State of Connecticut

DDS

Mortality

ANNUAL REPORT

FY 2010

This is the ninth 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.

Issue Date: March, 2011

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 2010 fiscal year (July 1, 2009- June 30, 2010) 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 137 deaths reviewed by the DDS nurse investigators, regional review committees and Independent Mortality Review Board (IMRB) for the period of July 1, 2009 – June 30, 2010.

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, 2009 to June 30, 2010.
Data in this report was obtained from the CT DDS Database system.

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Executive Summary 2010 Report

- There were 182 deaths resulting in a crude mortality rate of 11.6/1000
- The strongest predictors of mortality are age, mobility status, the need for special assistance when eating, and the amount of supervision provided
- Women served by DDS continue to have a higher mortality rate
- The average life expectancy of people with ID is 58.3 years
- Starting early in the fifth decade of life there is a progressive increase in the mortality rate for people with intellectual disabilities
- People with intellectual disabilities have a decreased life span as compared to the general population which may be related to the onset of multiple chronic and acute co-morbidities at a younger age
- Mortality is highly related to the level of intellectual disability, the greater the level of disability the higher the mortality rate
- Heart disease continues to be the leading cause of death in the CT DDS population (28%)
- Aspiration pneumonia/pneumonia accounted for 20.9% of all deaths
- The incidence of deaths related to cancer in the DDS population (12.9%) is lower than the national (23.7%) and state (23.5%) [25,27]
- Accidental deaths continue to occur at a rate below that of the general state and national population [25, 27]
- The average age of death for people with Down syndrome is 58.4 years
- Respiratory failure and cardiac arrest were the leading causes of death for people with Down syndrome
- The “aging in place” phenomenon continues to be a leading risk factor as individuals served by DDS become older and more disabled over time

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. 42, 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.

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)

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 three 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 three tier system includes an Abridged Review, 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).

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?

Abridged Review
Criteria for Review

Any death that had a DNR in force that was reviewed per the DDS DNR review process, was related to a pre-existing condition/diagnosis, did not have an allegation/investigation of abuse/neglect at time of death and did not have a post mortem examination. Individual was not a Class Member and did not reside in a ICF/MR.

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 Management Services and/or the Director of Health and Clinical Services.

Nurse Investigators Medical Desk Review

In addition to the regional mortality review committees and the Independent Mortality Review 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 abridged review, a 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
- Associate 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)
- 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, 2009 – JUNE 30, 2010) NUMBER OF DEATHS REPORTED = 182

Overall Mortality Rate

During the 12 month time period between July 1, 2009 and June 30, 2010 a **total of 182** individuals supported by CT DDS passed away **resulting in a mortality rate of 11.6** (Figure 1 & 2 below). Both the number of deaths and mortality rate decreased in FY 10.

Figure 1

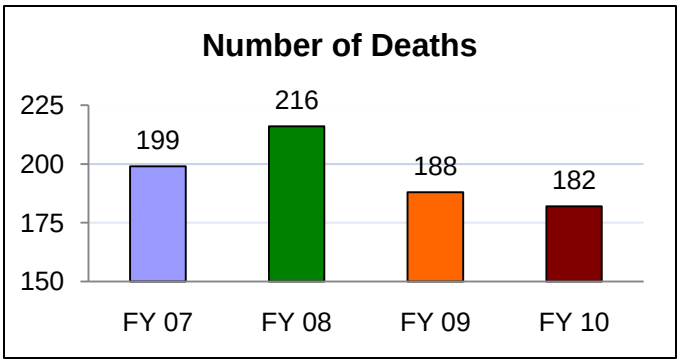
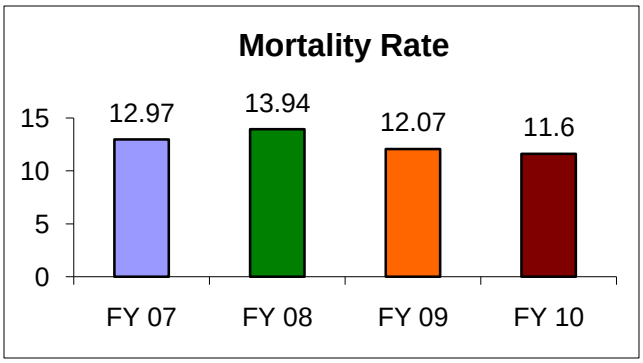


Figure 2



Mortality and Residence

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

	% Deaths	% DDS population
CLA	33	24
SNF	28	2
Family	18	51
STS	14	3
IHS	2	13
RC	2	1
CTH	2	3
Other	1	3

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

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

Figure 3

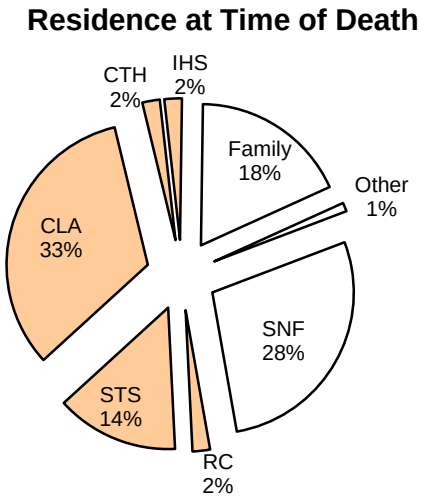
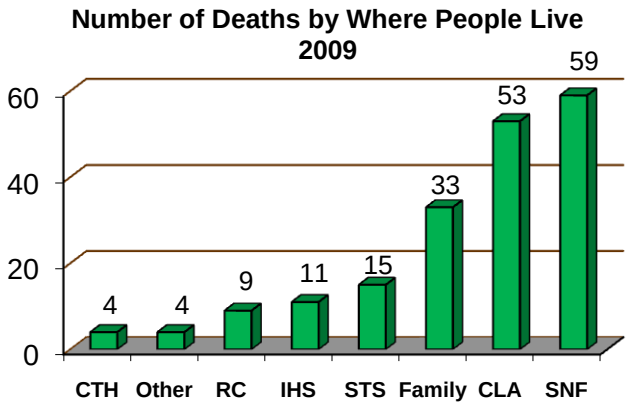


Figure 4



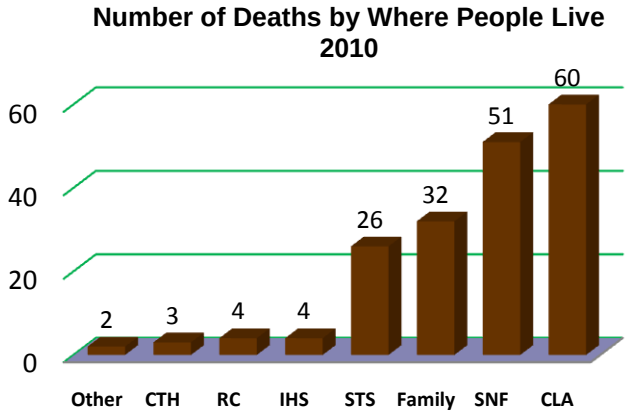


Figure 4 (above) depicts the actual number of deaths by where people live. This year the greatest number of deaths occurred in CLA's followed by skilled nursing facilities, family homes and STS. Of note: Sixty-one (61%) of the people DDS supports live in family homes or in their own home with individualized supports, 24% in group homes (CLA's) and only 2% in skilled nursing facilities.

Figure 5

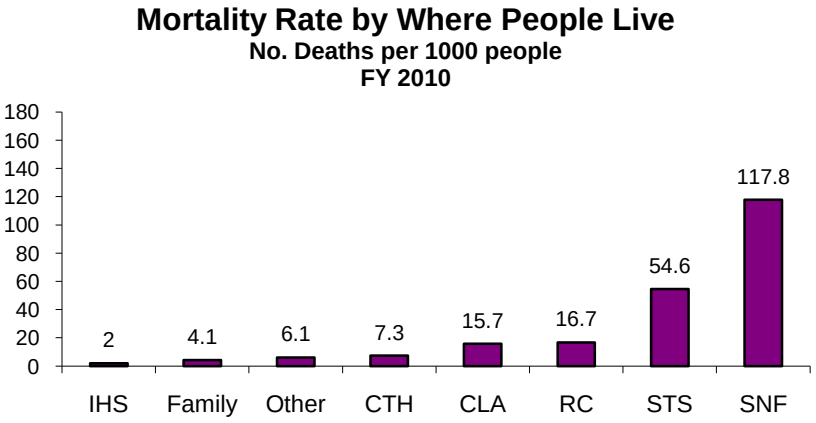


Figure 5 (left) depicts the number of people who died for every 1000 people served by type of support.

