

# **Mortality**

# **ANNUAL REPORT**

**FY 2008**

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This is the seventh 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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*Issue Date: May, 2009*

# Mortality ANNUAL REPORT – 2008

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## CT DDS Mortality Report

### SECTION ONE OF THIS REPORT:

#### *CT DDS MORTALITY REVIEW PROCESS*

This section describes the CT DDS Mortality Reporting and Review Process.

### 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 2008 fiscal year (July 1, 2007- June 30, 2008) including death rates and life expectancy.

### SECTION THREE OF THIS REPORT:

#### *DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS*

This section includes information and analysis of data generated for the 133 deaths reviewed by the DDS regional review committees and Independent Mortality Review Board (IMRB) for the period of July 1, 2007 – June 30, 2008.

### SECTION FOUR OF THIS REPORT:

#### *MORTALITY TRENDS CT DDS*

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

### SECTION FIVE OF THIS REPORT:

#### *LEADING CAUSES OF DEATH*

This section presents CT DDS leading cause of death data.

### SECTION SIX OF THIS REPORT:

#### *BENCHMARKS*

This section presents and compares CT DDS, National, and State mortality statistics and leading cause of death information.

### SECTION SEVEN OF THIS REPORT:

#### *SUMMARY MORTALITY CASE REVIEW FINDINGS*

This section includes information on the findings identified through the DDS mortality review process and examples of quality initiatives implemented as a result of the CT Mortality Review Process.

Appendix: Includes demographic information on the population served by the CT DDS

This report represents a review of the period between July 1, 2007 to June 30, 2008.  
Data in this report was obtained from the CT DDS Database system.

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## CT DDS MORTALITY REVIEW

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

## CT DDS DEATH REPORTING PROCESS

Per State of Connecticut Executive Order No. 25, the Department of Developmental Services shall report all deaths of persons placed or treated under the direction of the Commissioner of the Department of Developmental Services to the Office of Protection and Advocacy whether or not abuse or neglect is suspected or contributed to the individual's death.

The CT DDS death reporting process is a dynamic process that ensures that all deaths are immediately reported to the department and death report forms submitted to department within 24 hours of the death notification.

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## **SECTION ONE: CT DDS MORTALITY REVIEW PROCESS**

### **CRITICAL COMPONENTS OF THE CT DDS MORTALITY PROCESS:**

- Uniform death reporting system
- Screen individual death reports with standard information
- Standardized mortality review process (regional and state)
- Medical professionals participate in the process
- External stakeholders included in the review process
- State level interdisciplinary/independent mortality review board (IMRB) aggregates mortality data over time to identify trends
- Direct link between mortality findings and improvement
- Publically report and document mortality information (Annual CT DDS Mortality Report)

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Section One Continued

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 a final review of all IMRB cases by the CT DDS Commissioner and Director of Health and Clinical Services (IMRB Chair). For DDS policy and procedures regarding death reporting and review please see Appendix.

## 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.

The CT DDS does not review the deaths of individuals who live at home with their families or who were placed by their family/guardian into a licensed nursing facility.

### Independent Mortality Review Board

#### Criteria for Review

- Determined necessary by the regional mortality review 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 at the request of the Director of Quality Assurance and/or the Director of Health and Clinical Services.

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Section One Continued

## 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** (MDR), 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

The Nurse Investigator will forward the Medical Desk Review and associated documents to the DDS Director of Investigations, DDS Director of Health Services (Chair of the Regional Mortality Review Committee) and the DDS Director of Health and Clinical Services (Chair of the Independent Mortality Review Board) when:

- 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 TWO: ANALYSIS OF ALL CT DDS MORTALITIES**  
**(JULY 1, 2007 – JUNE 30, 2008)**  
**NUMBER OF DEATHS REPORTED = 216**

## Overall Mortality Rate

During the 12 month time period between July 1, 2007 and June 30, 2008 a **total of 216** individuals supported by CT DDS passed away **resulting in a mortality rate of 13.94** (Figure 1 & 2 below). Both the number of deaths and mortality rate increased in FY 08.

Figure 1

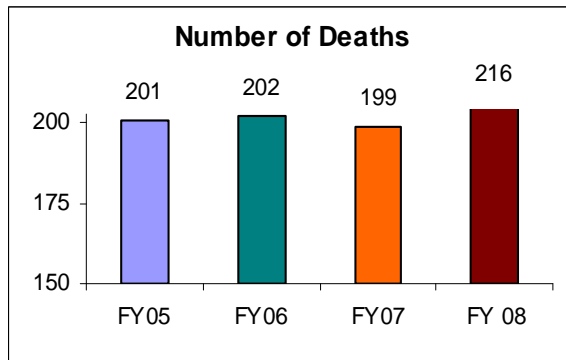
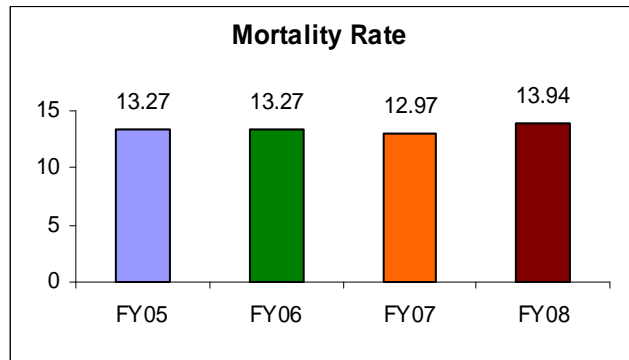


Figure 2



## Mortality and Residence

As can be seen in Figure 3 (to the right) fifty-four percent of deaths occurred in settings that were not operated, funded or licensed by CT DDS.

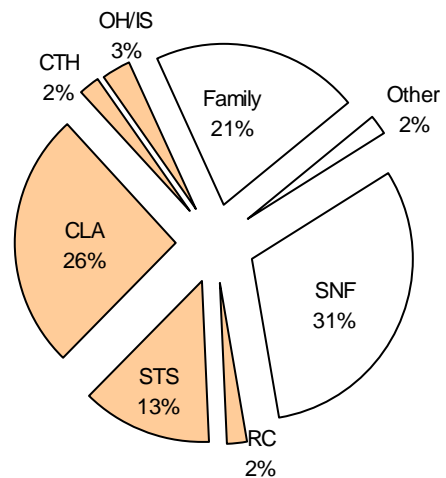
	% Deaths	% DDS population
SNF	31	2
CLA	26	24
Family	21	50
STS	13	3
OH/IS	3	13
CTH	2	3
RC	2	2
Other	2	3

SNF = skilled nursing facility; RC = regional center; STS = Southbury Training School; CLA = community living arrangement (group home); CTH = community training home; OH/IS = own home/individualized supports; Family = live with family at home.

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

Figure 3

### Residence at Time of Death





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Figure 4

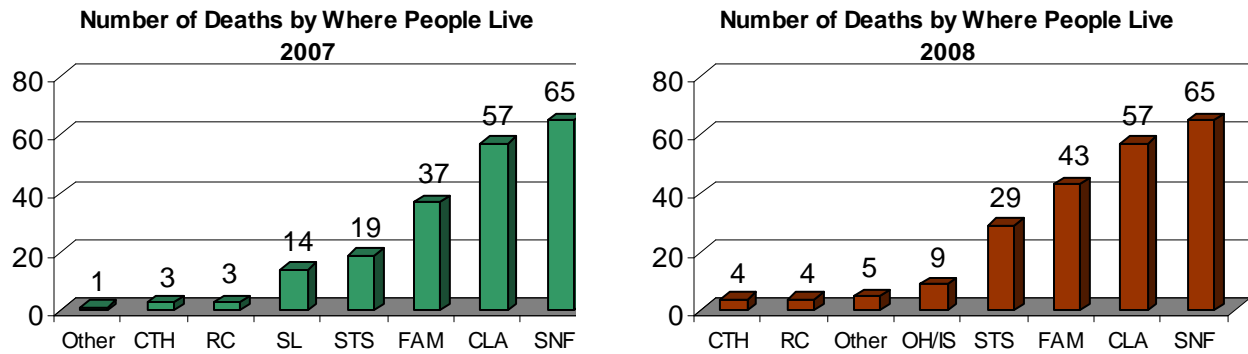


Figure 4 (above) depicts the actual number of deaths by where people live. In line with last year's data the greatest number of deaths occurred in skilled nursing facilities followed by CLA's, family homes and STS. Of note: Sixty-three (63%) of the people DDS supports live in family homes or in their own home with individualized supports, 24% in group homes (CLA's) and only 2% in skilled nursing facilities. Family homes and the Training School saw the greatest increase in the number of deaths in FY 08.

Figure 5

## Mortality Rate by Where People Live

No. Deaths per 1000 people  
FY 2008

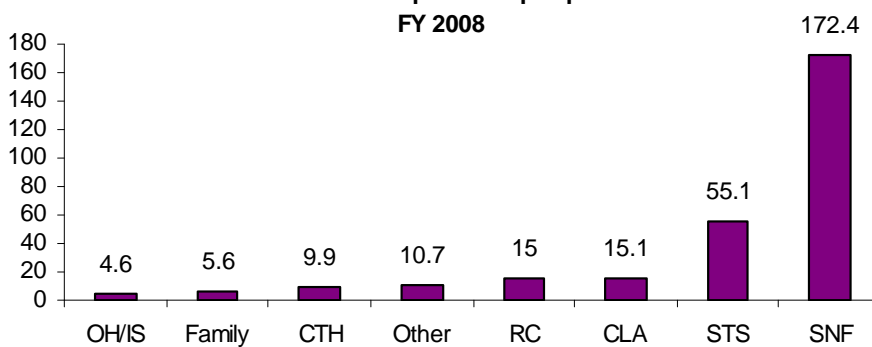


Figure 5 (left) depicts the number of people who died for every 1000 people served by type of support.

Of note: In general, individuals supported by DDS who live in skilled nursing facilities and at STS tend to be older, are more impaired both cognitively and functionally. They also have considerable health co-morbidities.

The estimated 2004 crude mortality rate in nursing homes (SNF) for the U.S. population is 363.5 per thousand.<sup>74</sup>

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## Mortality and Residence

**Family Home:** People who live with their family or independently without significant residential DDS supports represent 50% of the DDS population. However, in FY 2008 only 43 deaths (21% of all deaths) occurred a family home with an associated mortality rate of 5.4. All CT DDS deaths of children were for those who lived with their families. (24 of the 43 people died in a hospital or hospital emergency department)

**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 15.1 for this type of residence. In FY 2008, 57 or 26.4% of all deaths occurred in CLA's compared to 29% in FY 07. (48 of the 57 people died in a hospital or hospital emergency department).

**CTH:** There were only 4 reported deaths in the community training homes in line with the 3 deaths reported in FY 07. These deaths were anticipated and related to an existing condition. The CTH mortality rate of 9.9 was greater than the mortality rate for people living at home with their family or people living in their own home or independently with supports. People living in CTH's represent 2.6% of the DDS population and accounted for less than 2% of the reported deaths. All of these deaths were pronounced at the persons home/CTH.

**OH/IS:** People receiving intermittent individualized supports in their own homes in most cases are less medically involved than people living in other settings and therefore, do not require 24 hour direct supports. Only 4 percent (4%) of reported deaths occurred in this environment compared with 7% last year. For this reporting year the mortality rate of 4.6 for people receiving limited supports was lower than any other setting. Five of the nine people died at their home the rest (4) died in the hospital or hospital emergency department.

**STS:** This larger campus setting serves a population of older adults (average age of 60 years). Many of these individuals present with severe to profound intellectual disabilities and have multiple co-morbidities. The higher mortality rate of 55.1 is not surprising in this medically fragile population. Twenty-nine deaths were reported at STS this past fiscal year representing 13.4% of all DDS deaths. Last year the Training School accounted for 10% of all deaths. (17 of the 29 people died in a hospital or hospital emergency department).

**RC:** Similar to people living at the STS campus the majority of people supported in publically operated regional centers have multiple co-morbidities that require 24 hour direct support and nursing supervision. Only 4 RC residents died in FY 2008 accounting for less than 2% of all DDS deaths. Less than 2% of DDS consumers reside at DDS regional centers. The mortality rate of 15 was only slightly higher than the overall CT DDS mortality rate of 13.94 which may be attributed to a younger population at the regional centers (average age 42.3 years). All of these individuals were pronounced at the regional center.

**SNF:** Only 2% of people served by CT DDS live in a skilled nursing facility. This older (average age 64.9 years) and medically fragile population accounted for 65 or 31% of all reported deaths. People living in licensed nursing facilities had the highest mortality rate 172 per thousand. Sixteen percent (16%) of all DDS consumers over 65 years of age live in a skilled nursing facility. It is important to note that 24 of the 65 people died in a hospital or hospital emergency department.

- Community Living arrangement (CLA): 24 hour support is provided with staff in small group home settings people share an apartment or house also known as a group home.
- Community Training Home (CTH): A family setting that is not the consumer's own family. CTH provider has received training and is licensed by DDS to provide services.
- Own Home/Individualized Supports (OH/IS): 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.
- Regional Center (RC): Regional Centers are facilities for over 16 people that provide 24 hour staffing.
- Skilled Nursing Facility (SNF): a Department of Public Health licensed nursing facility for people requiring skilled nursing level of care not licensed or funded by the Department of Developmental Services also known as a nursing home.

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## Mortality and Gender

Table 1

### Mortality Rate by Gender - FY 2008

GENDER	Percent DDS Pop.	Total DDS Pop.	No. Deaths	Percentage of Deaths	Mortality Rate
Males	57%	8,701	122	56.5%	13.82
Females	43%	6,569	94	43.5%	14.1
<b>Total</b>	<b>100%</b>	<b>15,270</b>	<b>216</b>	<b>100%</b>	<b>13.94</b>

In FY 2008 both the number of males and females who died within the DDS mirrored that of the gender distribution of those people served by the department.

