time of their death.* One third of the individuals who required enteral feedings died within one year of the initiation of the tube feeding and another 21% died within two years of tube placement. In the vast majority of these cases the cause of death was attributed to pneumonia or aspiration pneumonia. These findings support other research findings regarding the prognosis and survival for people who require tube feeding and who also have significant cognitive and/or neurological conditions.^{41,42,45,46,48,50} Other data also suggest that the elderly do not benefit from enteral feedings and that people who required enteral feeding tubes had a significantly higher rate of pneumonia and pneumonia related death.^{38,39,42,48}

*Based on all cases reviewed by the CT mortality review process

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RECOGNITION OF ALZHEIMER'S DISEASE

For the 137 mortality cases reviewed by the CT DDS in FY 07 twelve percent 12% of the **individuals had a diagnosis of Alzheimer's Disease at the time of their death** and almost 80% of all people diagnosed with Alzheimer's Disease at the time of their death also had a diagnosis of Down syndrome.

The prevalence of Alzheimer's Disease is not included in the CT DDS leading cause of death statistics because Alzheimer's Disease is not consistently noted as an immediate cause of death or underlying cause of death on certificates of death or noted in CT DDS Death Reports because many practitioners have a tendency to 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. In addition, Alzheimer's Disease is not included as a leading cause of death in this report because the department does not receive certificates of death for **every** reported death.



LIFE EXPECTANCY

There is a dramatic difference in the average life expectancy of people with ID (57.9) compared to the general CT State and US population (77.9 and 75 years respectively).^{2,11}

As mentioned earlier in this report although the increasing survival rate of people with ID in the CT DDS system may be associated with improved knowledge, medical technology and supports. The average age of death for people with ID is still 20 years less than the CT State and US general populations.

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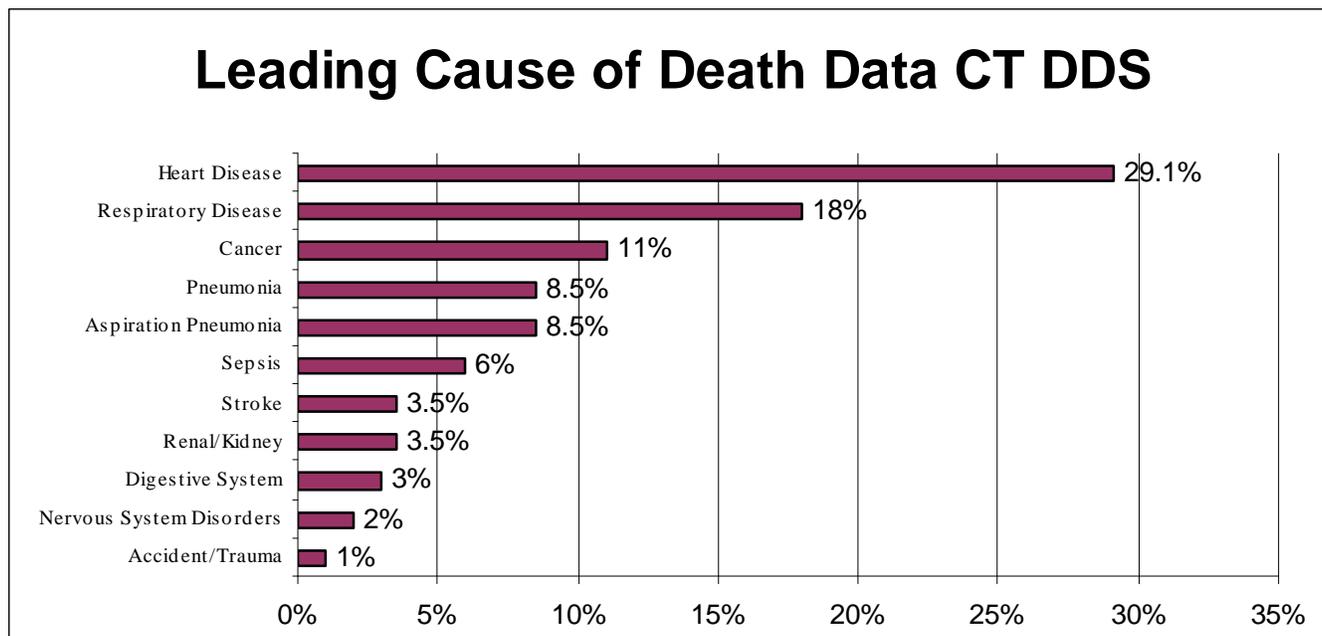
Table 18