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

Mortality and Residence

Family Home: People who live with their family without significant residential DDS supports represent 51% of the DDS population. However, in FY 2010 only 32 deaths (17.6% of all deaths) occurred in a family home with an associated mortality rate of 3.7. All but one CT DDS deaths of children were for those who lived with their families. Twenty-two of the 32 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 15.7 for this type of residence. In FY 2010, 60 or 32.9% of all deaths occurred in CLA's compared to 28.1% in FY 09. Thirty-six of the 60 people died in a hospital or hospital emergency department.

CTH: There were only 3 reported deaths in the community training homes in line with the 4 deaths reported in FY 09. These deaths were anticipated and related to an existing condition. The CTH mortality rate of 7.3 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 2% of the reported deaths. Two of the 3 people died in a hospital or hospital emergency department.

IHS: 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 2 percent (2%) of reported deaths occurred in this environment compared with 6% last year. One of the 4 people died at their home the rest (3) died in the hospital or hospital emergency department or SNF.

STS: This larger campus setting serves a population of older adults (average age of 61.8 years). Many of these individuals present with severe to profound intellectual disabilities and have multiple co-morbidities. The higher mortality rate of 54.6 is not surprising in this medically fragile population. Twenty-six deaths were reported at STS this past fiscal year representing 14% of all DDS deaths. Last year the Training School accounted for 8% of all deaths. Fourteen of the 26 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. Less than 2% of DDS consumers reside at DDS regional centers. Only 4 RC residents died in FY 2010 accounting for 2% of all DDS deaths. One of these individuals were pronounced at the regional center the other 3 died in a hospital or hospital emergency department.

SNF: Only 2% of people served by CT DDS live in a skilled nursing facility. This older (average age 64.7 years) and medically fragile population accounted for 51 or 28% of all reported deaths. People living in licensed nursing facilities had the highest mortality rate 117.8 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 19 of the 51 people died in a hospital, hospital emergency room or hospice.

- 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.
- Individualized Home Supports (IHS): 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.
- Southbury Training School (STS): 24 hour support is provided in a large campus setting serving a population of older adults with severe to profound intellectual disabilities.
- 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.

Mortality and Gender

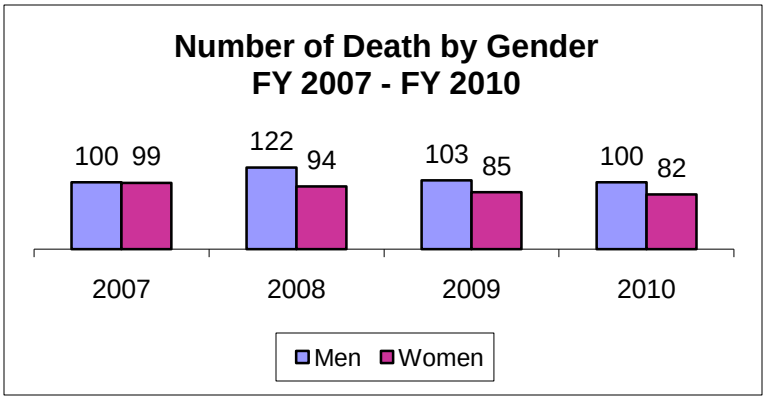
Table 1

Mortality Rate by Gender - 2010

GENDER	All Individuals Served by DDS	Total Number of Consumers	No. Deaths	Percentage of Deaths	Rate (No. Deaths Per 1000)
Men	57%	8,895	100	57.4%	11.11
Women	43%	6,600	82	42.6%	12.27
Total	**100%**	**15,495**	**182**	**100%**	**23.38**

In FY 2010 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



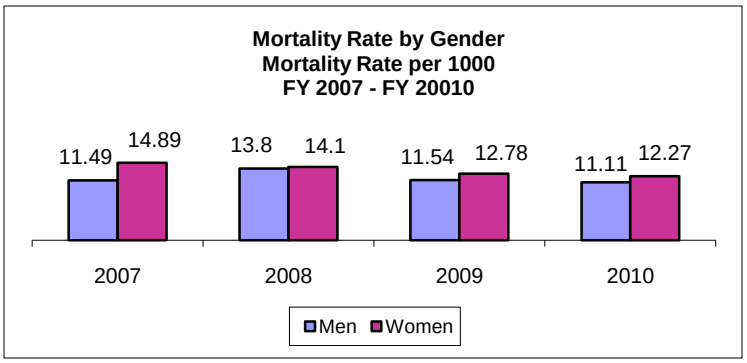


Figure 7

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.

Mortality and Age

Table 2

Age of Death

Year	Men	Women	Average Age
CT DDS FY 2010	**55.7**	**61.5**	**58.3**
CT DDS FY 2009	58	56.2	57.1
CT DDS FY 2008	56.4	58.7	57.4
CT DDS FY 2007	56.9	59	57.9

Figure 8

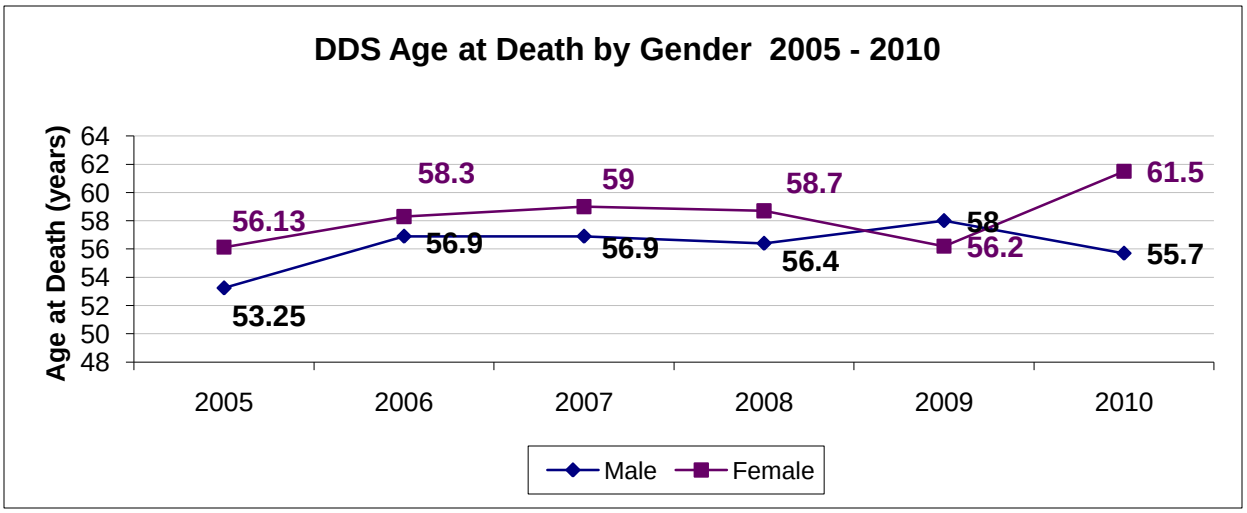
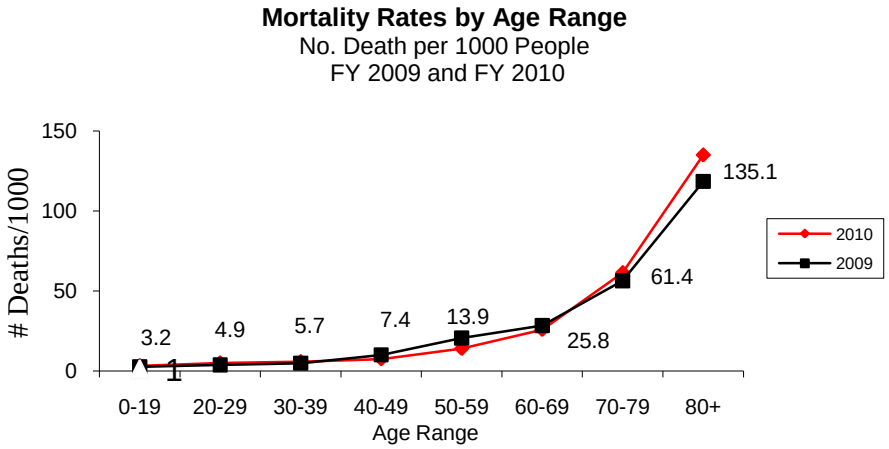


Figure 9



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 an 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.