Figure 6

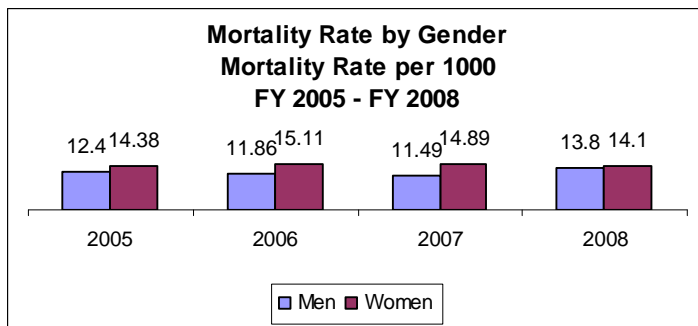
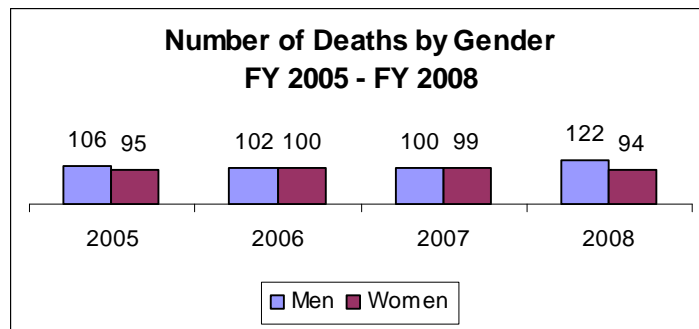


Figure 7

Although there are year to year variations in the actual number of deaths by gender, the data consistently demonstrate that more men than women die each year and that women have a higher mortality rate.

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## Mortality and Age

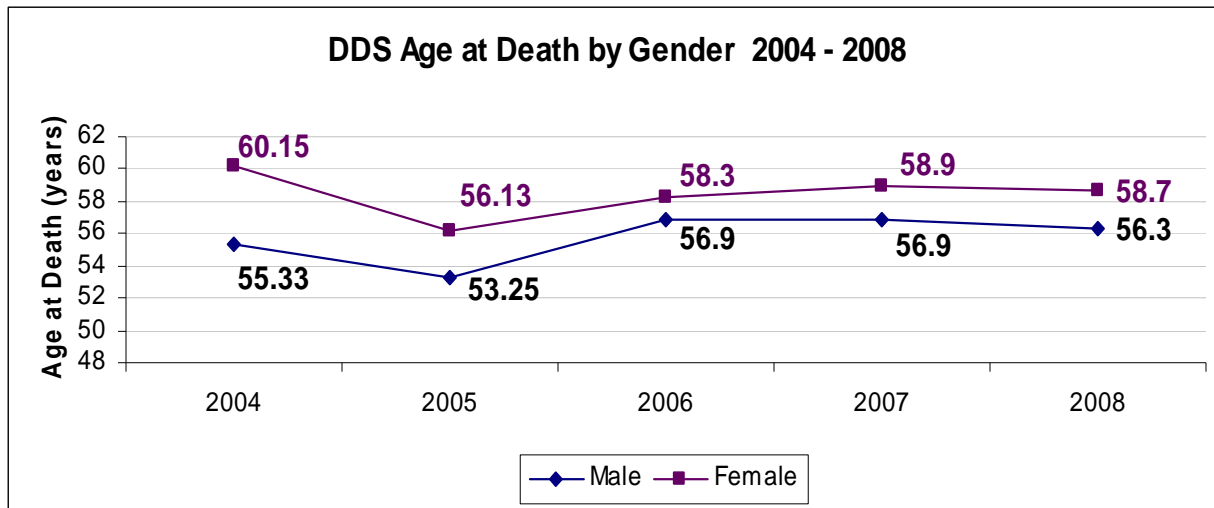
Table 2

### Age of Death

Year	Men	Women	Average Age
CT DDS 2008	56.9	62.1	59.3
CT DDS 2007	56.3	56	56.2
CT DDS 2006	58	60.4	59.1
CT 2006	72	79	75.5
US 2006	75.4	80.7	78.1

The average age of death for people with intellectual disabilities who are supported by the CT DDS has increased along with the lifespan of the CT and US population. However, the typical lifespan for persons with intellectual disabilities is less than 60 years of age.

Figure 8



CT DDS statistics reveal that females in both the general non-disabled population and the DDS population live longer than males.

# Mortality ANNUAL REPORT - 2008

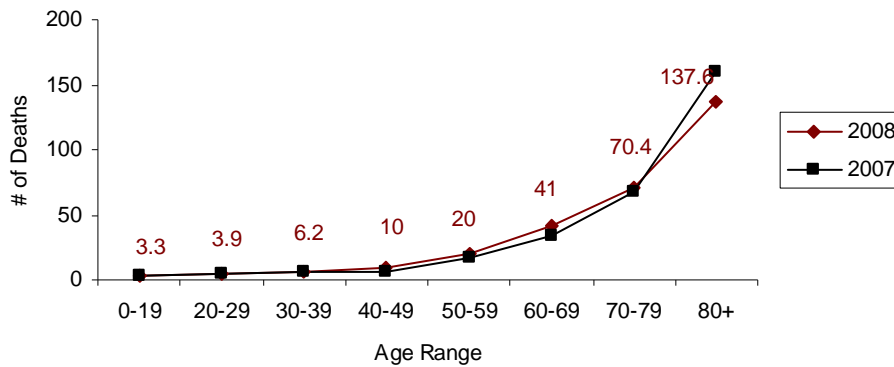
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Figure 9

## Mortality Rates by Age Range

No. Death per 1000 People  
FY 2007 and FY 2008



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 9, there is a dramatic increase in the mortality rate that begins early in the fifth decade of life that continues to increase with advancing age. This finding is consistent with previous CT DDS mortality rate by age data.

Table 3

## Mortality Age Range Distribution Data FY 2008

AGE RANGE	# OF DEATHS	% OF DEATHS	MORTALITY RATE
Age 0-19	12	5.5%	3.3
Age 20-29	12	5.5%	3.9
Age 30-39	13	6%	6.2
Age 40-49	27	12.5%	10
Age 50-59	43	20%	20
Age 60-69	48	22.2%	41
Age 70-79	31	14.4%	70.4
Age 80+	30	13.9%	137.6
<b>TOTAL</b>	<b>216</b>	<b>100%</b>	

Mortality statistics for the DDS population in Table 3 reveal a progressive increase in the number of deaths as the DDS population. Above the age of 70 years the number of deaths declines as the number of individuals supported by DDS declines.

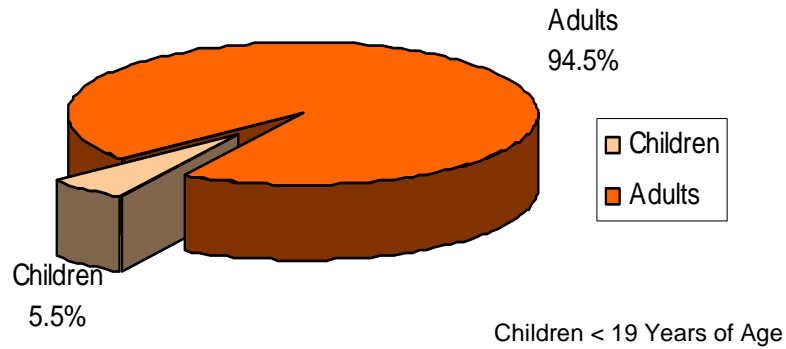
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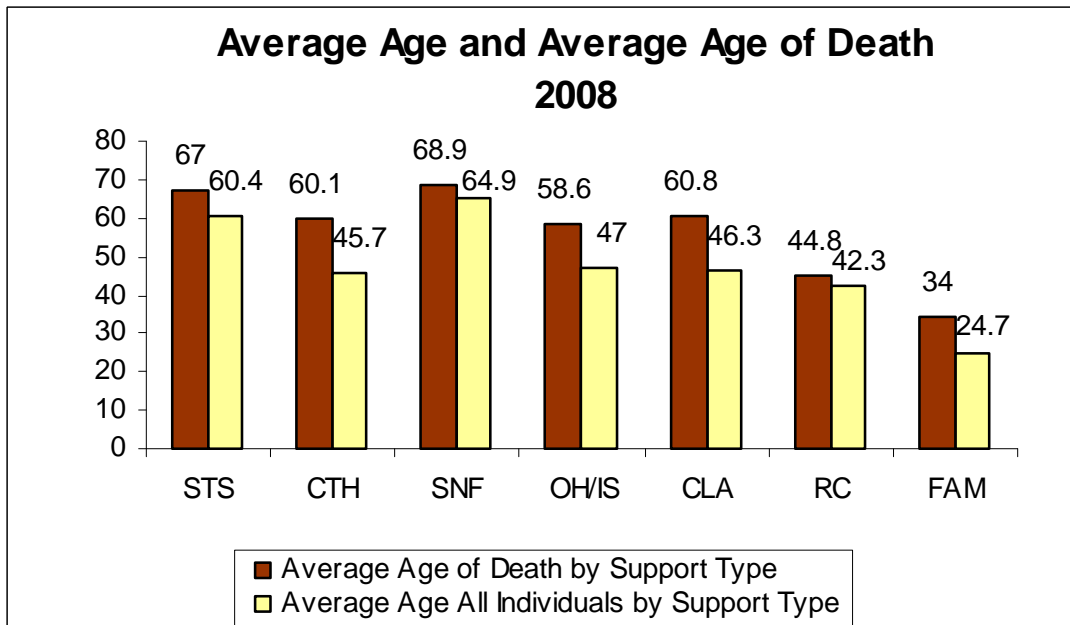
Figure 10

## Deaths of Children and Adults



In FY 08 twelve children died and in every case these children lived at home with their family.

Figure 11



The average age of death for individuals living in nursing facilities and the Training School are higher than for the rest of the DDS population that receive other types of support. And although this finding is of interest there are many unique population specific variables related to a specific support type that may account for it. For example, the lower age of death in the regional centers may be a result of the small number of deaths (4) that occurred in that particular setting. Also almost all of the children served by DDS live at home with their family that translates into a much lower average age and age of death. Excluding children the average age of death in the CT DDS population is 60.8 years.

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## SECTION THREE: DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS

### IMPORTANT PLEASE NOTE:

THE INFORMATION PRESENTED IN THIS SECTION SUMMARIZES ONLY THOSE DEATHS THAT WERE REVIEWED BY THE REGIONAL COMMITTEE AND/OR STATE INDEPENDENT MORTALITY REVIEW BOARD IN FY 2008

THEREFORE THE MORTALITY DATA WILL DIFFER FROM THE INFORMATION PRESENTED AND DISCUSSED IN SECTION TWO OF THIS REPORT

DDS MORTALITY COMMITTEE/BOARD REVIEWS = 133 cases (of total 216 deaths)

## 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, Southbury Training School, community living arrangements, community training homes, own home/individualized supports and family homes. This includes state of the art palliative and hospice care to provide end of life support, hope and comfort to individuals either in the home or in a hospital setting.

The use of hospice services allowed CT DDS to support people through the final stages of a terminal illness while remaining in their current residence. Forty-five individuals received hospice services: 38% lived in group homes, 35% lived in a nursing home, 18% lived at the training school, 7% lived in a community training home and 2% lived in their own home. The average age of death for people receiving hospice services was 64.5.

Forty-five people (34% of all reviewed deaths) received hospice supports

## 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 hospital based pathology departments when DDS requests and the family consents to the autopsy.

### 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

Number of post mortem examinations performed:	17 (13% of reviewed deaths)
Number of post mortem examination performed by CT OCME:	9

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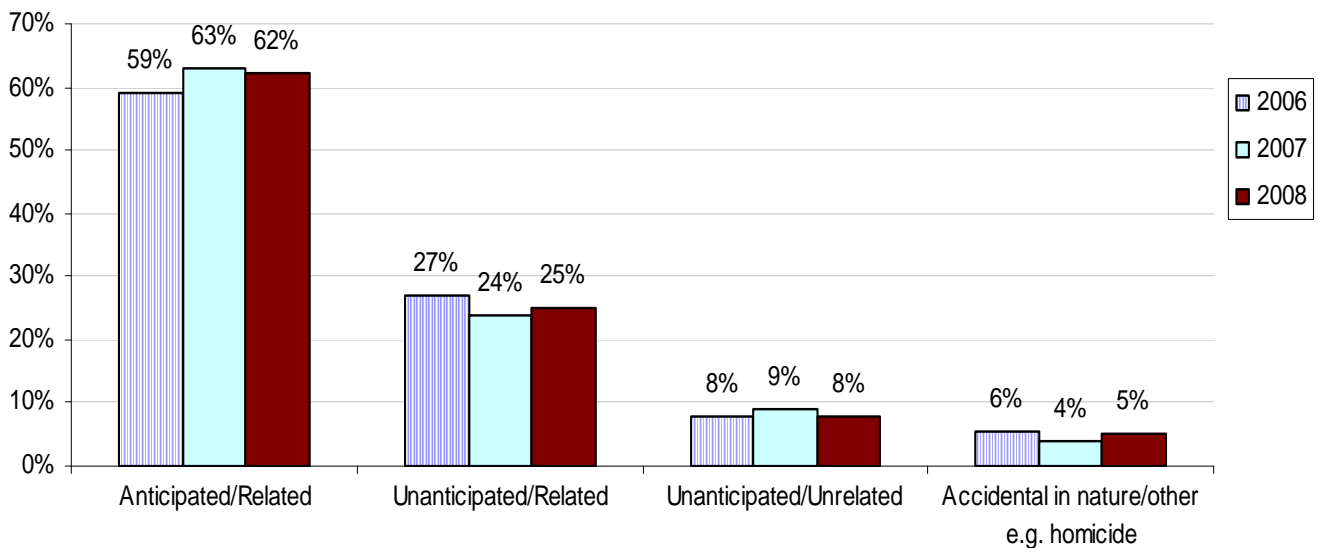
## Predictability

Analysis of the mortality review data indicates a relationship between an individual's pre-existing diagnosed medical condition(s) and his/her immediate cause of death (see Figure 12 below). In eighty-seven percent of all deaths, an individual's immediate cause of death was related to a known or previously diagnosed medical condition/disease. For example: an individual who died as a result of a cardiac arrest had a medical history that included coronary artery disease.

- Death was anticipated and related to a preexisting diagnosis: 62%
- Death was unanticipated but related to a preexisting diagnosis: 25%
- Death was unanticipated and unrelated to a preexisting diagnosis: 13% (includes accidental deaths)

Figure 12

### Predictability of Death



#### OF NOTE:

For individuals living in skilled nursing facilities the condition(s)/diagnoses that contributed or was the immediate cause of death was known to health care providers 97% of the time.

For the majority of individuals over 65 years of age their death was anticipated due to or related to an existing medical condition. The CT DDS data illustrates that for people over the age of 65 the cause of death was directly related to a pre-existing or known medical condition 96% of the time. This finding seems to support the conclusion that age and specific pre-existing medical conditions are very reliable predictors of death in the ID population.



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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*.

In the State of CT deaths for 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 133 cases reviewed during FY 08, 127 (95%) were classified as due to natural causes. The other 6 cases were determined to be the result of an accident or homicide.