Leading Cause of Death Data CT DDS

(based on the calendar year 2007)

29.1%	of deaths were due to	Heart Disease	including	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
18%	of deaths were due to	Respiratory Disease	including	Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma
11%	of deaths were due to	Cancer	including	Wide variety of primary origin sites
8.5%	of deaths were due to	Pneumonia		Pneumonia/influenza
8.5%	of deaths were due to	Aspiration Pneumonia		Aspiration Pneumonia
6%	of deaths were due to	Sepsis	including	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
3.5%	of deaths were due to	Stroke/CVA	including	Intercerebral Hemorrhage
3.5%	of deaths were due to	Renal/Kidney	including	Renal Failure chronic and acute
3%	of deaths were due to	Digestive System	including	Intestinal Obstruction, Liver Disease
2%	of deaths were due to	Nervous System Disorders	including	Encephalopathy, Epilepsy
1%	of deaths were due to	Accident/Trauma	including	Unintentional Injuries Falls, Asphyxia, Choking, Trauma

Figure 24



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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 DDS.

The CT DDS 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 **13.8% of all deaths reviewed in FY 2007.**

Aspiration pneumonia was the leading cause of death for persons with Down Syndrome followed by cardiac arrest and respiratory failure. Sixty-eight (68%) of people with Down syndrome had a diagnosis of pneumonia or aspiration pneumonia at the time of their death.

Sixty-three percent (63%) of the people with Down Syndrome who died also had a diagnosis of Alzheimer's Disease. These figures corroborate other studies which suggest that people with Down Syndrome develop Alzheimer's Disease at a far younger age (40 yrs') than the general population.^{8,10,14} DDS mortality findings are also in line with other research studies that indicate that the life expectancy among adults with Down Syndrome is about 55 years of age.^{15,16,19,20}

It is very encouraging to report that people with Down Syndrome in the CT DDS system are living almost as long (56.3 years) as the general DDS population (57.9 years). The recent trend toward earlier and more comprehensive medical treatment, evaluation and person centered supports by caregivers and family members have most likely resulted in this increased life expectancy.

Table 19

FY 07		FY 06	
Primary Cause of Death/Down Syndrome		Primary Cause of Death/Down Syndrome	
Aspiration pneumonia	9	Cardiac Arrest	9
Cardiac Arrest	4	Aspiration pneumonia	8
Renal Failure	2	Respiratory failure	4
Respiratory Failure	1	Gastrointestinal hemorrhage	2
CVA	1	Subdural hematoma	1
Asphyxia	1	Renal Failure	1
Cancer	1	Sepsis	1
Total	19	Total	26

Table 20

Average Age of Death

Down Syndrome (ALL)	56.3
Down Men	55.3
Down Women	58
Down & Alzheimer's:	58.3
Down without Alzheimer's:	52.3

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Analysis of Cancer Deaths

In FY 2007 cancer was the third leading cause of death for people supported by the CT DDS representing 23 deaths or 11.5% of all deaths.

- The rate of death due to cancer in the CT DDS population (1.5/1000) 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 DDS system accounted for 8 of the 23 cancer related deaths.
- The cancers which resulted in the death of women were: lymphoma (non-Hodgkins), lung, renal, ovarian, brain, esophageal, pancreatic and aplastic anemia.
- In the male population the cancers which resulted in death were lung (5), pancreatic (3) renal (2) parotid gland(1) prostate(1) testicular (1) angio sarcoma (1) and cholagio carcinoma(1).
- Men with cancer lived longer than women 61.6 years vs. 56.7 years.
- The average age of death for all cancer victims (60 years) exceeded the survival rate for all CT DDS deaths (57.9 years).