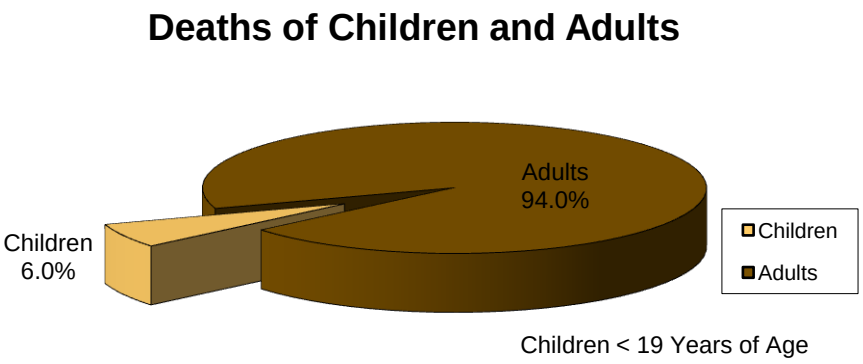
Table 3

Mortality Age Range Distribution Data
FY 2010

AGE RANGE	# OF DEATHS	% OF DEATHS	MORTALITY RATE
Age 0-19	11	6%	3.2
Age 20-29	16	8.8%	4.9
Age 30-39	12	6.6%	5.7
Age 40-49	19	10.4%	7.4
Age 50-59	32	17.6%	13.9
Age 60-69	33	18.1%	25.8
Age 70-79	29	16%	61.4
Age 80+	30	16.5%	135.1
TOTAL	**182**	**100%**	

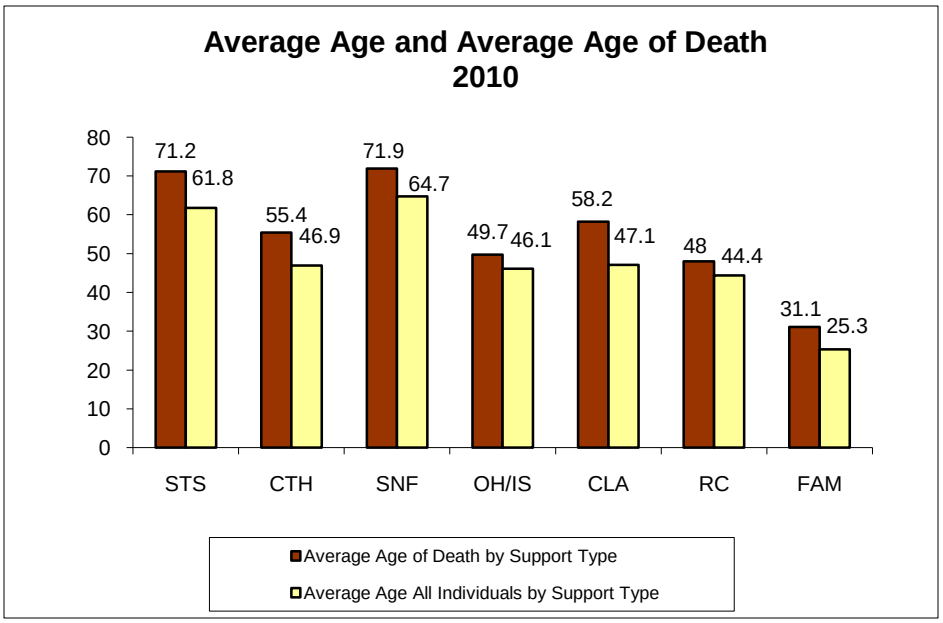
Mortality statistics for the DDS population in Table 3 reveal a progressive increase in the mortality rate as the age range increases.

Figure 10



In FY 10 eleven children died, one lived in a CTH and ten lived at home with their family.

Figure 11



The average age of death in the CT DDS population is 58.28. The average ages 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. 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 60.5 years.

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 NURSE INVESTIGATORS, REGIONALCOMMITTEE AND/OR STATE INDEPENDENT MORTALITY REVIEW BOARD IN FY 2010

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

DDS NURSE INVESTIGATORS/MORTALITY COMMITTEE/BOARD REVIEWS = 137 cases (of total 182 deaths)

*** 16 of the 137 cases reviewed were Abridged Reviews ***

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. Thirty-nine individuals received hospice services: 36% lived in group homes, 36% lived at the training school, 21% lived in a nursing home, 5% lived at the regional campus, 2% lived in their own home with individualized supports. The average age of death for people receiving hospice services was 67.6.

Thirty-nine people (32% 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:	**14**	**(10% of reviewed deaths)**
Number of post mortem examination performed by CT OCME:	**8**	

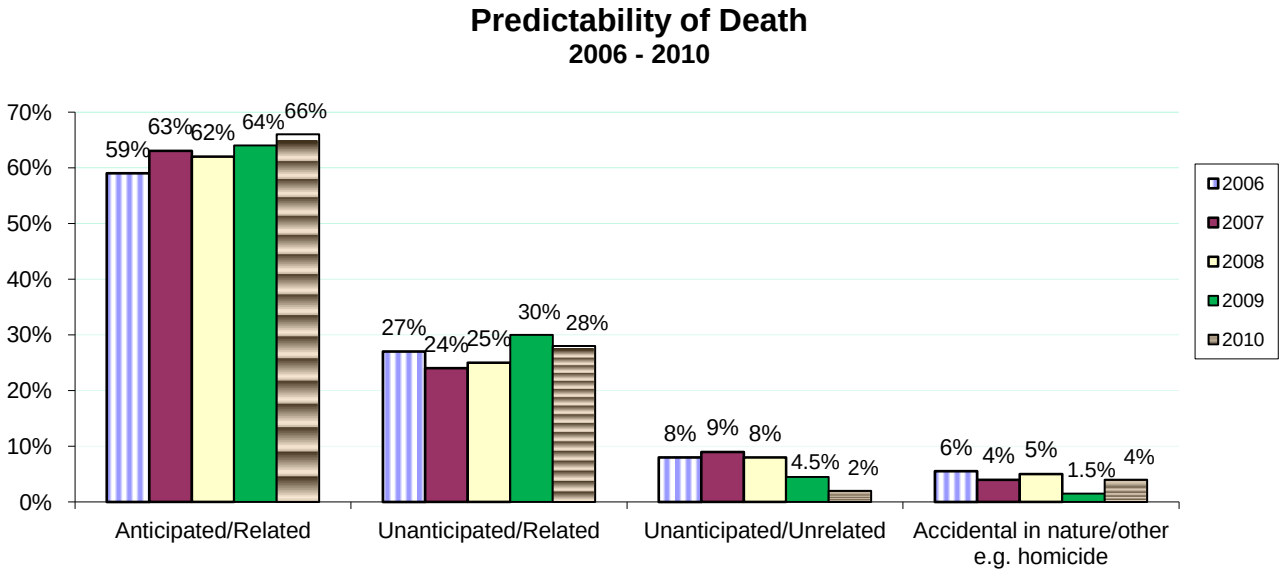
* Does not include Abridged Reviews

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 ninety-four 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: 66%**
- **Death was unanticipated but related to a preexisting diagnosis: 28%**
- **Death was unanticipated and unrelated to a preexisting diagnosis: 6% (includes accidental deaths)**

Figure 12



OF NOTE:

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 100% of the time.

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 137 cases reviewed during FY 10, 130 (95%) were classified as due to natural causes. The other 7 cases were determined to be the result of an accident or undetermined.