Table 4

### FY 08 Manner of Death

<i>Manner of Death</i>	<i>No.</i>	<i>Percent</i>
<i>Natural</i>	<i>127</i>	<i>95%</i>
<i>Accident</i>	<i>4</i>	<i>3%</i>
<i>Homicide</i>	<i>2</i>	<i>2%</i>
<i>Total</i>	<i>133</i>	<i>100%</i>

Cause of death for those deaths determined by the CT OCME to be accidental in nature:

Drowning	(1)
Motor Vehicle Accident	(1)
Trauma	(1)
Fall	(1)

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## UNANTICIPATED/UNRELATED DEATHS:

Of the 16 deaths that were unanticipated and not related to a known condition 4 were accidental in nature, 2 were homicides and 10 were due to natural causes. The causes of mortality for the (10) unanticipated deaths due to natural causes were: Cardiac arrest (5); stroke (2); pneumonia (1); ischemia bowel (1); Ileus bowel (1).

## ACCIDENTAL DEATHS

Except for one case 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 one case that was determined to be accidental in nature was the result of a brief period of inattention, poor judgment on the part of support staff and a failure of staff responsible for supervising the individual to follow prescribed programs.

## **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 and Clinical Services).

For the 133 mortality cases reviewed in FY 2008

**101 cases had a DNR order in place**  
**90% of the DNR orders were formally reviewed by DDS**  
**100% of the DNR orders met the established DDS medical criteria**

In 10% of all cases in which a DNR was ordered by a medical practitioner DDS was not notified prior to the implementation of the DNR order as is required by DDS procedure. *However, the DDS mortality review process determined that in every case the medical criteria to support the decision to initiate the DNR was met.*

OF NOTE: Eighty-three percent (83%) of DDS consumers residing in *skilled nursing facilities* had a DNR order in place at the time of their death.

# Mortality ANNUAL REPORT - 2008

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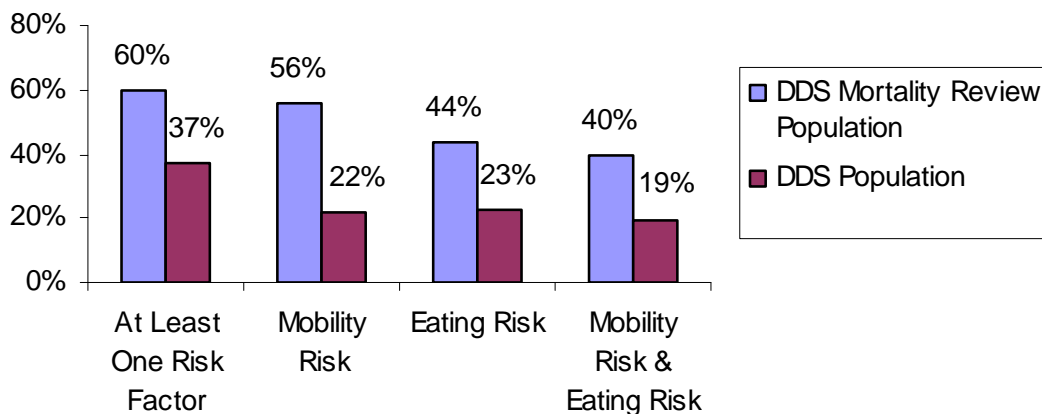
Section Three Continued

## 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 2008 data illustrates the relationship between these risk factors and mortality (see Figure 13 below).

Figure 13

### Risk Factors 2008



It is well documented in the literature that the more compromised an individual's level of mobility, the greater the likelihood of death.<sup>5,7,31,34</sup> CT mortality data supports the importance of mobility as an indicator of morbidity and mortality. In FY 2008, fifty-six (56%) of the the deceased did not ambulate independently.

In addition to the data presented in Figure 13 above, thirty-percent (30%) of all CT DDS consumers who require direct care support for 24 hours a day have been diagnosed with maladaptive behaviors or swallowing dysfunction (dysphagia) which place them at risk for aspiration.

**MORTALITY REVIEW POPULATION ONLY**

56% did not ambulate independently  
44% did not eat independently

**\* DDS POPULATION**

22% do not ambulate independently  
23% do not eat independently

\*Does not include family homes

**Of note: Information regarding the presence and/or risk of silent aspiration is not available and therefore is not included in the eating risk factor data.**

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## Mortality and Complex Health Conditions

Another important factor which seems to affect life expectancy of individuals with intellectual disabilities is the presence of one or more 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, genetic syndromes, severe intellectual disability, mobility, eating dysfunction, and/or enteral feedings had a higher mortality rate than individuals who had fewer health concerns.

Table 5  
Relationship Between Mortality and Complex Health Conditions

	FY 08 % of All Deaths	FY 07 % of All Deaths	FY 06 % of All Deaths	FY 08 Death Rate	FY 07 Death Rate	FY 06 Death Rate
24 HOUR SKILLED NURSING SERVICES:	46%	44%	45.5%	73	70.8	73.6
24 HOUR SUPERVISION NURSING COORD:	33%	37%	32.7%	12.2	13.8	17.1
24 HOUR SUPERVISION LIMITED NURSING:	21%	19%	23.3%	5.7	4.5	4.8

As noted in the table above, the death rate for those individuals who receive 24 hour skilled nursing supports (living in nursing homes, the Training School and regional centers) had a mortality rate of 73 in FY 08. This mortality rate greatly exceeded the death rate for individuals needing limited nursing coordination (12.2) (living in group homes and community training homes) and for those individuals requiring less than 24 hour supervision (5.7) living in their own home or receiving individualized supports. These findings are consistent with the FY 06 & 07 mortality data which also illustrate a direct relationship between the level of nursing/medical support and mortality rate.

Table 6  
Level of Intellectual Disability and Mortality Rate

	2002	2003	2004	2006	2007	2008	Percent of Population
<b>Mild</b>	8.78	8.69	10.75	5.48	3.6	13.6	37
<b>Moderate</b>	8.51	7.69	6.38	9.36	8	15.6	31
<b>Severe</b>	19.95	12.26	14.45	12	14.5	19.9	15
<b>Profound</b>	26.04	25.21	22.86	27.6	22.5	28.4	10

Table 6 above illustrates the relationship between an individual's level of intellectual disability and mortality rate. There is an inverse relationship between the level of intellectual disability and the mortality rate within the DDS population. Over the years, individuals with severe or profound intellectual disabilities have a higher mortality rate than those with moderate or mild intellectual disability.

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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 Abuse Investigations Division (OPA/AID) which determines if abuse or neglect was involved in the death.

Of the 133 mortality cases reviewed by DDS, 11 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 several 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>	<b>5</b>
<i>Neglect not substantiated</i>	<b>4</b>
<i>Cases still open</i>	<b>2</b>

In 2 of the cases where neglect was substantiated, the neglect directly resulted in injuries/ incidents which directly contributed to the individual's death.

In 3 other cases where neglect was substantiated, the lack of supervision by direct care staff, delay in treatment, delay in recognition of a 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 2008 eight (8) 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 for further investigation by the Facilities and/or the Practitioner and Licensing Section.

#### **Disposition of DPH Investigations**

The 8 cases referred to DPH generated 8 investigations

<u>Practitioner Division Investigations – (2)</u> cases open – 2
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<u>Facility Division Investigations – (6)</u> cases open – 5 citations, violations found – 1
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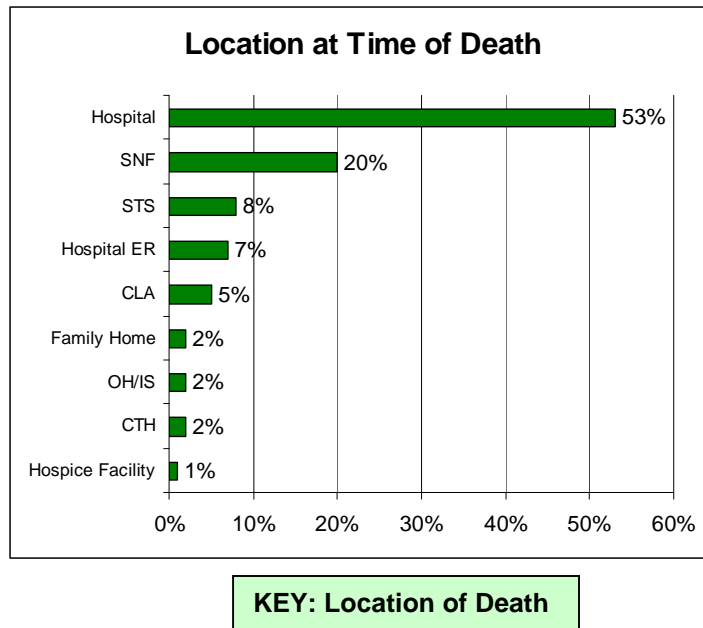
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## Pronouncement of Death (Location at Time of Death)

Figure 14 below depicts the location where death was pronounced.

Figure 14



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

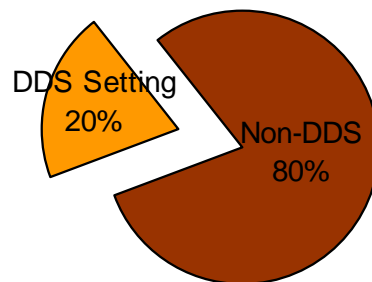
Hospital ER = Evaluated in hospital ER, died in ER, while receiving treatment, not admitted to the hospital.

All Other = Died where the person lived or worked or other community location, for example a day program. RC- regional center, STS- training school.

Figure 15

### Where People Died FY 2008 Mortality Reviews

As can be seen in Figure 15 to the right, 80% of all deaths reviewed by the mortality review committee during FY 08 occurred outside of a DDS operated, licensed or funded residential setting, this represents a slight decrease in the number of people dying outside of a DDS setting compared to FY 07 (81%).



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## **SUMMARY OF MORTALITY DATA**

**for the 133 deaths that were reviewed in FY08**

- **100%** of required cases were reviewed **Regionally**.
- **48%** of all cases were reviewed by the **IMRB**.
- **33%** of the individuals received **Hospice** supports prior to their deaths.
- **13%** of the individuals had **Autopsies** performed.
- **88%** of all deaths were **Related** to an existing medical diagnosis.
- **76%** 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).
- **40%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance).
- **95%** of the deaths reviewed were due to **Natural** causes.
- **36%** lived in **Skilled Nursing Facilities**.
- **4** number of deaths that were classified as **Accidental**.
- **8** number of referrals to **Department of Public Health**.
- **11** number of referrals to **Office of Protection & Advocacy Abuse Investigation Division**.
- **5** number of cases **Neglect** was substantiated by OPA or DDS.

# **Mortality ANNUAL REPORT - 2008**

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## **SECTION FOUR: MORTALITY TRENDS CT DDS**

**For the past seven years the Connecticut Department of Developmental Services has collected, reviewed and analyzed mortality data.**

**Data collection has focused on mortality and residence, mortality and age, mortality and gender and leading causes and factors associated with death.**

**The consistency of the cumulative data/statistics 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.**



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Figure 16

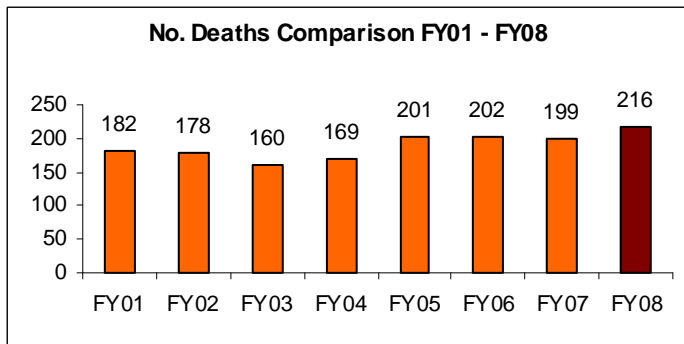
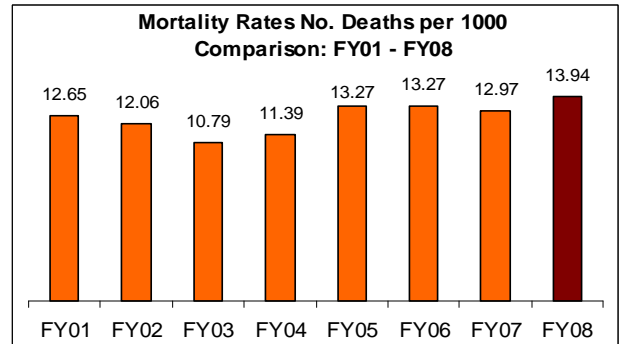


Figure 17



Figures 16 and 17 depict on an annual basis the number of deaths and the average death rate for FY 2001 - 2008 within the population served by DDS. The death rate average over the eight year period of time is 12.54/1000 people.

Figure 18  
Mortality Rate by Where People Live  
6 Year Trend

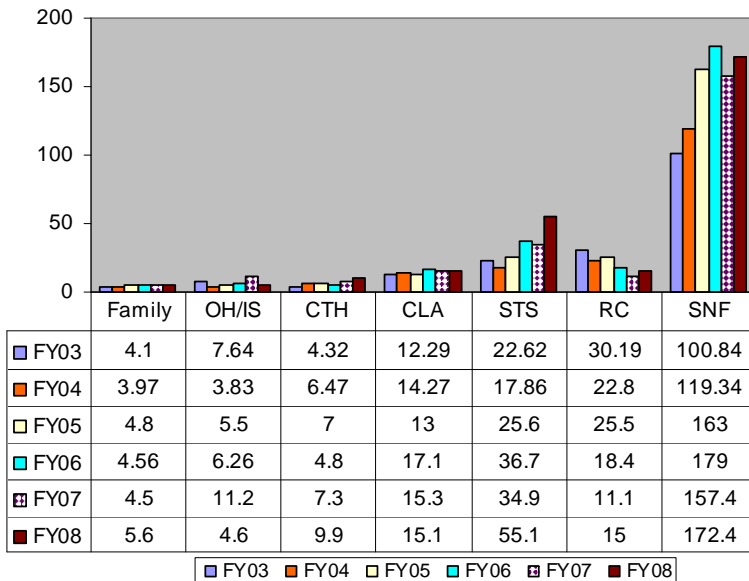


Figure 18 (to the left) compares the death rate (the number of deaths per 1000 persons served) for the past six (6) fiscal years by type of support.