Table 21

FY 07 Cancer Death Analysis			FY 06 Cancer Death Analysis		
Primary Site	Number of Deaths	Average Age at Death	Primary Site	Number of Deaths	Average Age at Death
Lung	5	60.2	Stomach	3	67
Pancreas	3	68.3	Colorectal	3	71
Renal	2	55	Breast	3	62
Esophagus	1	53	Lung	2	59
Brain	1	59	Bladder	2	48
Cholagio	1	86	Liver	1	53
Angiosarcoma	1	53	Pancreas	1	67
Ovary	1	43	Prostate	1	73
Testicular	1	63	Endocrine/ Adrenal gland	1	61
Prostate	1	83	Trachea/ Bronchus	1	81
Lymphoma non-Hodgkins	1	78	Oral/pharynx Carcinoma in situ	1	68
Parotid Gland	1	46	Lymphatic/ Hematopoietic	1	73
Aplastic Anemia	1	23	Esophagus	1	74
Unknown	3	67	TOTAL	21	68.4
TOTAL	23	60			

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Table 22

*Comparison Leading Causes of Death National, State of CT and CT DDS

Rank	US 2004	US 2005	CT 2004	CT 2005	CT DDS 2007	CT DDS 2006	CT DDS 2005	CT DDS 2004	CT DDS 2003
1	Heart Disease 27.2%	Heart Disease 26.5%	Heart Disease 26.8%	Heart Disease 25.9%	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%	Heart Disease 35%	Heart Disease 29%
2	Cancer 23.1%	Cancer 22.8%	Cancer 24.4%	Cancer 23.8%	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%	Respiratory Disease 17%	Pneumonia Aspiration 19%
3	Stroke 6.3%	Stroke 5.8%	Stroke 5.6%	Stroke 5.2%	Cancer 11%	Pneumonia 14.4%	Pneumonia Aspiration 12%	Pneumonia Aspiration 14%	Nervous System 16%
4	Respiratory Disease 5.1%	Respiratory Disease 5.3%	Respiratory Disease 4.9%	Respiratory Disease 5%	Pneumonia 8.5%	Cancer 11%	Cancer 8%	Septicemia 6%	Cancer 15%
5	Accidents 4.7%	Accidents 4.7%	Accidents 4.3%	Accidents 3.8%	Pneumonia Aspiration 8.5	Septicemia 7.8%	Septicemia 5.6%	Cancer 6%	Digestive System 4%
6	Diabetes 3.1%	Diabetes 3%	Pneumonia/ Influenza 2.9%	X	Septicemia 6%	Pneumonia Aspiration 5.5%	Stroke 3.7%	Nervous System 4%	Renal Failure 2%
7	Alzheimer's Disease 2.8%	Influenza/ Pneumonia 2.9%	X	X	Stroke 3.5%	Kidney/ Renal 4.4%	Accident 3.7%	Stroke 3.7%	X
8	Influenza/ Pneumonia 1.8%	Alzheimer's Disease 2.5%	X	X	Kidney Renal 3.5%	Accident 2.7%	Nervous System 3.3%	Accident 2%	X
9	Renal/ Kidney 1.4%	Nephritis/ Kidney 1.8%	X	X	Digestive System 3%	Stroke 2.2%	Digestive System 1.4%	Digestive System 1.6%	X
10	Septicemia 1.4%	Septicemia 1.4%	X	X	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%	Kidney Renal 1.6%	X

•Based on 2007 calendar year data

In this report pneumonia is classified as either pneumonia due to an acute infectious process or pneumonia secondary to aspiration of liquids and/or solids (aspiration pneumonia) resulting from dysphagia or silent aspiration

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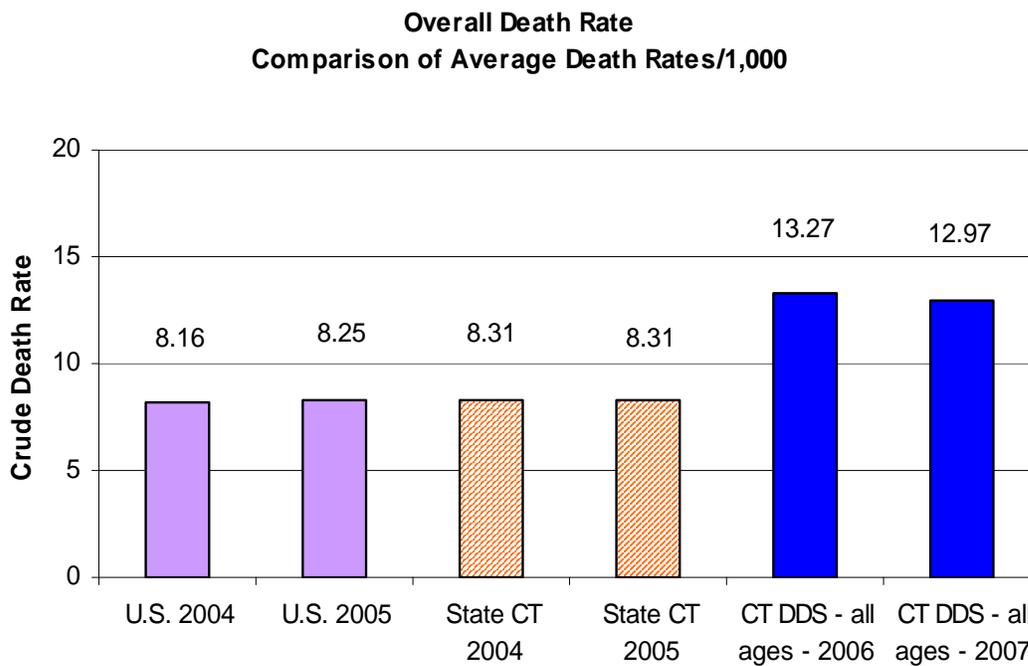
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MORTALITY RATE COMPARISON