Table 4

FY 10 Manner of Death

Manner of Death	*No.*	*Percent*
Natural	*130*	*95%*
Accident	*5*	*4%*
Undetermined	*2*	*1%*
Total	*137*	*100%*

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

Fall	(2)
Fire	(2)
Blunt Head Trauma	(1)

UNANTICIPATED/UNRELATED DEATHS:

Of the 8 deaths that were unanticipated and not related to a known condition 5 were due to accidents, 1 was due to natural causes and 2 were undetermined. The cause of mortality for the unanticipated death due to natural causes was cardiac arrest.

ACCIDENTAL DEATHS

Of the five cases of accidental deaths, two were a result of a fall, two were a result of fire and the other was the result of blunt head trauma.

UNDETERMINED DEATH

In the two cases of undetermined death the final causes of death were Hypotension, possible GI Bleed with or without Sepsis and Respiratory Failure.

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 137 mortality cases reviewed in FY 2010

94 cases had a DNR order in place

96% of the DNR orders were formally reviewed by DDS

100% of the DNR orders met the established DDS medical criteria

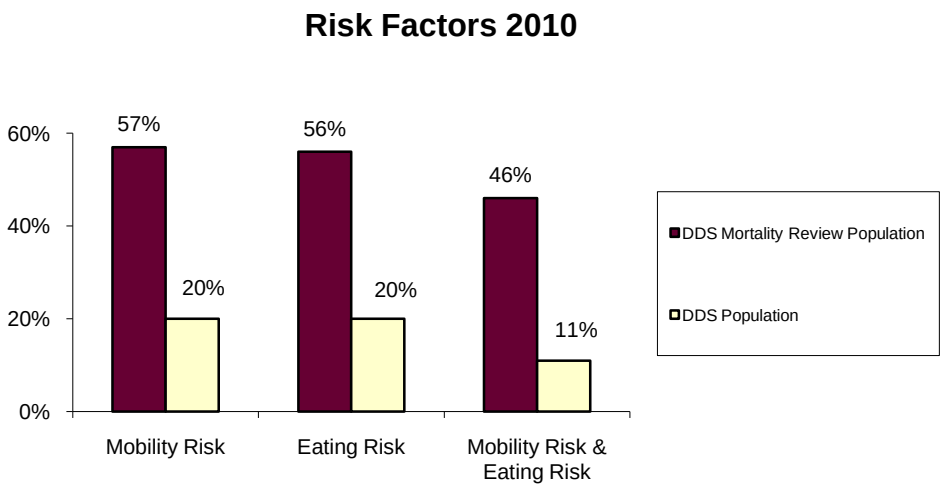
In 4% of all cases in which a DNR was ordered by a medical practitioner DDS was not notified prior to the implementation of the DNR order as is required by DDS procedure. However, the DDS mortality review process determined that in every case the medical criteria to support the decision to initiate the DNR was met.

OF NOTE: Eighty-nine percent (89%) of DDS consumers residing in *skilled nursing facilities* had a DNR order in place at the time of their death.

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 2010 data illustrates the relationship between these risk factors and mortality (see Figure 13 below).

Figure 13



It is well documented in the literature that the more compromised an individual's level of mobility, the greater the likelihood of death.[3,9,10] CT mortality data supports the importance of mobility as an indicator of morbidity and mortality. In FY 2010, sixty-nine (57%) of the deceased did not ambulate independently.

MORTALITY REVIEW POPULATION ONLY *	* DDS POPULATION
57% did not ambulate independently 56% did not eat independently	20% do not ambulate independently 20% 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.

* Does not include Abridged Reviews.

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 10 % of All Deaths	FY 09 % of All Deaths	FY 08 % of All Deaths	**FY 10 Death Rate**	FY 09 Death Rate	FY 08 Death Rate
24 HOUR SKILLED NURSING SUPPORT:	**45%**	46%	46%	**73.8**	70.9	73
24 HOUR NURSING SUPPORT:	**35%**	30%	33%	**14.9**	13.4	12.2
LESS THAN 24 HOUR NURSING SUPPORT:	**20%**	23%	21%	**3.8**	4.5	5.7

As noted in the table above, the death rate for those individuals who receive 24 hour skilled nursing support (living in nursing homes, the Training School and regional centers) had a mortality rate of 73.8 in FY 10. This mortality rate greatly exceeded the death rate for individuals needing 24 hour nursing support (14.9) (living in group homes and community training homes) and for those individuals requiring less than 24 hour nursing support (3.8) (living in their own home or receiving individualized supports). These findings are consistent with the FY 08 and FY 09 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

	2008	**2009**	**2010**	**Percent of Population**
Mild	13.6	12.9	**10.1**	39
Moderate	15.6	13.1	**10.7**	28
Severe	19.9	22.3	**21.7**	16
Profound	28.4	29.6	**28.8**	15

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.

* Denotes all 182 deaths.

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 137 mortality cases reviewed by DDS, 9 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.

Disposition of OPA/AID Cases	
Neglect substantiated	***3***
Neglect not substantiated	***1***
Cases still open	***5***

In 3 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, long term care/nursing facilities, dialysis facilities, ambulatory care centers and outpatient surgical centers.

During FY 2010 three (3) 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

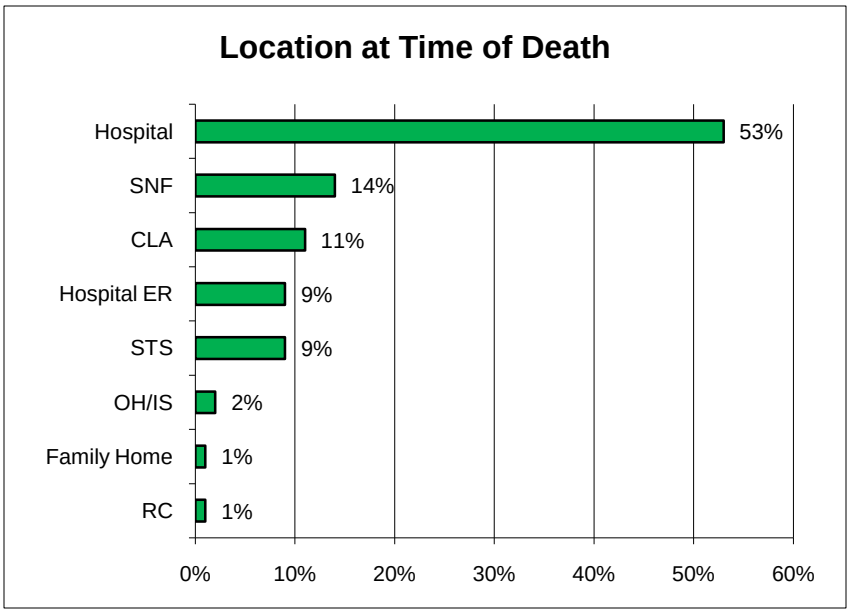
Practitioner Division Referrals– (1)
cases open – 0
cases closed - 1
citations, violations found - 0

Facility Division Investigations – (2)
cases open – 1
cases closed - 1
citations, violations found – 1

Pronouncement of Death (Location at Time of Death)

Figure 14 below depicts the location where death was pronounced.

Figure 14



KEY: Location of Death

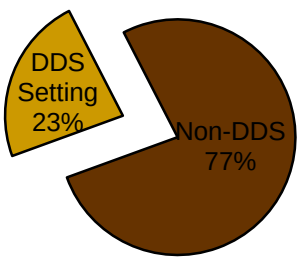
Hospital = Admission to the hospital as an inpatient, death occurred in the hospital.

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.

Figure 15

Where People Died
FY 2010 Mortality Reviews



As can be seen in Figure 15 to the right, 77% of all deaths reviewed by the mortality review committee during FY 10 occurred outside of a DDS operated, licensed or funded residential setting, this represents a decrease in the number of people dying outside of a DDS setting compared to FY 09 (81%).