Historically, individuals residing in residences (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 types of settings. These data differ from 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.<sup>21,33</sup>

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

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Table 7  
Mortality and Gender  
(2002 - 2008)

Year	# Deaths Men	# Deaths Women	Mortality Rate Men	Mortality Rate Women
2002	92	86	11.14	13.23
2003	96	64	11.54	9.84
2004	87	82	10.47	12.57
2005	106	95	12.40	14.38
2006	102	100	11.86	15.11
2007	100	99	11.61	15.13
<b>2008</b>	<b>122</b>	<b>94</b>	<b>13.8</b>	<b>14</b>

Over the past seven years more men died annually than women and with only one exception (2003) the mortality rate for women exceeded the mortality rate for men.

Figure 19

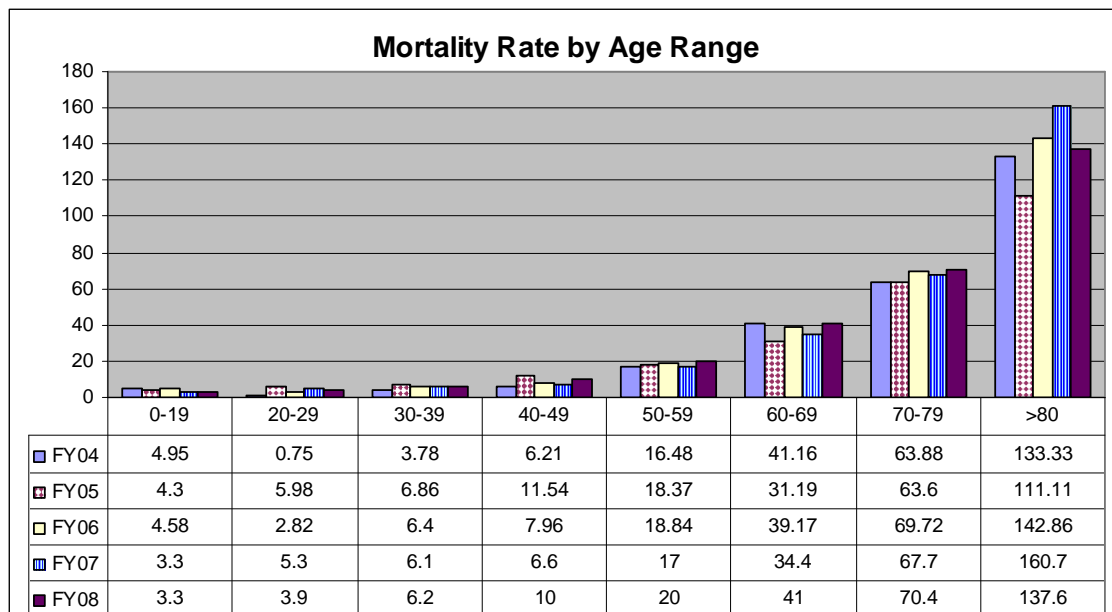


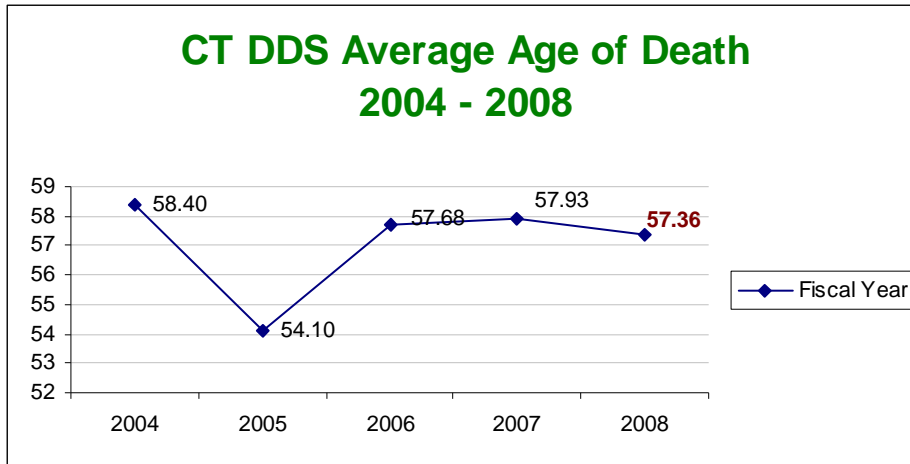
Figure 19 (above) illustrates mortality rate by age range. The data over the past five fiscal years reveals a consistent pattern of increasing mortality rates with each successive decade of life. The mortality rates increase markedly for adults who are in their fifth decade of life. The data also demonstrates that within each age range there is some fluctuation in mortality rates from one year to the next.

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Figure 20



For the last five fiscal years the average age of death has held in a tight range within the fifth decade of life.

Table 8

## RESIDENCE AT TIME OF DEATH TRENDS (2002 - 2008)

	2002	2003	2004	2005	2006	2007	2008
<b>SNF</b>	28%	30%	35%	40%	33%	33%	<b>30%</b>
<b>CLA</b>	30%	27%	31%	23%	31%	29%	<b>26%</b>
<b>Family</b>	19%	20%	15%	19%	18%	17%	<b>20%</b>
<b>STS</b>	*	9%	7%	7%	10%	10%	<b>13%</b>
<b>OH/IS</b>	3%	6%	3%	4%	4%	7%	<b>5%</b>
<b>RC</b>	*	5%	4%	4%	2%	2%	<b>2%</b>
<b>CTH</b>	3%	1%	2%	1%	1%	1%	<b>2%</b>
<b>Other</b>	2%	2%	0%	2%	0%	1%	<b>2%</b>
	100%	100%	100%	100%	100%	100%	<b>100%</b>

\* Data not available

Table 8 depicts the percentage of deaths within various support types over a seven year period of time.

Although there is some variability, the percentage of DDS deaths that occur in SNF's and CLA's is greater than other settings. For example as compared with individuals that live with their family or those who receive individualized supports.

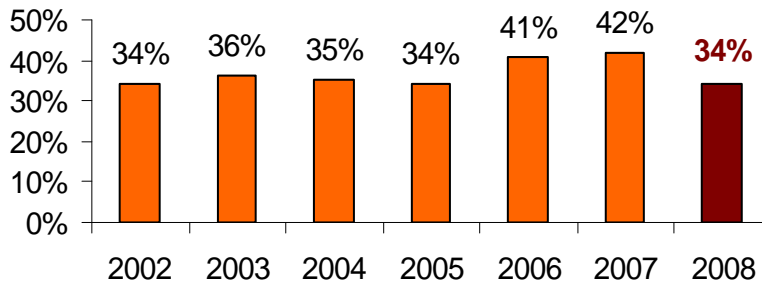
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Figure 21

## Percent of Hospice Supports (2002 - 2008)



End of life planning and hospice care has been a hallmark of the CT DDS system as noted above. 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 continued integration of hospice supports into the person's support plan can be 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 9

## Location Where Death Pronounced (FY 2002 - 2008)

Location	2002	2003	2004	2005	2006	2007	2008	7 Year Total
Hospital	41	34	35	64	58	63	71	366
SNF	13	22	26	35	30	28	26	180
CLA	17	16	18	16	17	15	7	106
Hospital ER	10	9	4	18	14	16	9	80
STS	4	1	5	4	14	6	11	45
RC	7	11	5	3	2	1	0	29
SL	4	4	3	4	5	3	3	26
Hospice	2	1	3	7	2	2	1	18
Other	1	1	0	1	3	3	5	14

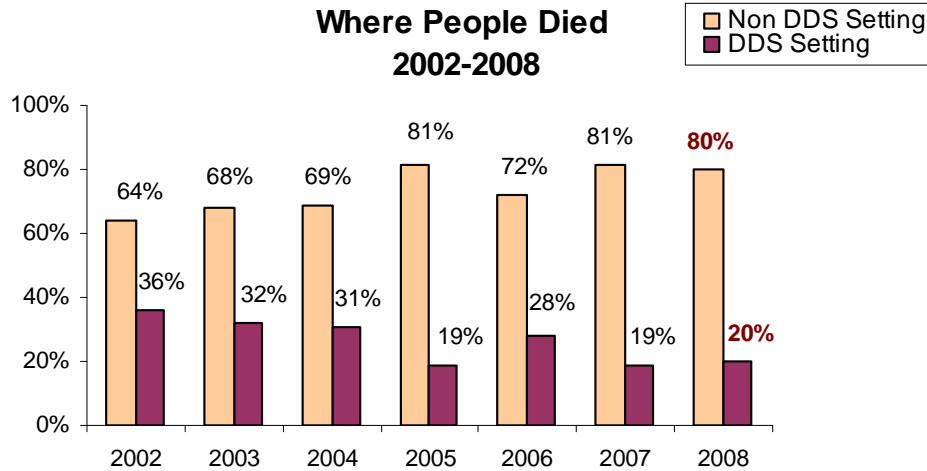
Over the past four years the number of people who died in acute care hospital settings and SNF's has remained relatively stable. Over the seven year period noted above 40% of deaths have occurred in hospitals, 21% in SNF's and 10% in Emergency Departments. It is reasonable to conclude that the stable number of deaths occurring in medical settings are due to the timely recognition of signs and symptoms of illness by non-licensed and licensed staff, and the general aging of the DDS population.

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Figure 22



The number of people served by DDS who expired in non DDS funded settings has decreased slightly in FY 2008 (80% compared to 81% in 2007). 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 past IMRB findings and recommendations. In addition, 24 hour monitoring and assessment by registered nurses for many consumers receiving DDS supports has led to more timely recognition of potential and/or actual acute health conditions that result in emergency department evaluation and often hospital admission.

Table 10

## Number of Autopsies (FY 2003 – FY 2008)

FY 03	28	21%
FY 04	16	16%
FY 05	20	13%
FY 06	17	12%
FY 07	11	8%
FY 08	17	13%

As noted in Table 10 above the number of autopsies performed vary from one review year to the next. This variation can be attributed to the number of deaths in a given year, the specific death related circumstances and requests for consent post mortems by family members. The number of post mortem examinations during FY 2008 increased significantly from 2007 (13% vs. 8%).

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## SECTION FIVE: LEADING CAUSES OF DEATH

This section discusses cause of death data for people served by the CT DDS in calendar year 2008. 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 addition the documented cause of death is also reviewed by the regional mortality committee and/or IMRB during the mortality review process.

Table 11

### Leading Cause of Death Data CT DDS (based on the calendar year 2008)

31%	of deaths were due to	<b>Heart Disease</b>	including	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
15%	of deaths were due to	<b>Aspiration Pneumonia</b>	including	Aspiration Pneumonia
12.3%	of deaths were due to	<b>Respiratory Disease</b>	including	Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma
10.7%	of deaths were due to	<b>Cancer</b>	including	Wide variety of primary origin sites
8.6%	of deaths were due to	<b>Pneumonia</b>	including	Pneumonia/influenza
8.6%	of deaths were due to	<b>Sepsis</b>	including	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
3.2%	of deaths were due to	<b>Renal/Kidney</b>	including	Renal Failure chronic and acute
2.7%	of deaths were due to	<b>Stroke/CVA</b>	including	Intercerebral Hemorrhage
2.1%	of deaths were due to	<b>Genetic Disorder</b>	including	Muscle diseases, etc.
1.6%	of deaths were due to	<b>Digestive System</b>	including	Intestinal Obstruction, Liver Disease, volvulus
<1%	of deaths were due to	<b>Accident/Trauma</b>	including	Unintentional Injuries Falls, Asphyxia, Choking, Trauma

The 10 leading causes of death in 2008 (Table 11) are noted above. Heart disease remains the leading cause of death for the DDS population with aspiration pneumonia, respiratory disease, cancer and pneumonia rounding out the top five.

### Heart Disease

Heart Disease/cardiovascular disease remains the leading cause of death for the CT DDS population (31%). 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.

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

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Table 12 provides an in-depth analysis of the cardiac deaths that were reviewed as part of the DDS mortality review process. The data reveal that more males than females died as a result of heart disease in FY 07 & 08 while women who died as a result of heart disease lived longer than men in each reporting period.

Table 12

## Deaths Due to Heart Disease

Year	# Deaths Male	# Deaths Female	Avg Age Male	Avg Age Female	Avg Age
FY 07	23	19	59.5	75.9	66.9
FY 08	18	15	66.5	69.2	67.7

As in the general population, many of the consumers who died as a result of cardiovascular disease had at least one or more identified risk factors prior to their death such as high blood cholesterol, high blood pressure, coronary artery disease, peripheral vascular disease, congenital heart defects, congestive heart failure, physical inactivity, obesity and diabetes mellitus.

In the general population over 83% of people who die of coronary heart disease are 65 or older<sup>58</sup> as compared with only 44% of individuals in the CT DDS population. Of the remaining cardiac related deaths in the DDS population group: twenty-two percent (22%) of the cardiac deaths occurred prior to the age of 50 years and 34% percent of between the ages of 50-65.

There is a greater prevalence of congenital heart conditions and atrioventricular septal defects<sup>60</sup> found in people with Down Syndrome. However, CT DDS data reveals that the incidence of cardiac deaths reported for people with Down Syndrome were in line with the rest of the DDS population.

## Respiratory Disease

The 2008 leading cause of death data demonstrates the significant impact of respiratory disease in the CT DDS population.

An analysis of the cases reviewed by the CT DDS mortality review process revealed that more men died as a result of respiratory disease/aspiration pneumonia/pneumonia than women and that they died at a younger age.