The overall CT DDS crude death rate of 12.97/1000 is higher than the rate of 8.31 in Connecticut (2005) and the rate of 8.25 in the general United States population(2005). This would be expected due to the many health and functional complications associated with intellectual disabilities.

Figure 25



While comparison of CT DDS mortality data with benchmarks from the general population (state and national) are of interest they are not very practical for direct comparison purposes due to differences in population characteristics, adjusted age and statistical methods etc.

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SECTION SEVEN: BENCHMARKS

Benchmarks are standards by which similar items can be compared and allow the reader to place findings in context. Thus, the 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 and trend data such as those presented in this report.

As mentioned in previous DDS Mortality Reports there are few relative benchmarks (data from other state agencies) available for use in comparing mortality data for persons with ID/DD and when data does exist, there may be differences in the way the data is reported and analyzed.

Benchmarks Other States

The Massachusetts Department of Mental Retardation (MA DMR) reviews the causes and circumstances of the death of individuals who receive DMR supports through an established process for death reporting and mortality reviews similar to the CT DDS. As part of this effort the University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research¹⁷ (CDDER) has prepared annual reports on mortality within this population of Massachusetts citizens since the year 2000. The Massachusetts DMR report represents population and mortality information for the period between January and December of 2006.

OF NOTE: In this section mortality data for the MA (DMR) will be presented with data from CT DDS. Since some of the CT DDS mortality statistics include children and MA DMR data does not, this will be noted in this section when making comparisons. 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). It is therefore important that readers exercise caution when reviewing comparative information. Direct comparisons of specific data should not be made.

MORTALITY RATE BENCHMARKS

Table 23

Comparison of Crude Mortality Rates for Selected State MR/DD Systems

Comparative Mortality Rates	MA DMR 2006	CT DDS 2007	AZ DDD 2004	TN DMRS FY 2005	VT FY 2005	OH 2006
Population Served	MR only	MR only	DDD	DD	DD	DD
Age Range (for computing rate)**	adults only (18+ yrs)	adults only (18+yrs)	children and adults	N/A	children and adults	children and adults
No. Deaths	383	188	216	108	26	746
Mortality Rate (no./1,000)	16.6	16.1	9.7	10	8.4	9.5

Similar to MA DMR crude mortality rate data, the CT DDS data for 2007 is based on the adult population only. Hence the higher rates for CT and MA are comparable and predictable.

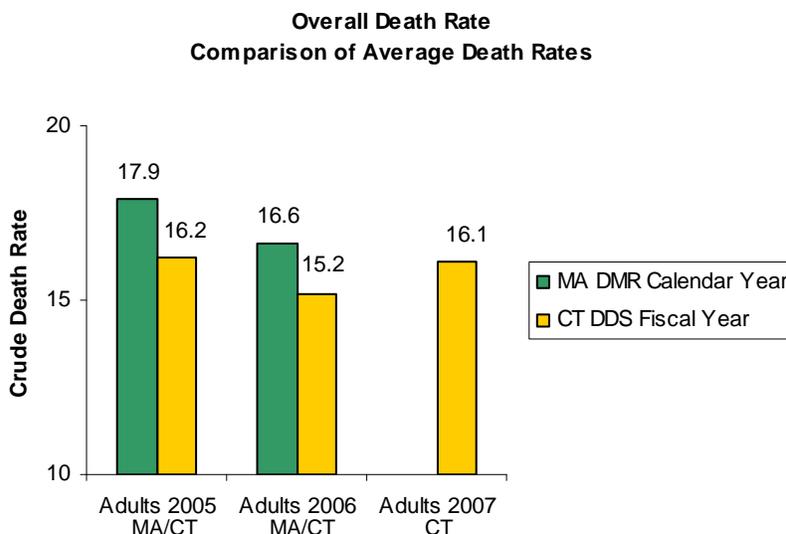
Findings from six states DD/MR mortality reports above include information on crude mortality rates. As mentioned in the MA DMR report, differences in population characteristics, age ranges included in the analysis, age distribution of persons served, service definitions, reporting time periods and requirements and the general absence of national conventions for organizing and reporting mortality data, make direct comparisons among state MR/DD systems difficult.