SUMMARY OF MORTALITY DATA

for the 137 deaths that were reviewed in FY10

- **100%** of required cases were reviewed **Regionally**.
- **41%** of all cases were reviewed by the **IMRB**.
- **32%** of the individuals received **Hospice** supports prior to their deaths.
- **10%** of the individuals had **Autopsies** performed.
- **94%** of all deaths were **Related** to an existing medical diagnosis.
- **69%** of the individuals had a **DNR** order in place at the time of death.
- **46%** 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.
- **5** number of deaths that were classified as **Accidental**.
- **3** number of referrals to **Department of Public Health**.
- **9** number of referrals to **Office of Protection & Advocacy Abuse Investigation Division**.
- **3** number of cases **Neglect** was substantiated by OPA or DDS.

* Does not include Abridged Reviews

SECTION FOUR: MORTALITY TRENDS CT DDS

For the past nine 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.

Figure 16

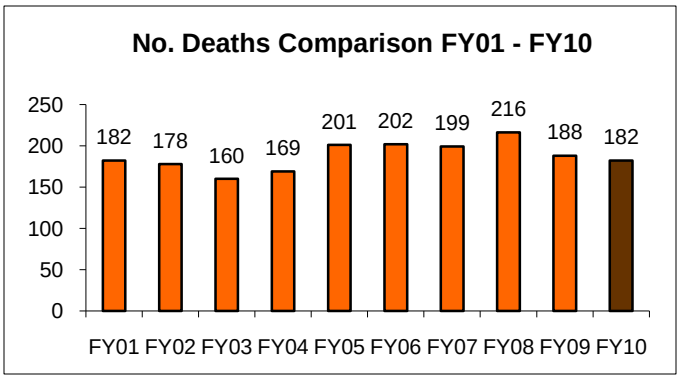
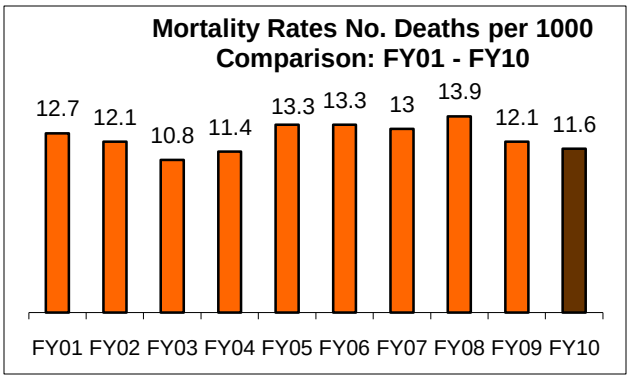


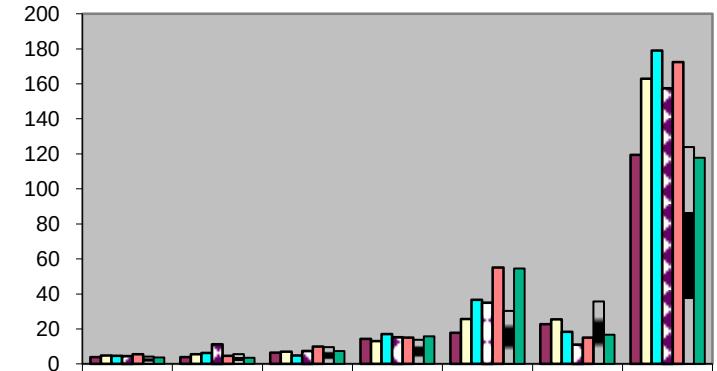
Figure 17



Figures 16 and 17 depict on an annual basis the number of deaths and the average death rate for FY 2001 - 2010 within the population served by DDS. The death rate average over the ten year period of time is 12.02/1000 people.

Figure 18

Mortality Rate by Where People Live
7 Year Trend



	Family	IHS	CTH	CLA	STS	RC	SNF
FY04	3.97	3.83	6.47	14.27	17.86	22.8	119.34
FY05	4.8	5.5	7	13	25.6	25.5	163
FY06	4.56	6.26	4.8	17.1	36.7	18.4	179
FY07	4.5	11.2	7.3	15.3	34.9	11.1	157.4
FY08	5.6	4.6	9.9	15.1	55.1	15	172.4
FY09	4.2	5.6	9.6	13.8	30.3	35.7	123.9
FY10	3.7	3.5	7.3	15.7	54.6	16.7	117.8

FY04 FY05 FY06 FY07 FY08 FY09 FY10

Figure 18 (to the left) compares the death rate (the number of deaths per 1000 persons served) for the past seven (7) 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. For FY 10 there was a variation in the this trend with a decrease in the death rate in SNF and Regional Center residences.

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

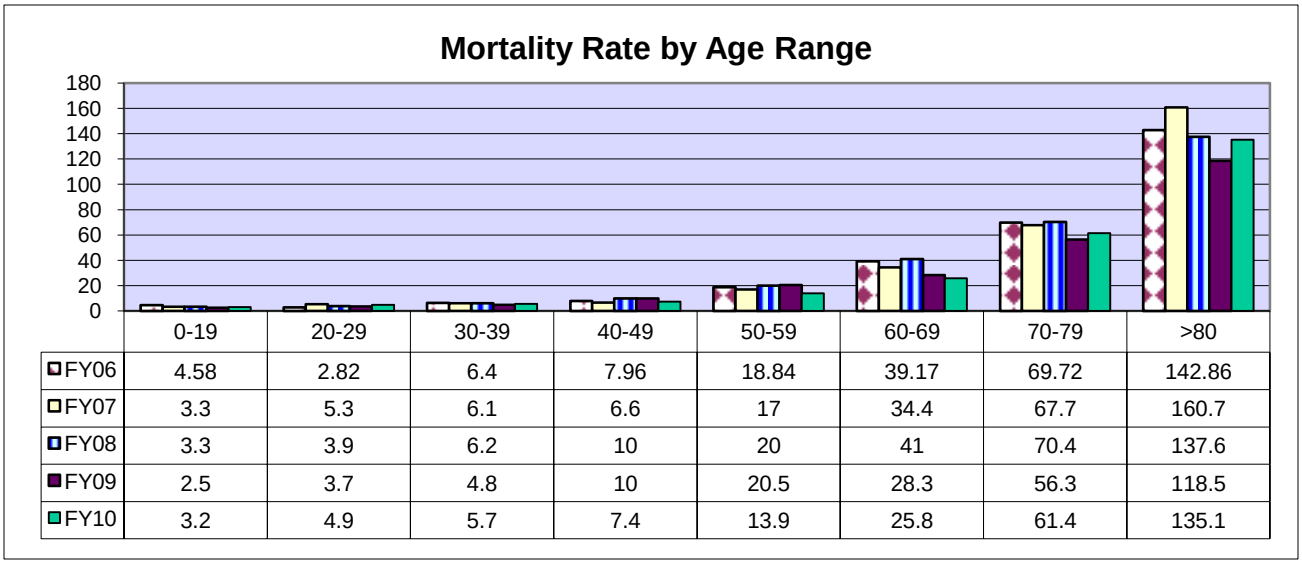
Table 7

Mortality and Gender
(2002 - 2010)

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
2008	122	94	13.8	14
2009	103	85	11.54	12.78
2010	**100**	**82**	**11.11**	**12.27**

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

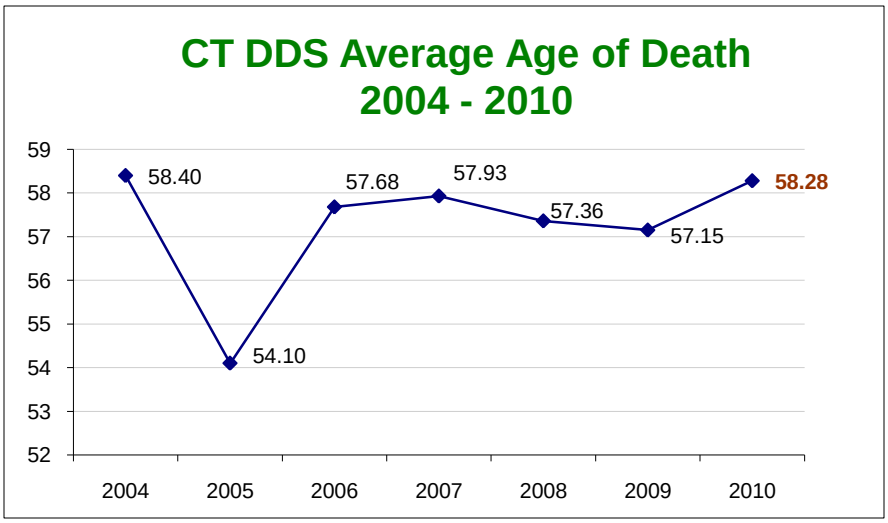
Figure 19



	0-19	20-29	30-39	40-49	50-59	60-69	70-79	>80
FY06	4.58	2.82	6.4	7.96	18.84	39.17	69.72	142.86
FY07	3.3	5.3	6.1	6.6	17	34.4	67.7	160.7
FY08	3.3	3.9	6.2	10	20	41	70.4	137.6
FY09	2.5	3.7	4.8	10	20.5	28.3	56.3	118.5
FY10	3.2	4.9	5.7	7.4	13.9	25.8	61.4	135.1

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.