Table 13

## Deaths Due to Respiratory Disease, Pneumonia and Aspiration Pneumonia

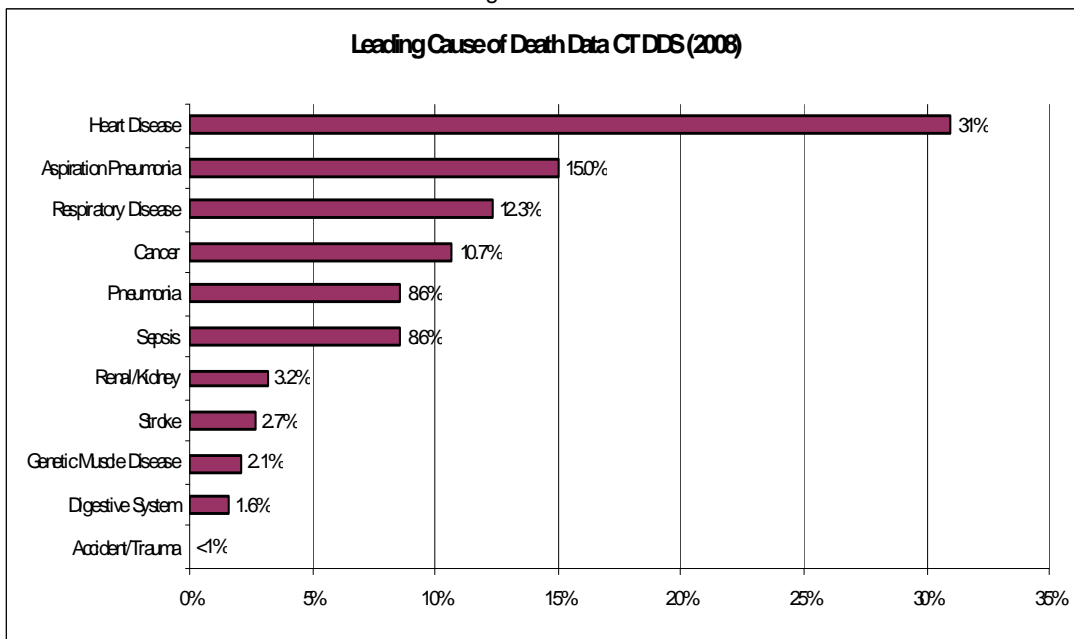
Year	# Males	#Females	Avg. Age Males	Avg. Age Females	Ave. Age
FY 07	24	34	60.1	69.7	65.7
FY 08	31	23	63.4	67.7	65.3

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Figure 23



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 36% of all deaths in 2008 eclipsing the number of deaths caused by cardiac disease (31%).

The frequency of respiratory disease (specifically pneumonia and aspiration pneumonia) and the resultant 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, cerebral palsy, genetic syndromes, 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 the population of people with intellectual disabilities has also been identified and reported by other state ID/DD agencies.<sup>44,51,52,53,54,55</sup>

The incidence of mortalities related to respiratory diseases is even more striking in the DDS Down Syndrome population illustrated by the fact that almost 80% of people with Down Syndrome died as a result of pneumonia, aspiration pneumonia respiratory or generalized sepsis related to a respiratory infection.

## Alzheimer's Disease

Alzheimer's Disease is not included in the CT DDS leading cause of death statistics because Alzheimer's Disease is rarely identified as an immediate cause of death or underlying cause of death on certificates of death or noted on CT DDS Death Reports. However, during the mortality review process it was determined that in 24% of the 133 deaths, the person had a diagnosis of Alzheimer's Disease at the time of their death. For comparison, in 2006 the MA DMR reported that 14.4% of all deaths resulted from Alzheimer's Disease.



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Table 14

## Leading Causes of Death CT DDS

Rank	CT DDS 2008	CT DDS 2007	CT DDS 2006	CT DDS 2005	CT DDS 2004
1	<b>Heart Disease 31%</b>	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%	Heart Disease 35%
2	<b>Aspiratory Pneumonia 15%</b>	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%	Respiratory Disease 17%
3	<b>Respiratory Disease 12.3%</b>	Cancer 11%	Pneumonia 14.4%	Pneumonia Aspiration 12%	Pneumonia Aspiration 14%
4	<b>Cancer 10.7%</b>	Pneumonia 8.5%	Cancer 11%	Cancer 8%	Septicemia 6%
5	<b>Pneumonia 8.6%</b>	Aspiration Pneumonia 8.5	Septicemia 7.8%	Septicemia 5.6%	Cancer 6%
6	<b>Septicemia 8.6%</b>	Septicemia 6%	Aspiration Pneumonia 5.5%	Stroke 3.7%	Nervous System 4%
7	<b>Nervous System 3.7%</b>	Stroke 3.5%	Kidney/ Renal 4.4%	Accident 3.7%	Stroke 3.7%
8	<b>Kidney/ Renal 3.2%</b>	Kidney Renal 3.5%	Accident 2.7%	Nervous System 3.3%	Accident 2%
9	<b>Stroke 2.7%</b>	Digestive System 3%	Stroke 2.2%	Digestive System 1.4%	Digestive System 1.6%
10	<b>Digestive System 1.6%</b>	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%	Kidney Renal 1.6%

Based on 2008 calendar year data

Table 14 compares the top ten leading causes of death with CT DDS data from previous years. Other than heart disease as the leading cause of death in the CT DDS population there were many changes in the cause of death rankings compared to the 2007 data. For example: aspiration pneumonia passed pneumonia, cancer and respiratory disease to become the second leading cause of death. Pneumonia was the fifth leading cause moving down one notch, respiratory disease dropped to third from second, cancer dropped to the fourth leading cause from third, while septicemia remained the sixth leading cause of death. There were minor changes on a percentile basis for the other leading causes of death (7-10<sup>th</sup>). Of note: Over the past two years accidental deaths did not make the top 10 causes of death. Respiratory disease, aspiration pneumonia and pneumonia as a cause of death once again represented over 1/3 of all CT DDS deaths. The increase in deaths due to aspiration pneumonia is due in part to the clinical cause of death criteria used in this report.

In this report pneumonia is classified as an acute infectious process.

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Section Five Continued

## Leading Causes of Death for People with DOWN SYNDROME

Table 15

FY 08

### Primary Cause of Death/Down Syndrome

Respiratory Failure	16
Aspiration Pneumonia	4
Cardiac Arrest	3
Liver Disease	1
Lymphoma	1
Sepsis	1
<b>Total</b>	<b>26</b>

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.<sup>15,16,19,20</sup> People with Down Syndrome in the CT DDS system are living almost as long ( 58.3 years) as the general DDS population (57.36 years).

Since 2006 aspiration pneumonia and respiratory failure have accounted for almost 60% of all deaths for people with Down Syndrome.

Based on the DDS Down Syndrome and death data (Table 17) there is no appreciable difference in lifespan for those individuals with or without Alzheimer's Disease.

It is estimated that between 300,000 and 350,000 people in the United States have Down Syndrome. In the State of Connecticut approximately 2,400 people have Down Syndrome. This number would represent 14% of the CT DDS population.

This year respiratory failure was the leading cause of death for persons with Down Syndrome (62%) followed by aspiration pneumonia and cardiac arrest.

Although Alzheimer's Disease was rarely documented as a cause of death the majority of people with Down Syndrome had a diagnosis of Alzheimer's Disease at the time of their death (59%). This data supports other research studies that found increased prevalence of Alzheimer's Disease in people with Down Syndrome.

Table 16

FY 06 - FY 08

### Primary Cause of Death/Down Syndrome

Aspiration Pneumonia	21
Respiratory Failure	21
Cardiac Arrest	16
Renal Failure	3
Gastrointestinal hemorrhage	2
Sepsis	2
Asphyxia	1
Cancer	1
CVA	1
Liver Disease	1
Lymphoma	1
Subdural hematoma	1
<b>Total</b>	<b>71</b>

Table 17

### Average Age of Death Data

	2007	2008
Down Syndrome	56.3	58.3
Down Syndrome & Alzheimer's disease	58.3	59.4
Down Syndrome w/o Alzheimers disease	52.3	55.2

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Section Five Continued

## Analysis of Cancer Deaths

Table 18

FY 08

### Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	3	67.7
Larynx	2	51.5
Lymphoma	2	65
Adeno Carcinoma	1	46
Bladder	1	53
Brain	1	82
Ethmoid Sinus	1	48
Gallbladder	1	60
Liver	1	61
Ovary	1	48
Pancreas	1	72
Prostate	1	83
Renal	1	43
<b>TOTAL</b>	<b>17</b>	<b>60.7</b>

For FY 08 the distribution of cancers in men were lung (2), larynx (2), renal (1), prostate(1), liver (1), gallbladder (1), bladder (1), adeno carcinoma (1), lymphoma (1).

The average age of death for all cancer victims (60 years) exceeded the average age of death for all CT DDS deaths (57.9 years).

Cancer deaths of women in the CT DDS system accounted for one-third (6/17) of the cancer related deaths.

The FY 08 distribution of cancers in women were: lung, ovarian, brain, pancreatic, ethmoid sinus and lymphoma.

### In FY 2008 cancer was the fourth leading cause of death for people supported by the CT DDS

The rate of death due to cancer in the CT DDS population (1.1/1000) was lower than the rate of 2.0/1000 in the state of CT and 1.9/1000 nationally.<sup>2,11</sup>

Over the past 3 years cancers have represented 11% of CT DDS mortalities.

Lung and pancreatic cancers were the two most common types of cancer at 16% and 8% respectively.

Table 19

FY 06 - FY08

### Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	10	62.3
Pancreas	5	69.1
Bladder	3	50.5
Breast	3	62
Colorectal	3	71
Prostate	3	79.7
Renal	3	49
Stomach	3	67
Brain	2	70.5
Esophagus	2	63.5
Larynx	2	51.5
Liver	2	57
Lymphoma	2	65
Ovary	2	45.5
Adeno Carcinoma	1	46
Angiosarcoma	1	53
Aplastic Anemia	1	23
Cholagio	1	86
Endocrine/Adrenal Gland	1	61
Ethmoid Sinus	1	48
Gallbladder	1	60
Lymphatic/Hemotopoietic	1	73
Lymphoma non-Hodgkins	1	78
Oral/pharynx	1	68
Parotid Gland	1	46
Testicular	1	63
Trachael/Bronchus	1	81
Unknown	3	67
<b>TOTAL</b>	<b>61</b>	<b>63</b>

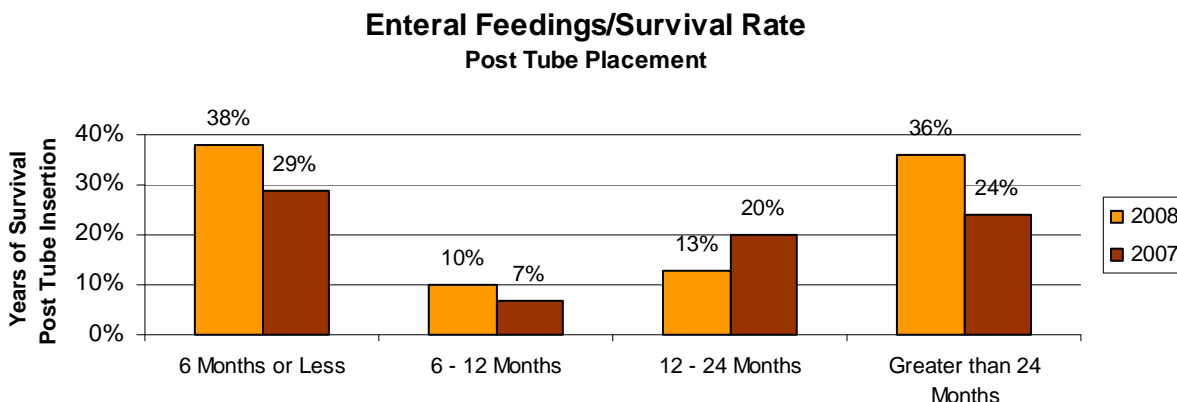
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## Enteral Feedings

Figure 24



As a result of the CT DDS mortality review process and resulting data analysis the department has identified that there is a relationship between survival and initiation of gastrostomy or jejunostomy tube feedings. The data reveals that during the past two years 80 individuals were tube fed prior to their death. Sixty-nine individuals had a gastrostomy tube, 11 had a jejunostomy tube and 10 had a gastrostomy and jejunostomy tube.

In most cases the enteral feedings were initiated for one or more of the following reasons: recurrent aspiration pneumonia, malnutrition and /or dementia. In fact, 90% of these individuals had a history of recurrent pneumonia or aspiration pneumonia or dementia before insertion of the feeding tube.

In FY 08, 30% of the people (133) who died were fed enterally at the time of their death. Six month survival following placement of a feeding tube was 62% (24/39); 1 - year survival was 52%; 2-year survival was 39%. Therefore, 61% died within two years of initiating the tube feeding. The 2007 CT DDS mortality data (Figure 24) demonstrates that the 1-year survival was 66% and the 2-year survival was 49%. The CT DDS data enteral feeding data supports other research findings that suggest that enteral feedings do not prolong survival for the elderly and/or people who have significant cognitive or neurological conditions.<sup>41,42,45,46,48,50,69,70,71</sup>

The immediate cause of death in the majority of these cases was attributed to pneumonia, aspiration pneumonia or respiratory failure. And within the CT DDS mortality population there did seem to be an increase in the incidence of pneumonia/aspiration pneumonia or risk of mortality associated with enteral tube feeding. Therefore, the DDS data seemed to validate other studies which suggest that people who require enteral feeding tubes have a significantly higher rate of pneumonia and pneumonia related death.<sup>38,39,42,48,66</sup>

The gender and/or level of intellectual disability of CT DDS individuals who were tube fed did not have an impact on mortality. However, an individual's unique clinical profile did seem to be an important factor in predicting risk of mortality post artificial enteral nutrition.

\* This preliminary analysis of the CT DDS mortality data suggests that the risk associated with tube feeding outweighs the benefits. In this regard the CT DDS data is consistent with other studies that failed to show that intervention by tube feeding is an effective treatment approach in supporting people who are on a dying trajectory due to a chronic illness.<sup>48,50,69,70,71</sup> However, the lack of evidence based research to support the practice of feeding tube placement (G/J) in the ID/DD population suggests that further investigation would be of considerable importance to practitioners in this field.

\* Based on data from all 133 cases reviewed by the CT mortality review process.

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## SECTION SIX: BENCHMARKS

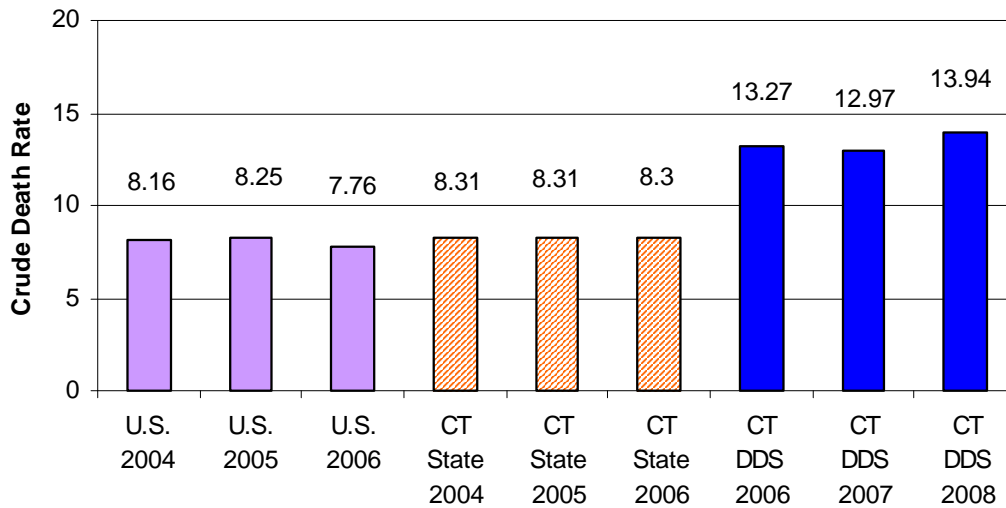
### Mortality Rate Comparison

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.