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Figure 26



Crude death rate above based on adult population (18+).

Crude mortality rates for CT and MA are similar for comparable adult population groups.

Table 24

Comparison of Deaths by Gender CT DDS and MA DMR

Gender	Measure	CT DDS 2007	MA DMR 2006
Male	Percentage of Deaths	50.3%	52%
	Death Rate	11.5%	15.8%
	Ave. Age of Death	56.9	60.4
Female	Percentage of Deaths	49.7%	48%
	Death Rate	14.9%	17.6%
	Ave. Age of Death	59	62.9

Note: Death rate for CT DDS includes children and adults
Death Rate for MA DMR includes only adults

Women typically live longer and have a higher death rate in both CT DDS and MA DMR.

MA DMR is one of the only state DD/MR agencies that reports mortality statistics by gender.

The gender and overall death rate data for CT DDS is based on FY 2007 data.

MA DMR gender and mortality data is based on calendar year data.

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Residential Benchmarks

Table 25

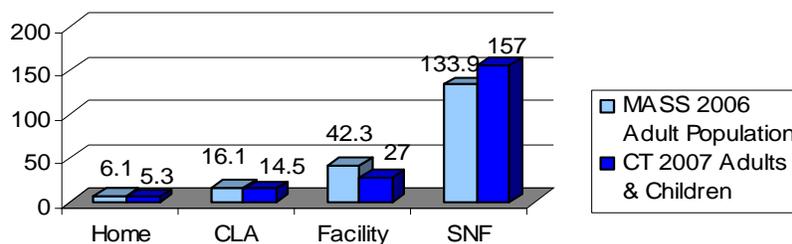
Comparison of the Mortality Rate by Residential Setting
For the MA DMR and CT DDS

Type of Residential Setting	Mortality Rate (per thousand)	
	MA DMR 2006	CT DDS 2007
At Home/Family Independent & Supported Living	6.1	5.3
Community Group Home Community Training Home	16.1	14.5
*Regional Center *Facility-ICF/MR	42.3	27
Nursing Facility	133.9	157

Differences in the population characteristics within residential settings supported by the MA DMR and CT DDS make direct comparisons less than ideal. For example MA DMR does not include children in their population base for calculating mortality rates. However, there are distinct similarities in types of residential settings between the two service systems which make crude mortality rate comparisons of interest.* For example less than 3% of the CT CLA population are children, and of the people living in CT DDS facilities/ICF programs, 99.5% are adults. Therefore these populations are almost identical and these residential populations are very comparable. The differences in mortality rate between CT and MA regional/ICF programs are most likely due to the relatively small number of residents (700) and therefore minor fluctuations in the number of deaths greatly impacts the mortality rate. Crude death rates in CT DDS for comparable residential service types appear to be very consistent with available benchmark data as reported in Massachusetts DMR Mortality Report. The ICF/MR rate is lower in CT. General patterns are similar, with the highest mortality rates in settings with a greater need for supervision.

Figure 27

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



*Where not specified the CT DDS mortality data is based on all people served by the CT DDS (children & adults). MA DMR data is for the adult population only. 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.