Figure 20



For the last seven 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 - 2010)

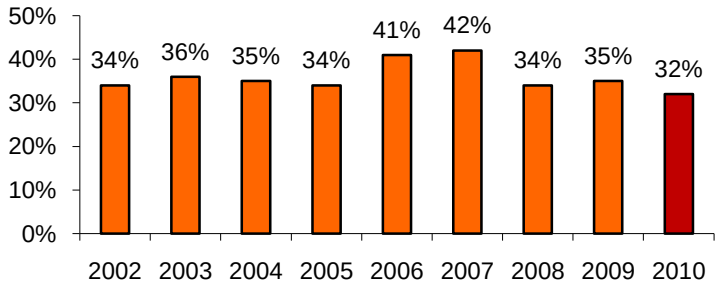
	2002	2003	2004	2005	2006	2007	2008	2009	2010
SNF	28%	30%	35%	40%	33%	33%	30%	31%	**28%**
CLA	30%	27%	31%	23%	31%	29%	26%	28%	**33%**
Family	19%	20%	15%	19%	18%	17%	20%	18%	**18%**
STS	*	9%	7%	7%	10%	10%	13%	8%	**14%**
IHS	3%	6%	3%	4%	4%	7%	5%	6%	**2%**
RC	*	5%	4%	4%	2%	2%	2%	5%	**2%**
CTH	3%	1%	2%	1%	1%	1%	2%	2%	**2%**
Other	2%	2%	0%	2%	0%	1%	2%	2%	**1%**
	100%	100%	100%	100%	100%	100%	100%	100%	**100%**

Table 8 depicts the percentage of deaths within various support types over an nine 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.

Figure 21

Percent of Hospice Supports (2002 - 2010)



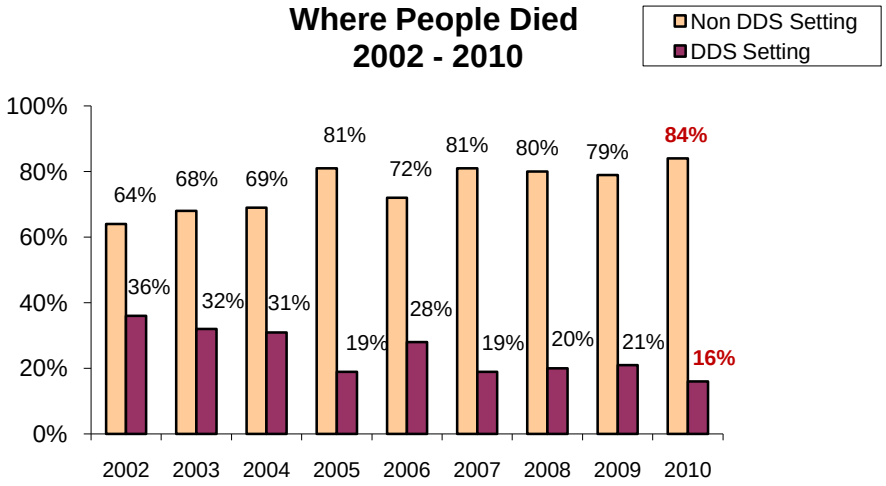
End of life planning and hospice care has been a hallmark of the CT DDS system as noted above. Where appropriate, end of life planning and support services were provided prior to death with the individual's team involved in the planning process. The continued integration of hospice supports into the 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 - 2010)

Location	2002	2003	2004	2005	2006	2007	2008	2009	2010	9 Year Total
Hospital	41	34	35	64	58	63	71	**71**	**61**	**498**
SNF	13	22	26	35	30	28	26	**14**	**18**	**212**
CLA	17	16	18	16	17	15	7	**10**	**12**	**128**
Hospital ER	10	9	4	18	14	16	9	**13**	**12**	**105**
STS	4	1	5	4	14	6	11	**10**	**13**	**68**
RC	7	11	5	3	2	1	0	**1**	**1**	**31**
OH/IS	4	4	3	4	5	3	3	**5**	**3**	**34**
Hospice	2	1	3	7	2	2	1	**5**	**0**	**23**
Other	1	1	0	1	3	3	5	**4**	**1**	**19**

Figure 22



The number of people served by DDS who expired in non DDS funded settings has increased in FY 2010 (84% compared to 79% in 2009). 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 2010)

FY 03	28	21%
FY 04	16	16%
FY 05	20	13%
FY 06	17	12%
FY 07	11	8%
FY 08	17	13%
FY 09	14	11%
FY 10	**14**	**10%**

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 percent of post mortem examinations during FY 2010 decreased from 2009 (10% vs. 11%).

SECTION FIVE: LEADING CAUSES OF DEATH

This section discusses cause of death data for people served by the CT DDS in calendar year 2010. 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 2010)

28%	*of deaths were due to*	**Heart Disease**	*including*	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
14.6%	*of deaths were due to*	**Respiratory Disease**	*including*	Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma
12.9%	*of deaths were due to*	**Sepsis**	*including*	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
12.9%	*of deaths were due to*	**Cancer**	*including*	Wide variety of primary origin sites
12.3%	*of deaths were due to*	**Aspiration Pneumonia**	*including*	Aspiration Pneumonia
7.6%	*of deaths were due to*	**Pneumonia**	*including*	Pneumonia/influenza
4%	*of deaths were due to*	**Stroke/CVA**	*including*	Intercerebral Hemorrhage
3%	*of deaths were due to*	**Digestive System**	*including*	Intestinal Obstruction, Liver Disease, Volvulus
2%	*of deaths were due to*	**Renal/Kidney**	*including*	Renal Failure chronic and acute
2%	*of deaths were due to*	**Genetic Disorder**	*including*	Muscle diseases, etc.

The 10 leading causes of death in 2010 (Table 11) are noted above. Heart disease remains the leading cause of death for the DDS population with respiratory disease, sepsis, cancer and aspiration pneumonia rounding out the top five.

Heart Disease

Heart Disease/cardiovascular disease remains the leading cause of death for the CT DDS population (28%). 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*.

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 08 and 09. However, in FY 10, unlike the prior two years, more women died as a result of heart disease than men and men lived longer than women.

Table 12

Deaths Due to Heart Disease

Year	Number of Male Deaths	Number of Female Deaths	Average Age Male	Average Age Female	Average Age
FY 08	18	15	66.5	69.2	67.7
FY 09	21	20	61.8	60.2	61
FY 10	**23**	**24**	**63.8**	**62.7**	**63.2**

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 81% of people who die of coronary heart disease are 65 or older[19] as compared with only 45% of individuals in the CT DDS population. Of the remaining cardiac related deaths in the DDS population group: twenty-one percent (21%) of the cardiac deaths occurred prior to the age of 50 years and 34% percent of the cardiac deaths occurred between the ages of 50-65.

There is a greater prevalence of congenital heart conditions and atrioventricular septal defects found in people with Down syndrome.[20] However, CT DDS data reveals that the incidence of cardiac deaths reported for people with Down syndrome was in line with the rest of the DDS population.