The overall CT DDS crude death rate of 13.94/1000 is higher than the rate of 8.30 in Connecticut (2006) and the rate of 7.76 in the general United States population(2006). This would be expected due to the many health and functional complications associated with intellectual disabilities.

Figure 25  
Overall Death Rate  
Comparison of Average Death Rates/1,000



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.

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 a measure of how many people out of every thousand served by CT DDS died within the fiscal year. It is determined by multiplying the number of individuals who died during the year times one thousand and dividing this number by the total number of individuals served by DDS during the same period of time.

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Table 20

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

Rank	US 2006	US 2005	STATE CT 2006	STATE CT 2005	<b>CT DDS 2008</b>	CT DDS 2007	CT DDS 2006	CT DDS 2005
1	Heart Disease 25.9%	Heart Disease 26.5%	Heart Disease 25.5%	Heart Disease 25.9%	<b>Heart Disease 31.0%</b>	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%
2	Cancer 23.1%	Cancer 22.8%	Cancer 24%	Cancer 23.8%	<b>Aspiration Pneumonia 15%</b>	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%
3	Stroke 5.6%	Stroke 5.8%	Stroke 5.2%	Stroke 5.2%	<b>Respiratory Disease 12.30%</b>	Cancer 11%	Pneumonia 14.4%	Pneumonia Aspiration 12%
4	Respiratory Disease 5.1%	Respiratory Disease 5.3%	Respiratory Disease 5%	Respiratory Disease 5%	<b>Cancer 10.70%</b>	Pneumonia 8.5%	Cancer 11%	Cancer 8%
5	Accidents 4.8%	Accidents 4.7%	Accidents 4.3%	Accidents 3.8%	<b>Pneumonia 8.6%</b>	Pneumonia Aspiration 8.5	Septicemia 7.8%	Septicemia 5.6%
6	Alzheimer's Disease 3%	Diabetes 3%	X	X	<b>Septicemia 8.60%</b>	Septicemia 6%	Pneumonia Aspiration 5.5%	Stroke 3.7%
7	Diabetes 2.90%	Influenza/ Pneumonia 2.9%	X	X	<b>Nervous System 3.70%</b>	Stroke 3.5%	Kidney/ Renal 4.4%	Accident 3.7%
8	Influenza/ Pneumonia 2.3%	Alzheimer's Disease 2.5%	X	X	<b>Kidney/ Renal 3.20%</b>	Kidney Renal 3.5%	Accident 2.7%	Nervous System 3.3%
9	Nephritis/ Kidney 1.8%	Nephritis/ Kidney 1.8%	X	X	<b>Stroke 2.70%</b>	Digestive System 3%	Stroke 2.2%	Digestive System 1.4%
10	Septicemia 1.4%	Septicemia 1.4%	X	X	<b>Digestive System 1.60%</b>	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%

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## Leading Causes of Death Benchmarks: National, State of CT and CT DDS

Table 20 compares the top ten leading causes of death for people served by CT DDS with vital statistics benchmarks data for the State of Connecticut, and United States. Year over year data comparisons continue to demonstrate consistency in the leading causes of death data.

**Heart Disease:** (Due to various cardiac diagnoses) is the number one cause of death for all of the referenced populations. As in past years the prevalence of cardiac disease is slightly greater in the DDS population at 31% versus 25.5 in the CT general population and 25.9 nationally.<sup>2,11</sup>

**Aspiration Pneumonia:** Is the second leading cause of death in the DDS population (15%) and as mentioned earlier in this report is unique to the ID/DD population due to many factors including the prevalence of dysphagia, Down syndrome, Alzheimer's disease and enteral feedings. In comparison, aspiration pneumonia is not reflected in the state of CT or national vital statistics as one of the top ten leading causes of death.

**Respiratory Diseases:** Remained the third leading cause of death within the CT DDS population (12.3%). This category which includes influenza causes death in the CT DDS population at a rate almost 2 ½ times reported in the CT and national vital statistics data base (5%) and (5.1) respectively<sup>2</sup>.

**Cancer:** Is the fourth leading cause of death in the CT DDS population responsible for almost 11% deaths. Unlike the the previously mentioned leading causes of death, cancer in DDS which occurs less frequently in the CT DDS population, than in the CT (24%) and national (23.1%) general populations. This dissimilarity in the prevalence of cancer related death is may be related to the the significantly lower survival rate in the CT DDS population.

**Pneumonia:** Is the fifth leading cause of death accounting for 8.6% of CT DDS deaths compared to <3% in the general CT and US population.<sup>2,11</sup> Many of the multiple co-morbidities found in the CT DDS ID/DD population such as cerebral palsy, congenital syndromes, epilepsy, GERD, hiatal hernia, and immuno-deficiency disorders result in a compromised pulmonary system that makes this population vulnerable for developing pneumonia.

**Septicemia:** Originating from various sites and usually acute in onset is the 6th leading cause of death in the CT DDS population resulting in 8.6% of deaths while only 1.4% of deaths in the US general population are caused by sepsis.<sup>2,11</sup>

**Accidental Deaths:** In calendar year 2008 the percent of deaths resulting from accidents in the CT DDS system (1%) did not make the top 10 leading causes of death and once again was lower than the number of accidental deaths reported in the 2006 CT population (4.3%)<sup>2</sup> and US population (4.8%)

**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 2008 had a diagnosis of cerebral palsy at the time of their death compared to less than 1% in the general population.<sup>56</sup> Also, many individuals in the CT DDS system had a diagnosis of dysphagia and or gastroesophageal reflux disease at the time of their death. Both of which have been linked to aspiration pneumonia, respiratory failure, sepsis and death in the ID/MR population.<sup>6,31,44,45,47,49,50</sup>

**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 2008. 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 (2006) calendar year.**

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## 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 Research<sup>17</sup> (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 2007.

**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 21

### Comparison of Crude Mortality Rates for Selected State MRDD Systems

Comparative Mortality Rates	MA DMR 2007	CT DDS 2008	AZ DDD 2004	TN DMRS FY 2005	VT FY 2005	OH 2007
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	416	205	216	108	26	693
<b>Mortality Rate (no./1,000)</b>	17.6	16.3	9.7	10	8.4	8.7

Similar to MA DMR crude mortality rate data, the CT DDS data for 2008 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.



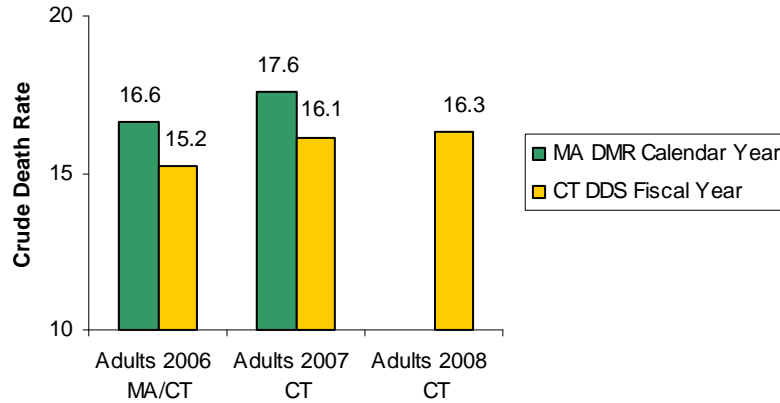
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Figure 26

**Overall Death Rate  
Comparison of Average Death Rates**



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

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

Table 22

**Comparison of the Percentage of Deaths by Gender  
CT DDS and MA DMR**

Gender	Measure	CT DDS 2008	MA DMR 2007
<b>Male</b>	Percentage of Deaths	56.5%	52.6%
	Death Rate	13.8	16.9
	Ave. Age of Death	56.4	60
<b>Female</b>	Percentage of Deaths	43.5%	47.4%
	Death Rate	14.1	18.5
	Ave. Age of Death	58.7	64.2

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

CT DDS and MA DMR gender related mortality data demonstrate similarities in all areas: percentage of death; mortality rate and average age of death.

\*MA DMR gender and mortality data is based on calendar year data

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## Residential Benchmarks

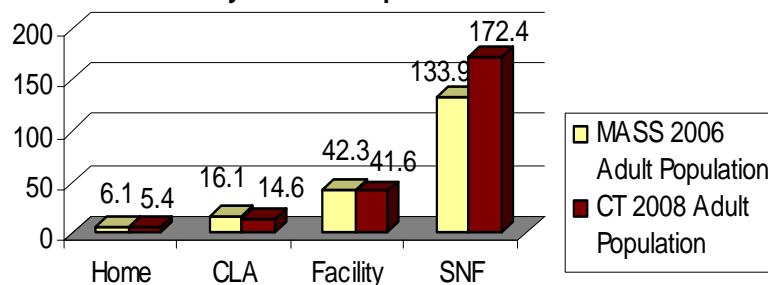
Table 23  
**Comparison of the Mortality Rate by Residential Setting  
 For the Massachusetts DMR and Connecticut DDS**

Type of Residential Setting	Mortality Rate (per thousand)	
	MA DMR 2006	CT DDS 2008
At Home/Family IS/OH Independent & Supported Living*	6.1	5.6*
Community Group Home Community Training Home	16.1	14.6
Facility-ICF/MR	42.3	41.6
Nursing Facility	133.9	172.4

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 support 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 can be used for comparison purposes. For example the facility/ICF/MR mortality rates. 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. General patterns are similar, with the highest mortality rates in support settings where individuals require a higher level of 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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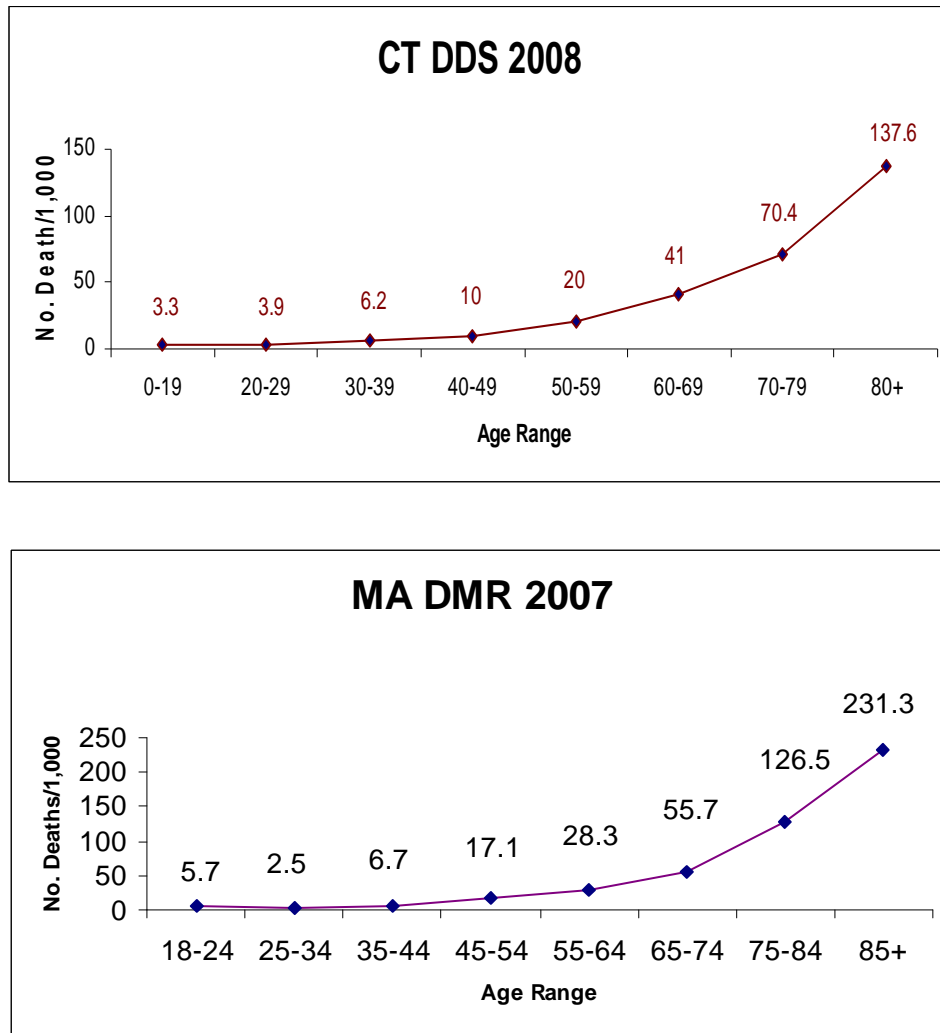
Section Six Continued

## Mortality and Age Benchmarks

Crude mortality rates by age range are presented for CT DDS and MA DMR, and although the age range used by each state differs and a direct comparison is not possible a common pattern is apparent with the mortality rate increasing with age. In both states the death rates increase markedly after the age 60-65 years. Again differences in data distribution make it difficult to draw direct comparisons.