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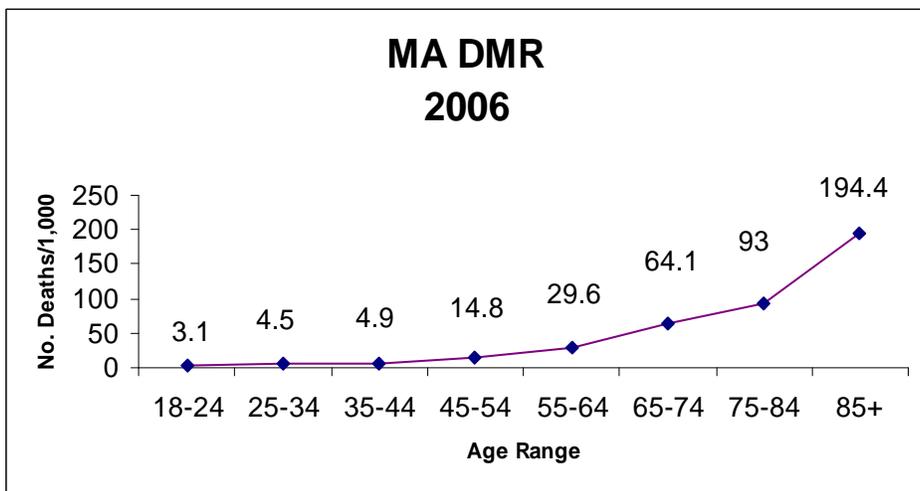
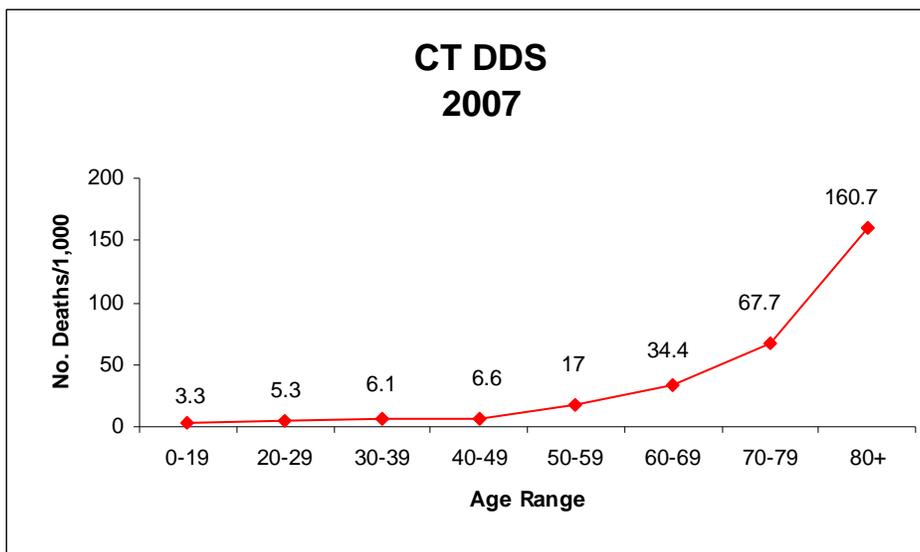
Section Seven Continued

Mortality and Age Benchmarks

Crude mortality rates by age range are presented for CT DDS and MA DMR, however age range used by each state differs. Therefore, a direct comparison is not possible. However a common pattern of mortality rate increasing with age is similar between CT and MA. Death rates increase markedly after the age 60-65 years. Again differences in data distribution make it difficult to draw direct comparisons.

CT DDS and MA DMR Mortality Rates by Age

Figure 28



When age is adjusted for the CT DDS population to individuals over the age of 18 years, the average age of death of 60.8 years is very similar to the MA DMR average age of death of 61.6 years

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Table 26

*Leading Causes of Death CT and MA

Rank	CT DDS 2007	CT DDS 2006	CT DDS 2005	CT DDS 2004	CT DDS 2003	MASS DMR 2006	MASS DMR 2005	MASS DMR 2004
1	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%	Heart Disease 35%	Heart Disease 29%	Heart Disease 21.9%	Heart Disease 16.4%	Heart Disease 18.5%
2	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%	Respiratory Disease 17%	Aspiration Pneumonia 19%	Alzheimer's 14.4%	Cancer 12%	Cancer 12.5%
3	Cancer 11%	Pneumonia 14.4%	Aspiration Pneumonia 12%	Aspiration Pneumonia 14%	Nervous System 16%	Cancer 9.9%	Influenza/ Pneumonia 10.8%	Aspiration Pneumonia 11.2%
4	Pneumonia 8.5%	Cancer 11%	Cancer 8%	Sepsis 6%	Cancer 15%	Aspiration Pneumonia 8.4	C-P Arrest Seizure 10.8%	Influenza Pneumonia 10.9%
5	Pneumonia Aspiration 8.5	Sepsis 7.8%	Sepsis 5.6%	Cancer 6%	Digestive System 4%	CLRD 5.7%	Aspiration Pneumonia 9.3%	Alzheimer's Disease 7.5%
6	Septicemia 6%	Aspiration Pneumonia 5.5%	Stroke 3.7%	Nervous System 4%	Renal Failure 2%	C-P Arrest Seizure 5.5	Alzheimer's Disease 8.60%	C-P Arrest/ Seizure 6.8%
7	Stroke 3.5%	Kidney/ Renal 4.4%	Accident 3.7%	Stroke 3.7%	Diabetes 1.5%	Stroke 5.2%	Septicemia 5.9%	Septicemia 6.6%
8	Kidney Renal 3.5%	Accident 2.7%	Nervous System 3.3%	Accident 2%	X	Septecemia 5.2%	CLRD 4.6%	CLRD 5.7%
9	Digestive System 3%	Stroke 2.2%	Digestive System 1.4%	Digestive System 1.6%	X	Influenza Pneumonia 3.9	Stroke 4.2%	Nephritis 3.6%
10	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%	Kidney Renal 1.6%	X	Unintentional Injuries 3.7	Unintentional Injuries 3.4%	Stroke 3.6%