Respiratory Disease

The 2010 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.*

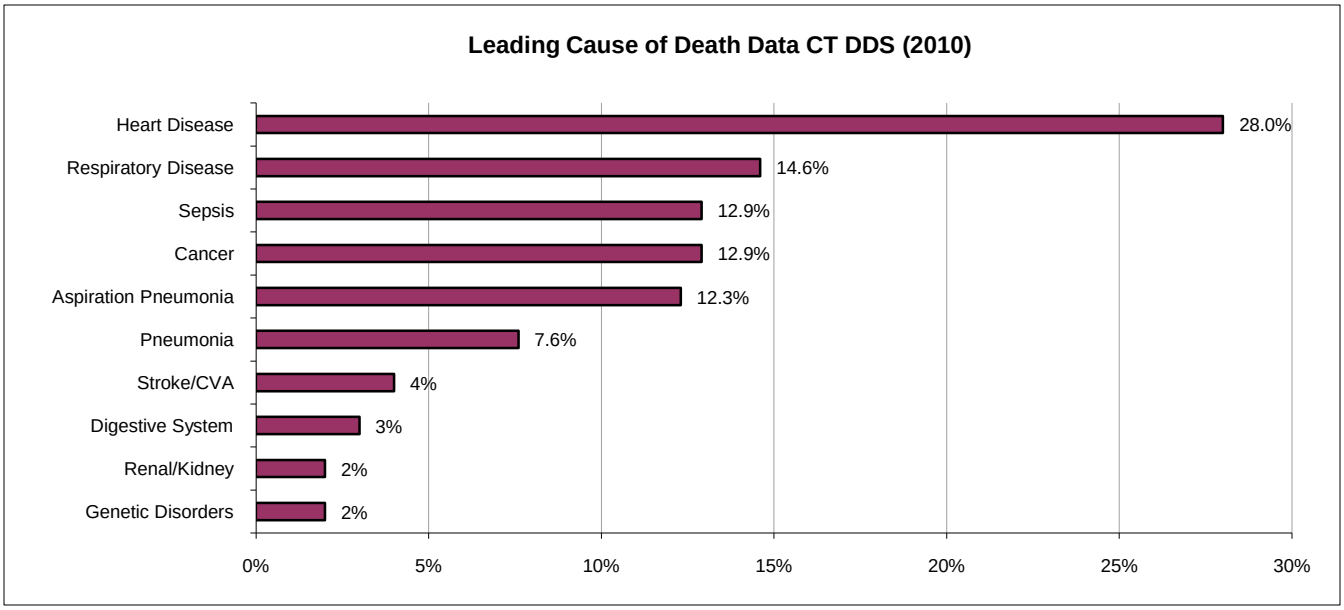
Table 13

Deaths Due to Respiratory Disease, Pneumonia and Aspiration Pneumonia

Year	Number of Males	Number of Females	Avg. Age of Males	Avg. Age of Females	Ave. Age
FY 08	31	23	63.4	67.7	65.3
FY 09	32	23	60.4	65.9	62.7
FY 10	**26**	**13**	**61**	**64**	**62**

* Does not include Abridged Reviews

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 34.5% of all deaths in 2010 eclipsing the number of deaths caused by cardiac disease (28%).

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.

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 16% of the 121 deaths, the person had a diagnosis of Alzheimer's Disease at the time of their death.

Table 14

Leading Causes of Death CT DDS

Rank	CT DDS 2010	CT DDS 2009	CT DDS 2008	CT DDS 2007	CT DDS 2006	CT DDS 2005
1	**Heart Disease 28%**	Heart Disease 29.9%	Heart Disease 31%	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%
2	**Respiratory Disease 14.6%**	Respiratory Disease 13.7%	Aspiration Pneumonia 15%	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%
3	**Sepsis 12.9%**	Pneumonia 12.8%	Respiratory Disease 12.3%	Cancer 11%	Pneumonia 14.4%	Pneumonia Aspiration 12%
4	**Cancer 12.9%**	Aspiration Pneumonia 10.3%	Cancer 10.7%	Pneumonia 8.5%	Cancer 11%	Cancer 8%
5	**Aspiration Pneumonia 12.3%**	Septicemia 9.8%	Pneumonia 8.6%	Pneumonia Aspiration 8.5	Septicemia 7.8%	Septicemia 5.6%
6	**Pneumonia 7.6%**	Cancer 7.4%	Septicemia 8.6%	Septicemia 6%	Pneumonia Aspiration 5.5%	Stroke 3.7%
7	**Stroke 4%**	Stroke 3.4%	Nervous System 3.7%	Stroke 3.5%	Kidney/ Renal 4.4%	Accident 3.7%
8	**Digestive System 3%**	Kidney/ Renal 2.5%	Kidney/ Renal 3.2%	Kidney Renal 3.5%	Accident 2.7%	Nervous System 3.3%
9	**Kidney/ Renal 2%**	Digestive System 2.5%	Stroke 2.7%	Digestive System 3%	Stroke 2.2%	Digestive System 1.4%
10	**Genetic Disorder 2%**	Genetic Disorder 2.5%	Digestive System 1.6%	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%

Based on 2010 calendar year data

Table 14 compares the top ten leading causes of death with CT DDS data from previous years. Other than heart disease and respiratory disease as the leading causes of death in the CT DDS population there were many changes in the cause of death rankings compared to the 2009 data. For example: Sepsis passed pneumonia to become the third leading cause of death. Cancer was the forth leading cause moving up two notches, aspiration pneumonia dropped to the fifth leading cause from fourth and pneumonia dropped from the third leading cause of death to the sixth. There were minor changes on a percentile basis for the leading causes of death (7-9). Of note: Over the past three 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.

Leading Causes of Death for People with Down Syndrome

Table 15

FY10

Primary Cause of Death/Down Syndrome

Respiratory Failure	5
Cardiac Arrest	5
Pneumonia	1
Anoxic Brain Damage	1
Renal Failure	1
Liver Disease	1
Pancreatic Cancer	1
Total	**15**

This year respiratory failure and cardiac arrest were the leading causes of death for persons with Down syndrome (33% each). (Table 15)

Since 2006 aspiration pneumonia and respiratory failure have accounted for 58% of all deaths for people with Down syndrome. (Table 16)

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.[5,6,7,8] The average age of death for people with Down syndrome in the CT DDS system is 58.4.

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.

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 (60%). This data supports other research studies that found increased prevalence of Alzheimer's Disease in people with Down syndrome.[28]

Table 16

FY 06 - FY 10
Primary Cause of Death/Down Syndrome

Respiratory Failure	41
Cardiac Arrest	28
Aspiration Pneumonia	24
Renal Failure	4
Gastrointestinal hemorrhage	2
Sepsis	2
Subdural hematoma	2
Cancer	2
Liver Disease	2
Pneumonia	2
Asphyxia	1
CVA	1
Anoxic brain damage	1
Lymphoma	1
Total	**113**

Table 17

Average Age of Death Data

	2009	2010
Down Syndrome:	57.2	**58.4**
Down & Alzheimer's:	57.8	**59.7**
Down without Alzheimer's:	57.1	**56.3**

Analysis of Cancer Deaths

Table 18

FY 10
Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	4	53.3
Breast	2	65.1
Brain	1	35.6
Esophagus	1	39
Leukemia	1	12.1
Lymphoma	1	55.6
Myeloma	1	64.6
Pancreas	1	56.6
Renal	1	46.7
Stomach	1	50.9
Vulva	1	61.8
TOTAL	**15**	**36.1**

In FY 2010 cancer was the forth leading cause of death for people supported by the CT DDS

For FY 10 the distribution of cancers in men were: esophagus (1), leukemia (1), lung (1), lymphoma (1), myeloma (1) and renal (1).

The FY 10 distribution of cancers in women were: lung (3), breast (2), brain (1), pancreas (1), stomach (1), vulva (1).

The average age of death for all cancer victims (36.1 years) was below the average age of death for all CT DDS deaths (57.1 years).

The rate of death due to cancer in the CT DDS population (1.1/1000) was lower than the rate of 1.9/1000 in the state of CT and 1.9/1000 nationally.[25,27]

Over the past 6 years cancers have represented 10% of CT DDS mortalities.