Figure 28

### CT DDS and MA DMR Mortality Rates by Age



When age is adjusted for the CT DDS population to reflect only individuals over the age of 18 years, the CT DDS average age of death of 60.8 years is very similar to the MA DMR average age of death of 62 years

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Table 24

## Leading Causes of Death CT, MA and Ohio

Rank	CT DDS 2008	CT DDS 2007	CT DDS 2006	CT DDS 2005	MA DMR 2006	MA DMR 2005	OHIO DMRDD 2007
1	<b>Heart Disease 31%</b>	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%	Heart Disease 21.9%	Heart Disease 16.4%	Heart Disease 18.5%
2	<b>Aspiration Pneumonia 15%</b>	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%	Alzheimer's 14.4%	Cancer 12%	All Other Causes 16%
3	<b>Respiratory Disease 12.3%</b>	Cancer 11%	Pneumonia 14.4%	Aspiration Pneumonia 12%	Cancer 9.9%	Influenza/ Pneumonia 10.8%	Pneumonia 10.2%
4	<b>Cancer 10.7%</b>	Pneumonia 8.5%	Cancer 11%	Cancer 8%	Aspiration Pneumonia 8.4	C-P Arrest Seizure 10.8%	Cancer 9.7%
5	<b>Pneumonia 8.6%</b>	Pneumonia Aspiration 8.5	Sepsis 7.8%	Sepsis 5.6%	CLRD 5.7%	Aspiration Pneumonia 9.3%	Congenital Disease 9.5
6	<b>Septicemia 8.6%</b>	Septicemia 6%	Aspiration Pneumonia 5.5%	CVA 3.7%	C-P Arrest Seizure 5.5	Alzheimer's Disease 8.60%	Aspiration Pneumonia 9.9%
7	<b>Nervous System 3.7%</b>	CVA 3.5%	Kidney/ Renal 4.4%	Accident 3.7%	Stroke 5.2%	Septicemia 5.9%	Infection 5.8%
8	<b>Kidney/ Renal 3.2%</b>	Kidney/ Renal 3.5%	Accident 2.7%	Nervous System 3.3%	Septecemia 5.2%	CLRD 4.6%	Seizure 3.9%
9	<b>Stroke 2.7%</b>	Digestive System 3%	CVA Stroke 2.2%	Digestive System 1.4%	Influenza Pneumonia 3.9	Stroke 4.2%	Accidents 3.80%
10	<b>Digestive System 1.6%</b>	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%	Unintentional Injuries 3.7	Unintentional Injuries 3.4%	Lung Disease 3.6%

A review of state mortality data from CT DDS, MA DMR and Ohio DMRDD demonstrate similarities in leading cause of death data for people with ID/DD. Heart disease remains the leading cause of death for people with ID/DD in the states noted in Table 24 above. Respiratory disease, pneumonia and aspiration pneumonia are a significant leading cause of death in the ID population. In the three reference states the prevalence of cancer is almost identical accounting for 10% of all deaths. MA DMR data indicates a year over year increase in the percentage of deaths due to Alzheimer's disease (14.4%) a finding that is consistent with CT DDS data which found that 15% of the mortality population had a diagnosis of Alzheimer's disease at the time of their death.

Differences in state cause of death data and ranking may be due to the differences in the population analyzed (age range) and variations in immediate cause of death documented by practitioners on the certificate of death. For example, CT DDS mortality data includes children (5.5% of all reported deaths) and adults.

\* Based on calendar year data

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## SECTION SEVEN: SUMMARY MORTALITY CASE REVIEW FINDINGS

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 the CT DDS. 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 within DDS and has extended to community based health care providers including practitioners in private practice licensed nursing facilities, acute care hospitals, hospice providers, health and dental clinics and other state agencies.

Table 25

### Mortality Case Review Summary (FY 2008)

<i><b>Deaths Reviewed By Regional Committees</b></i>	<i><b>Cases Closed at Regional Level</b></i>	<i><b>Cases Referred and Reviewed By IMRB</b></i>	<i><b>QA Cases Closed by Region IMRB Review</b></i>	<i><b>Total Cases Reviewed By IMRB</b></i>
133	98 (74%)	35 ( 26%)	29 (22%)	64 (48%)

Table 25 above provides a summary of all deaths reviewed by the CT DDS Mortality Review Committees. Seventy-four percent of the 133 cases reviewed were closed by local regional mortality committees. The regional committees referred 35 mortality cases to the state Independent Mortality Review Board for further review. The reasons for the case referrals are noted in Table 26 (below).

The CT DDS Mortality Review Process requires that at least 10% of all cases that are closed at the regional level are reviewed by the Independent Mortality Review Board (IMRB) for quality assurance purposes. This year the IMRB reviewed 22% of cases closed by regional mortality committees.

Table 26

<b>Cases Referred to IMRB (35)</b>	
Medical/Health Care	17
Post mortem examination	17
Pending Abuse/Neglect Investigations	1

The DDS Commissioner reviews all cases that are reviewed by the IMRB

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## CT DDS Mortality Review: General Findings

### Predictors of Mortality in the ID Population

- age
- mobility status
- the need for special assistance when eating
- sudden or progressive weight loss
- level of intellectual disability
- a distinct cluster of co-morbidities
- chronic aspiration pneumonia
- pneumonias that result in hospitalization

- Health care coordination by registered nurses is an essential support for the ID/DD population who are at risk for chronic and acute health conditions. Timely nursing assessment results in appropriate referral and treatment by medical practitioners.
- The premature onset of acute and chronic health issues which lead to morbidity and mortality in people with ID presents a unique challenge to caregivers.
- The CT DDS process for reviewing advanced life directives including the withholding of cardiopulmonary resuscitation (DNRs) provides the team with a foundation for quality end of life planning.
- End of life planning that included hospice services and supports allowed many individuals with irreversible or terminal conditions to remain in their home or current residence.
- CT DDS mortality cases referred to the CT Department of Public Health resulted in improvements in healthcare facility and/or health care practitioners standards of practice which we expect will ultimately advance the quality of care for people with ID/DD.
- DDS Health and Nursing Standards and Protocols and other quality improvement initiatives developed as a result of the mortality review process have been adopted and implemented by provider agencies.
- Consumers living in their own home or receiving individualized supports benefit from health education and training that focuses on health promotion and disease prevention.
- Post mortem examinations are a valuable tool to confirm the cause and manner of death in cases where the cause of death was not immediately determined.
- Health care practitioners continue to benefit from continuing education opportunities that focus on the special health needs of persons with intellectual disabilities.
- From a resource and operational standpoint the “aging in place phenomenon” within the ID/DD population presents a future challenge for the CT DDS service system and for all care providers.
- Enteral feedings do not prolong survival and may not improve the quality of life for individuals with intellectual disabilities.
- The aging Down syndrome population requires specialized and comprehensive supports.
- As a result of the mortality review process the quality of supports for people served by the CT DDS service system have improved.

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Section Seven Continued

## Examples of CT DDS Mortality Findings and Quality Initiatives

<u>Areas of Review/Findings</u>	<u>Quality Initiatives</u>
<b>Professional nursing care and coordination</b>	Investigation recommendations regarding scope of nursing practice implemented. Continue to collaborate with CT Board of Examiners for Nursing to implement improvements in this area.
<b>Hospital Emergency Department evaluation and treatment.</b>	Timely evaluation and treatment by ED practitioners due to ongoing collaboration between DDS nursing staff, ED managers and physicians.
<b>Documentation Standards</b>	Best practice standards developed for documenting vital medical information, treatment decisions, diagnostic testing or physical examination findings Nursing assessments disseminated to all clinicians within DDS service system.
<b>Accidental Deaths</b>	Root Cause Analysis completed. Risk and potential risk factors identified and recommendations implemented.
<b>Reporting of Death and Abuse/Neglect Investigations</b>	All deaths were reported to CT DDS according to critical incident and death reporting procedure. Investigations were initiated in a timely manner.
<b>Hospital Discharge Planning</b>	Nursing Standard for Discharge Planning in final stages of development. DDS continuing audit of coordination of supports post discharge.
<b>Professional Nursing Services</b>	Standardization of nursing role in various residential support systems Professional nursing quality committee meets regularly to develop health and nursing best practice standards/procedures.
<b>Nursing / Medical/Dental Shortage in ID/DD Field</b>	CT DDS established clinical internships with several schools of nursing BSN and LPN technical programs. Orientation for nursing staff, DDS health and dental staff collaborating with hospital medical staff, and dental and medical schools.
<b>Registered Nursing On Call System</b>	Standardization and improvement in the implementation of nursing on call systems.
<b>DNR (Do not resuscitate)</b>	DDS continues to thoroughly review anticipated DNR requests per CT State Statute and DDS procedures
<b>Post Mortem Examinations</b>	Deaths reported to the Office of the Chief Medical Examiner per Protocol post mortems requested for all deaths of concern to the DDS
<b>Medical and Health</b>	A Health Standard for weight loss is in the development stage.  Nursing care plans consistently include pain management protocols where applicable.  CT DDS registered nurse monitors and reviews the quality of care provided for consumers residing in licensed nursing facilities.

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## Examples of IMRB Findings and CT DDS Quality Initiatives

<u>Areas of Review/Findings</u>	<u>Quality Initiatives</u>
<b>Medical and Health</b>	<p>IMRB Tracking System was established to monitor the progress of mortality review findings and recommendations.</p> <p>Dysphagia and swallowing risk training is provided annually for all staff – public and private.</p> <p>DDS North Region Managed Health Care Pilot Program was implemented to address the health issues of people receiving less than 24 hour supports</p> <p>Proposed new waiver service of Health Care Coordinator to address complex health needs of people who live in their own homes with less than 24 hour support.</p>
<b>Medication Administration</b>	<p>The CT DDS Medication Administration Certification Program continues to provide a high level of quality and oversight. There were no mortalities related to the administration of medication by certified non-licensed or nursing staff.</p>
<b>Oral Health</b>	<p>The increased access to and quality of dental services for people with ID was evident due to addition of the DDS Dental Coordinator. The level of interagency collaboration to increase the capacity of dental services for people with intellectual disabilities increased significantly.</p>
<b>Increased Monitoring and Oversight</b>	<p>Increased monitoring by DDS Quality Management as a result of IMRB findings improved the quality and supports for people in the CT DDS service system.</p>
<b>Interagency sharing of Health Records/ Information</b>	<p>Protocols have been established with community based health care providers (hospitals, nursing facilities etc.) which ensure the timely and accurate sharing of clinical information.</p>



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**The next Annual Mortality Report UPDATE will be issued in March of 2010**

For additional copies of this report or to contact DDS please visit us at [www.ct.gov/dds](http://www.ct.gov/dds)

**This report can be found on our website at: [www.ct.gov/dds](http://www.ct.gov/dds)**

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## **APPENDICES**

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**Appendix B: DDS Consumers by Residential Setting  
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**Appendix C: Percentage Population by Age Ranges  
Level of Intellectual Disability**

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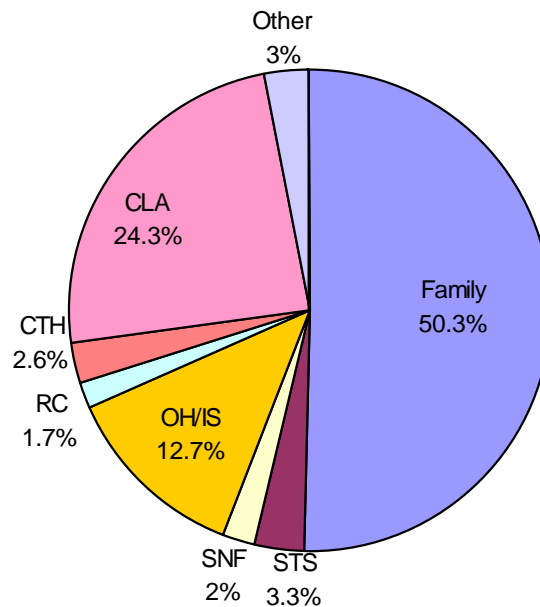
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Mortality Reporting: Reporting Deaths of Individuals Procedure  
Client Death: DMR Responsibilities Checklist  
Death Report Form**

## APPENDIX A

### 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, 2008 **15,270** individuals with intellectual disability were being supported by the department.

#### Overview of DDS Population Percentage by Setting



Half of the people served by CT DDS live at home with their family. The remainder of the people served by DDS receive funded supports. The majority of these supports are traditional in nature, with support services provided in community living arrangements (CLA's), community training homes (CTH), regional centers (RC) and a campus program, Southbury Training School (STS). While other consumers may receive individualized supports (OH/IS), 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.



## APPENDIX B

### \*DDS CONSUMERS BY RESIDENTIAL SETTING FY 2006 - FY 2008

Type of Support	2008	2008	2007	2007	2007 - 2008
	# of Consumers	Percent	# of Consumers	Percent	% Change
Family	7,688	50%	7,566	50%	1.60%
CLA (Group Home)	3,716	24%	3,680	24%	1.0%
Own Home/Ind. Services (OH/IS)	1,932	13%	1,909	13%	1.2%
Training School	497	3%	526	3%	(-5.5%)
Other	463	3%	443	3%	4.5%
Community Training Home (CTH)	399	3%	408	3%	(-2.2%)
SNF	312	2%	348	2%	(-10.3%)
Regional Center (RC)	263	2%	268	2%	(-1.9%)
<b>TOTAL</b>	<b>15,270</b>	<b>100%</b>	<b>15,148</b>	<b>100%</b>	<b>&lt; 1%</b>

### \*DDS Population By Age 2004 - 2008

	2008	2007	2006	2005	2004	2004 - 2008	
						Population Changes	Percent Change
Children (0-19)	3,594	3,575	3,663	3,766	3,815	-221	-5.8%
Adults (20 - over)	11,676	11,573	11,355	11,177	11,121	555	5.0%
<b>TOTAL ALL AGES</b>	<b>15,270</b>	<b>15,148</b>	<b>15,018</b>	<b>14,943</b>	<b>14,936</b>	<b>334</b>	<b>2.2%</b>

<b>Adults (55 - over)</b>	<b>2,628</b>	<b>2,587</b>	<b>2,470</b>	<b>2,397</b>	<b>2,318</b>	<b>310</b>	<b>13.4%</b>
<b>Adults (65 - over)</b>	<b>1,005</b>	<b>991</b>	<b>957</b>	<b>954</b>	<b>944</b>	<b>61</b>	<b>6.5%</b>

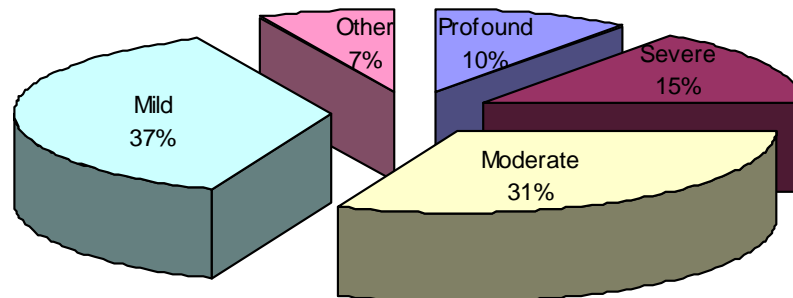
\* From DDS Management Information Report (2008)

**APPENDIX C**

**Percent Population by Age Ranges  
FY 2008**

<b>AGE RANGE</b>	<b>TOTAL</b>	<b>% OF TOTAL</b>
Age 0-19	3,594	23.5%
Age 20-29	3,101	20.3%
Age 30-39	2,080	13.7%
Age 40-49	2,662	17.4%
Age 50-59	2,119	13.9%
Age 60-69	1,117	7.3%
Age 70-79	409	2.7%
Age 80+	188	1.2%
<b>TOTAL</b>	<b>15,270</b>	<b>100%</b>

**CT DDS POPULATION - LEVEL OF INTELLECTUAL DISABILITY**



**APPENDIX D**

**AGE CATEGORY AND RESIDENCE  
FY 2008**

Restype	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
CLA (Group Home)	122	3,222	372	3,716
SNF	0	147	163	310
Campus	0	359	138	497
Own Home/Individualized Services	5	1,079	107	1,191
Other	215	191	59	465
Family Home	3,237	4,388	63	7,688
Independent Living	3	685	53	741
CTH (Community Training Home)	12	341	46	399
Regional Center	0	259	4	263
<b>TOTAL</b>	<b>3,594</b>	<b>10,671</b>	<b>1,005</b>	<b>15,270</b>
<b>PERCENT</b>	<b>24%</b>	<b>70%</b>	<b>6%</b>	<b>100%</b>

**Consumers Age 19 - 64 Years  
By Type of Support**

SNF	47%
STS	72%
CTH	85%
CLA	87%
OH/IS	91%
Family/Independent	57%
RC	98%

**Consumers over the Age of 65  
By Type of Support**

SNF	53%
STS	28%
CTH	12%
CLA	10%
OH/IS	9%
Family/Independent	1%
RC	2%

## **Appendix E**

### STATE OF CONNECTICUT DEPARTMENT OF MENTAL RETARDATION

**Policy No. I.D.PO.001**

**Issue Date:** March 15, 2002

**Subject:** Mortality Reporting and Review

**Effective Date:** March 15, 2002

**Designated Area of Responsibility:** Quality Enhancement

#### **A. Policy Statement**

The Department of Mental Retardation has a responsibility to the citizens it serves to ensure quality services including health care. One way to ensure quality is to receive timely notification of the death of every individual served by the department and to review the care provided for these individuals served prior to their deaths.