A review of the data from CT DDS and MA DMR indicates that heart disease remains the leading cause of death for people with ID/DD similar to the general population. However, unlike the general population respiratory disease (including pneumonia/ aspiration pneumonia) continue to be a much more prevalent causes of death in the ID population. 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. CT DDS data includes children and adults. Children (below the age of 19 accounted for only 11 or (5.5%) of all CT DDS deaths in 2007.

MA DMR data indicates an increase in the percentage of deaths due to Alzheimer's disease (14.4%). CT DDS mortality data of cases reviewed (137) revealed that over 12% of people had a diagnosis of Alzheimer's diseases at the time of their death.

* Based on calendar year data

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SECTION EIGHT: SUMMARY MORTALITY CASE REVIEW FINDINGS

An important component of the quality and risk management systems present within DDS 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 DDS continues to embrace a planned organization wide approach to design performance measurement, analysis and improvement by collecting information pertaining to the deaths of all individuals served by the department. The CT DDS mortality review system has proven to be a valuable quality assurance mechanism providing information to trigger corrective action and reduce future risk.

The CT DDS mortality review process provides a retrospective analysis

THAT

- assures compliance with standards
- reduces adverse events
- leads to ongoing improvement

AND GENERATES

- changes in policy & procedure
- protocol development
- practice standards
- focused training
- Systems improvement strategies

Table 27

Mortality Case Summary FY 2007

<i>Deaths Reviewed By Regional Committees</i>	<i>Cases Closed at Regional Level</i>	<i>Cases Referred and Reviewed By IMRB</i>	<i>QA Cases Closed by Region IMRB Review</i>	<i>Total Cases Reviewed By IMRB</i>
137	98 (71%)	39 (29%)	27 (20%)	66 (48%)

Cases Referred to IMRB (39)	
Post Mortem Examination	12
Medical/Health Care Issues	26
Pending Abuse/Neglect Investigations	1

Of the 98 cases closed at the regional committee level, medical and other aspects of care was determined to be appropriate.

Per the CT DDS 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 07 the IMRB exceeded this number with 27% of all cases audited as quality assurance checks by the IMRB. The DDS Director of Health and Clinical Services and the DDS Commissioner meet bimonthly to review mortality findings and recommendations.

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Section Eight Continued

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



The CT DDS mortality review process has evolved into a powerful quality assurance system for ensuring the delivery of optimal health care oversight and services in all DDS 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 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 are at times difficult to quantify but the number of positive outcomes has been notable. Future data collection in this regard may be of great value.



One direct example of actions that have taken place within the CT DDS system as a result of mortality review recommendations has been the improvement in coordination and oversight of health care as a result of the increasing numbers of registered nurses with specialized experience and training in the field of ID and DD nursing who are practicing in both the public and private sector. This infusion of expertise has resulted in better coordination, more direct clinical supports and healthcare oversight delivered by provider agency nursing and clinical staff. In addition, the competency of direct service staff in the area of health care monitoring has improved a great deal. Furthermore, in many situations community based healthcare practitioners have demonstrated an new found sensitivity toward people with ID/DD in their healthcare encounters.



In general 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.

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Section Eight Continued

Summary of IMRB Findings & CT DDS Quality Initiatives

<u>Findings/Recommendations</u>	<u>Quality Initiatives</u>
Professional nursing care and coordination. Compliance with CT Nurse Practice Act	Investigation recommendations regarding scope of nursing practice implemented. Protocols regarding scope of practice in CT DDS system established. Nursing delegation training and procedures implemented.
Emergency Department and hospital based evaluation and treatment.	Improvement in the timely evaluation and treatment by ER practitioners due to improved communication, documentation and collaboration between DDS nursing staff with ER managers and physicians.
Documentation standards	Documentation verified delivery of support services as identified in the individual plan of care in the vast majority of cases. Best practice standards for documenting vital medical information, rationale for treatment and communicating of diagnostic testing or physical examination findings were developed by CT DDS and disseminated to all clinicians within DDS.
Accidental Deaths	Root Cause Analysis of a death completed. Identification of risk and potential risk factors, investigations completed and recommendations implemented.
Reporting of Death and Abuse/Neglect Investigations	All deaths were reported to CT DDS per critical incident reporting procedure. Investigations were initiated in a timely manner.
Hospital Discharge Planning	Nursing Standard for Discharge Planning in final stages of development DDS has emphasized hospital and nursing home discharge planning for people with ID/DD. This has resulted in a noticeable improvement in coordination of supports post discharge.
Professional Nursing Services Coordination	Standardization of nursing coordination and role in various residential support systems. Development of health and nursing best practice standards/procedures. Professional nursing quality committees established.
Nursing Shortage in ID/DD Field	CT DDS 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
Registered Nursing On Call System	Most private provider agencies have adopted DDS formalized standards for On call documentation and communication systems
DNR (Do not resuscitate)	DNR process initiated and in all cases DNR met criteria DHS
Office of the Chief Medical Examiner	Protocol developed by Assoc. Medical Examiner with DHS for reporting and consultation regarding specific sudden and unexpected deaths.
Medical and Health	<ul style="list-style-type: none"> •Dysphagia guidelines and best practice standards developed and annual dysphagia training program initiated •Health standard for weight loss in early development stage •Pain management consistently included in nursing care planning •Process initiated for reviewing the clinical appropriateness of placement of individuals into licensed nursing facilities

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Section Eight Continued

Summary of IMRB Findings & CT DDS Quality Initiatives

<u>Findings/ recommendations</u>	<u>Quality Initiatives</u>
<u>Medical/health (cont.)</u>	<p>.IMRB process requires physicians/practitioners to respond to individual standard of care /practice issues within 30 days of the case review</p> <p>DDS staff development Department revised New Employee Training for recognition of signs and symptoms of illness</p> <p>.E Learning program initiated for new employees</p> <p>.Dysphagia and swallowing risk training provided each year to all public and private service providers</p> <p>.Managed Health Care Pilot Program initiated for individuals living in their own home with fewer support services</p> <p>.Health and Wellness Pilot Program initiated for consumers</p> <p>.Establishment of an Aging coordinator positions to focus on health issues related to aging in the DDS population</p> <p>.Role of the DDS Directors of Health Services (DHS) and Public Services Nursing Directors to ensure compliance with nursing standards of practice and communication of expectations</p> <p>.The regional DHS conduct case post IMRB case reviews with stakeholders at the local level based on IMRB findings</p> <p>.Recognition that community and hospital acquired infections and antibiotic resistant infections pose a great risk of morbidity and mortality for older and immuno-suppressed people with ID</p> <p>.Process initiated by IMRB for private provider administrators to meet with CT DDS managers regarding IMRB findings and recommendations</p>
<u>Medication Administration:</u>	<p>No reported mortalities or serious morbidity associated with errors in the administration of medications by licensed nursing staff or medication certified staff. Regulations regarding the Administration of Medications in the CT DDS service system are under revision to reflect changes in supports and practice.</p>
<u>Oral Health:</u>	<p>Established Oral Health Care Coordinator position to focus on prevention and capacity of oral health care services for DDS consumers. DDS participation on the State of CT Oral Health Task force focusing on the elderly population including those with ID residing in licensed nursing facilities as well as the community</p>
<u>Licensing and monitoring:</u>	<p>Cases of concern involving private provider agencies that are funded by the DDS are referred to the CT DDS Quality Management Division for the purpose of initiating additional monitoring by Quality Management Inspectors</p>
<u>Health Records/ Information:</u>	<p>A protocol to ensure the timely and accurate sharing of clinical information during transition from one placement to another or discharge to a hospital or licensed nursing facility is in the development stage</p>

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