Deaths of all people served by the department shall be reported and documented as detailed in DMR procedure # I-D-PR-001, Mortality Reporting: Reporting Deaths of Individuals.

Deaths of all individuals for whom the department bears direct or oversight responsibility for medical care shall be subject to mortality review as one means of monitoring and evaluating the quality of health care and overall care provided to individuals served by the department. Mortality reviews shall also include a review of the quality of life issues and mission principles such as dignity and respect. The review process as delineated in DMR Procedure #I-D-PR-005 shall identify issues and concerns that may have compromised the medical, health or overall care provided to individuals in order to trigger corrective actions and reduce future risk.

Autopsies shall be pursued as outlined in DMR Procedures # I-D-PR-003, Reporting Deaths to the Office of the Chief Medical Examiner and #I-D-PR-004, Autopsies.

Deaths in which abuse or neglect is suspected shall be reported for investigation as indicated in the DMR Policy 2, Abuse and Neglect.

#### **B. Applicability**

This policy shall apply to all individuals who are served by the department and who are registered in the department's mainframe database (CAMRIS) including children in the Birth-to-Three System and adults registered with the department due to the 1987 Omnibus Reconciliation Act (OBRA) requirements.

#### **C. References**

1. Statutes
  - a. CGS 7-62-56, "Death Certificates"
  - b. CGS 7-15h, "Abuse of Elderly Persons"

- a. CGS 18-38a, "Abuse of Children"
  - b. CGS 19-17b, "Peer Review"
  - c. CGS 19a-405-413, "Medicolegal Investigations"
  - d. CGS 19a-406 (b), 19a-413, "Autopsy"
  - e. CGS 19a-458, "Abuse of Persons who are Mentally Retarded"
  - f. CGS 53-73a, "Crimes"
2. Rules, Regulations and Policy – External
    - a. [Executive Order No. 25, issued by John G. Rowland, Governor, February 8, 2002](#)
3. Rules, Regulations and Policy – DMR
    - a. DMR Policy 2, Abuse Neglect
    - b. DMR 1-D-PR-001, Mortality Reporting: Reporting Deaths of Individuals
    - c. DMR 1-D-PR-002, Sudden/Unexpected Deaths
    - d. DMR 1-D-PR-003, Reporting a Death to the Office of the Chief Medical Examiner
    - e. DMR 1-D-PR-004, Autopsies
    - f. DMR 1-D-PR-005, Mortality Review

STATE OF CONNECTICUT  
DEPARTMENT OF MENTAL RETARDATION

**Procedure No. LD.PR.001**

**Issue Date:** March 15, 2002

**Subject:** Mortality Reporting: Reporting Deaths  
of Individuals

**Effective Date:** March 15, 2002

**Designated Area of Responsibility:** Quality Enhancement

**A. Purpose**

The purpose of this procedure is to ensure that deaths of all individuals who are served by the DMR are reported and documented.

**B. Applicability**

This procedure shall apply to all individuals who are clients of the department, who are monitored in the department's mainframe database, and/or who live in a DMR licensed facility.

**C. Definitions**

1. Direct or Oversight Responsibility for medical care: means all individuals who lived in DMR operated, funded, or licensed homes or facilities, who were placed in long-term-care facilities by the department, or who receive supported living services and do not independently manage their own medical regimens.
2. Do Not Resuscitate Order (DNR): A medical order to withhold cardiopulmonary resuscitation is known as a "*do not resuscitate*" or "*no code*" order.
3. Individual: for this procedure, means any person registered with the department and monitored in the department's mainframe database including children registered with the DMR in the Birth-to-Three System and adults registered through the OBRA system. It also includes a non-Connecticut resident who received services in a DMR operated, funded, and/or licensed facility or program.
4. OBRA-87: 1987 Omnibus Reconciliation Act that names the Department of Mental Retardation as lead agency for people with mental retardation and related conditions (e.g., seizure disorders, cerebral palsy, vision and hearing disabilities, etc.)
5. Sudden and/or Unexpected Death (SUD):
  - Death that was not expected or anticipated according to any previously known terminal medical diagnosis;

- Death that was the result of an accident (car accident, fall, choking, etc.), even if the person had a known terminal condition;
- Death that was due to a suspected/alleged homicide or suicide;
- Death suspected or alleged to be due to abuse or neglect.

#### **D. Implementation**

1. The death of every individual shall be immediately reported to the individual's family, the DMR regional or training school director or designee and regional health service director (See Attachment A).
2. Each DMR funded private agency shall develop and implement a procedure that identifies the responsible parties and details agency/region specific processes.
3. If the person's death was sudden and/or unexpected, DMR Procedures 1-D-PR-002, Sudden/Unexpected Deaths of Individual, 1-D-PR-003, Reporting A Death to the Office of the Chief Medical Examiner, and 1-D-PR-004, Autopsies, shall be followed.
4. On the first working day following an individual's death, the DMR case manager or other assigned staff shall telephone or fax a report of the death to the DMR special protections coordinator in central office, using the DMR Death Report Form (See Attachment B). A copy of the Death Report Form shall be sent to the regional health service director.
5. The special protections coordinator shall immediately notify the department's nurse investigator (NI) of the death of individuals for whom the department bears direct or oversight responsibility for medical care. The nurse investigator shall take the following actions:
  - a. Conduct a *Medical Desk Review* to determine the need for further review or investigation. This shall involve a review of the individual's health characteristics and circumstances surrounding the death through telephone contact with appropriate parties (e.g., DMR health service directors, staff) and a review of preliminary documents (DMR death report, death certificate, and as applicable, documentation of a Do No Resuscitate order, autopsy results and hospice documentation).
  - b. If no further review is needed, the NI will document the rationale and refer for mortality review.
  - c. If further review is indicated, the NI will request two copies of specific records (see attachment A). One copy shall be hand delivered to the DMR Hartford or Cheshire office within five working days and the other copy shall

be sent to the individual's case manager for inclusion in the mortality review packet.

- d. Following a review of the documents, the NI will document actions taken and rationale for those actions, as follows:
  - 1) Referral to the abuse/neglect system if abuse or neglect is suspected according to DMR Abuse/Neglect policy and procedures
  - 2) Referral for expedited mortality review if system deficiencies are identified or suspected
  - 3) Referral for routine mortality review as defined in DMR procedure I-D-PR-005, Mortality Review
6. The Regional Mortality Review Committee chairperson as defined in DMR procedure I-D-PR-005, shall be notified on the first working day following the death of an individual for whom the department bears direct or oversight responsibility for medical care.
7. For those cases requiring mortality review, the regional health service director shall provide the person's family and/or guardian with information regarding the review process and shall provide contact names and numbers for obtaining further information and/or discuss any concerns regarding the death.
8. The DMR special protections coordinator shall send a weekly report of all deaths to the DMR Commissioner, Deputy Commissioner, Director of Health and Clinical Services, Director of Quality Assurance and to the Office of Protection and Advocacy.

#### **E. References**

1. Rules, Regulations and Policy – External
  - a. Executive Order No. 25, issued by John G. Rowland, Governor, February 8, 2002
2. Rules, Regulations, Policy or Instructions – DMR
  - a. DMR Policy I-D-PO-001, Mortality Reporting and Review
  - b. DMR Procedure I-D-PR-002, Sudden/Unexpected Deaths of Individuals
  - c. DMR Procedure I-D-PR-003, Reporting a Death to the Office of the Chief Medical Examiner
  - d. DMR Procedure I-D-PR-004, Autopsies
  - e. DMR Procedure I-D-PR-005, Mortality Review
3. **Attachments:**
  - a. Attachment A: [Client Death: DMR Responsibilities Checklist](#)
  - b. Attachment B: [DMR Death Report Form](#)



**#3 and #4 Note:**

Guardianship ceases upon the individual's death. If the OCME accepts jurisdiction for the autopsy, the family (who may be the legal guardian) must be informed. If the OCME does not accept jurisdiction, and the person has no family, the DMR can authorize an autopsy.

If the deceased is in a hospital setting, the hospital will assume responsibility for the remains until a decision regarding the autopsy is determined. If the deceased has been transported to a funeral home, we must inform the funeral home director that an autopsy is pending.

Consent for autopsy must be obtained from the deceased individual's next-of-kin (see Autopsy procedure for list). A legal guardian who is not also *next-of-kin*, does not have the legal authority to consent to autopsy, therefore, DO NOT ask for his/her consent.

**Autopsies are strongly encouraged and should be pursued in the following situations:**

- sudden or unexpected death,
- unexplained or unwitnessed deaths,
- deaths involving earlier accidents or trauma;
- deaths involving questionable contributing factors; and
- cases in which the cause of death is not due to a previously diagnosed condition or disease.

**An autopsy is not required** if the individual was receiving regular medical supervision and death was due to the following:

- a known terminal illness such as metastatic cancer
- a previously diagnosed as appropriate; a known progressive condition such as severe progressive congestive heart failure, renal or liver failure
- a known degenerative process i.e. a previously diagnosed metabolic disorder with expected deterioration such as mucopolysaccharide disorders.

**FORM DISTRIBUTION:**

**Original:** Individual's Master File  
**Copy:** Regional Health Service Director for Mortality Review File  
**Copy:** Regional Director

3/8/02 Distribution: Original: Individual's Master File; Copies: 1) RD 2) HSD for Individual's Mortality Review File

**STATE OF CONNECTICUT  
DEPARTMENT OF DEVELOPMENTAL SERVICES  
DEATH REPORT FORM**

Region/TS:  NR  SR  WR  STS

Report Date: _____		Time: _____		Death Date: _____		Time: _____	
Consumer's Name: _____				DDS#: _____		DOB: _____	
Gender: <input type="checkbox"/> Male		<input type="checkbox"/> Female					
Address: _____							
Residence Type: _____						Phone No.: ( ) - _____	
Location of Death: _____							
Cause of Death: _____							
Was death anticipated as the result of a known condition? <input type="checkbox"/> Yes <input type="checkbox"/> No				DNR Order? <input type="checkbox"/> Yes <input type="checkbox"/> No			
Was death accidental? <input type="checkbox"/> Yes <input type="checkbox"/> No							
OCME contacted: <input type="checkbox"/> Yes <input type="checkbox"/> No		Date: _____		OCME# _____		(860) 679-3980 / 1-800-842-8820	
Accepted jurisdiction? <input type="checkbox"/> Yes <input type="checkbox"/> No							
Private autopsy requested: <input type="checkbox"/> Yes <input type="checkbox"/> No		Consent obtained? <input type="checkbox"/> Yes <input type="checkbox"/> No		Performed by: _____			
Is Abuse or Neglect Suspected? <input type="checkbox"/> Yes <input type="checkbox"/> No				Was an Abuse/Neglect Report Completed? <input type="checkbox"/> Yes <input type="checkbox"/> No			

**(NOTIFICATION) ALL DEATHS**

<input type="checkbox"/> DDS Case Manager	Name: _____	Date: _____
<input type="checkbox"/> Family <input type="checkbox"/> Guardian <input type="checkbox"/> Advocate	Name: _____	Date: _____
<input type="checkbox"/> Regional Director (On-Call Mgr.)	Name(s): _____	Date: _____
<input type="checkbox"/> DDS Health Service Director	Name: _____	Date: _____

**(NOTIFICATION) UNEXPECTED DEATHS**

<input type="checkbox"/> Commissioner/CO On-Call Mgr. Beeper (860-720-3110)	Name _____	Date: _____
<input type="checkbox"/> Health & Clinical Director Office/CO (860-418-6083)	Name _____	Date: _____
<input type="checkbox"/> Director of Investigations Nextel (860-250-2234)	Name _____	Date: _____
<input type="checkbox"/> Local/State Police	Name _____	Date: _____
<input type="checkbox"/> Abuse/Neglect Suspected Contact OPA (860-297-4300)	Name _____	Date: _____

**UNEXPECTED DEATHS**

- Death that was not expected or anticipated as a result of any previously known medical diagnosis or condition
- Death as a result of an accident (car accident, fall, choking, etc.) even if the person had a known terminal condition
- Death that was due to a suspected/alleged homicide or suicide
- Death for which there is an allegation of abuse or neglect

1. Police involvement: <input type="checkbox"/> Yes <input type="checkbox"/> No	3. Conduct on-site visit: <input type="checkbox"/> Yes <input type="checkbox"/> No
2. Secure records/environment: <input type="checkbox"/> Yes <input type="checkbox"/> No	4. Complete Immediate Safety Assessment Form: <input type="checkbox"/> Yes <input type="checkbox"/> No

**OTHER DETAILS**

_____	
_____	
_____	
_____	
_____	
_____	
Completed by (Name & Title): _____	Date: _____
Reporter's Name, Title & Agency: _____	
Address: _____	
Phone: - - _____	City: _____
State: _____	Zip Code: _____

Distribution: Original: Consumer Master File/Case Manager  
 Copies: Director of Health & Clinical Services – CO, Health Services Director, Regional Director, Nurse Investigator, Director of Investigations Fax# 860-667-6306

Revised 10/1/07