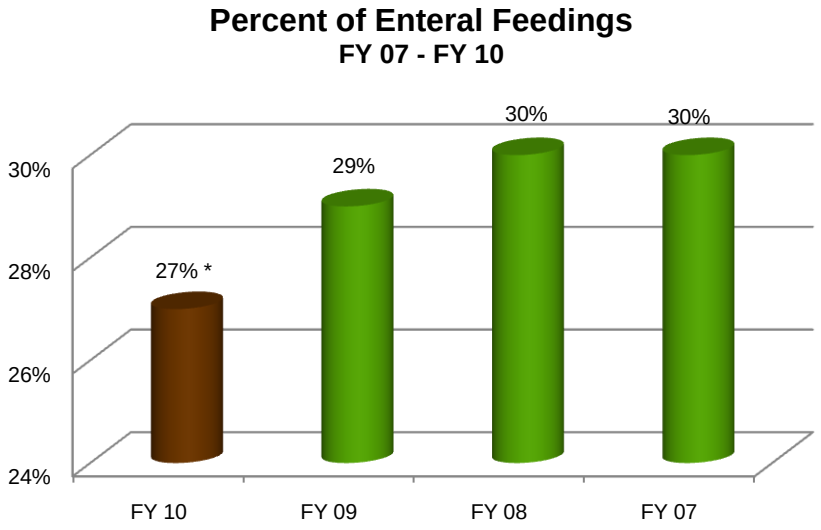
Table 19

FY 06 - FY10
Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	15	55.1
Pancreas	8	58.2
Breast	7	63.5
Bladder	4	61.9
Colorectal	4	63.1
Stomach	5	58.09
Brain	4	52
Esophagus	4	54.5
Lymphoma non-Hodgkins	4	57.7
Prostate	3	79.7
Renal	4	47.9
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
Leukemia	1	12.1
Lymphatic/Hemotopoietic	1	73
Myeloma	1	64.8
Nasopharyngeal	1	63.2
Oral/pharynx	1	68
Parotid Gland	1	46
Testicular	1	63
Trachael/Bronchus	1	81
Vulva	1	61.8
Unknown	4	61.9
TOTAL	**90**	**57.9**

Enteral Feedings

Figure 24



The data reveals that during the past four years 161 individuals were tube fed prior to their death. One hundred twenty-three individuals had a gastrostomy tube, 19 had a jejunostomy tube and 19 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, 58% of these individuals had a history of recurrent pneumonia or aspiration pneumonia or dementia before insertion of the feeding tube.

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 higher rate of pneumonia and pneumonia related death. [11.12.13.16,21]

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 may outweigh 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.[16,18,22,23,24] 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 121 cases reviewed by the CT mortality review process – does not include abridged reviews.

SECTION SIX: BENCHMARKS

Mortality Rate Comparison

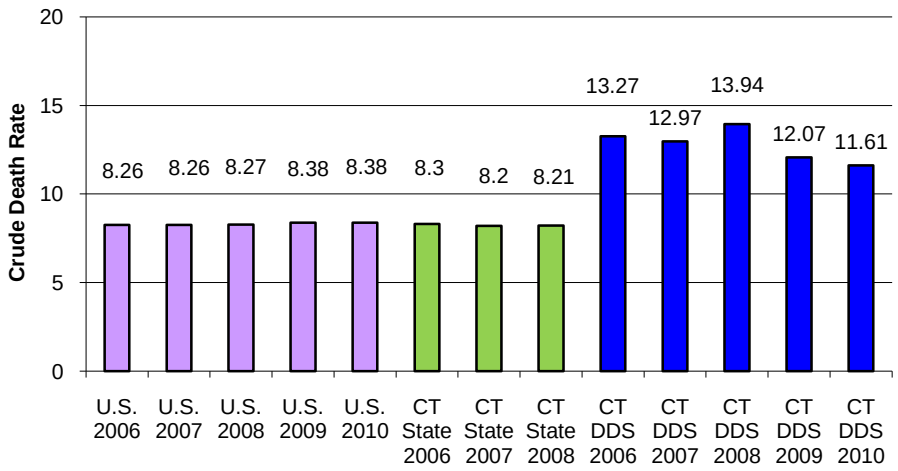
Benchmarks are standards by which similar items can be compared and allow the reader to place findings in context. Thus, the use of benchmarks including comparative data from other populations is an important mechanism for helping to understand analytical findings and trend data such as those presented 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 11.61/1000 is higher than the rate of 8.21 in Connecticut (2008) and the rate of 8.38 in the general United States population (2010).[1,27] 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. [1,4,25,26,27]

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.

Table 20

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

Rank	US 2008	US 2007	US 2006	STATE CT 2007	STATE CT 2006	STATE CT 2005	CT DDS 2010	CT DDS 2009	CT DDS 2008	CT DDS 2007	CT DDS 2006
1	Heart Disease 25%	Heart Disease 25.4%	Heart Disease 25.9%	Heart Disease 25.3%	Heart Disease 25.5%	Heart Disease 25.9%	**Heart Disease 28%**	Heart Disease 29.9%	Heart Disease 31.0%	Heart Disease 29.1%	Heart Disease 25.4%
2	Cancer 23.7%	Cancer 23.1%	Cancer 23.1%	Cancer 23.6%	Cancer 24%	Cancer 23.8%	**Respiratory Disease 14.6%**	Respiratory Disease 13.7%	Aspiration Pneumonia 15%	Respiratory Disease 18%	Respiratory Disease 18.2%
3	Respiratory Disease 5.7%	Stroke 5.5%	Stroke 5.6%	Stroke 5%	Stroke 5.2%	Stroke 5.2%	**Sepsis 12.9%**	Pneumonia 12.8%	Respiratory Disease 12.3%	Cancer 11%	Pneumonia 14.4%
4	Stroke 5.4%	Respiratory Disease 5.3%	Respiratory Disease 5.1%	Respiratory Disease 4.7%	Respiratory Disease 5%	Respiratory Disease 5%	**Cancer 12.9%**	Aspiration Pneumonia 10.3%	Cancer 10.7%	Pneumonia 8.5%	Cancer 11%
5	Accidents 4.9%	Accidents 4.8%	Accidents 4.8%	Accidents 4.6%	Accidents 4.3%	Accidents 3.8%	**Aspiration Pneumonia 12.3%**	Septicemia 9.8%	Pneumonia 8.6%	Pneumonia Aspiration 8.5	Septicemia 7.8%
6	Alzheimer's Disease 3.3%	Alzheimer's Disease 3.1%	Alzheimer's Disease 3%	X	X	X	**Pneumonia 7.6%**	Cancer 7.4%	Septicemia 8.6%	Septicemia 6%	Pneumonia Aspiration 5.5%
7	Diabetes 2.9%	Diabetes 2.9%	Diabetes 2.9%	X	X	X	**Stroke 4%**	Stroke 3.4%	Nervous System 3.7%	Stroke 3.5%	Kidney/ Renal 4.4%
8	Influenza/ Pneumonia 2.3%	Influenza/ Pneumonia 2.2%	Influenza/ Pneumonia 2.3%	X	X	X	**Digestive System 3%**	Kidney/ Renal 2.5%	Kidney/ Renal 3.2%	Kidney Renal 3.5%	Accident 2.7%
9	Nephritis/ Kidney 2%	Nephritis/ Kidney 1.9%	Nephritis/ Kidney 1.8%	X	X	X	**Kidney/ Renal 2%**	Digestive System 2.5%	Stroke 2.7%	Digestive System 3%	Stroke 2.2%
10	Septicemia 1.5%	Septicemia 1.4%	Septicemia 1.4%	X	X	X	**Genetic Disorder 2%**	Genetic Disorder 2.5%	Digestive System 1.6%	Nervous System 2%	Nervous System 2.2%

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. [1,4,25,26,27]

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 28% versus and 25.3% in the CT general population and 25.4% nationally.

Respiratory Diseases: Is the second leading cause of death in the CT DDS population (14.6%). This category which includes influenza causes death in the CT DDS population at a rate more than 2 ½ times reported in the CT and national vital statistics data base (5%) and (5.3%) respectively .

Septicemia: Originating from various sites and usually acute in onset is the third leading cause of death in the CT DDS population resulting in 12.9% of deaths while only 1.4% of deaths in the US general population are caused by sepsis.

Cancer: Is the fourth leading cause of death in the CT DDS population responsible for almost 12.9% deaths. Unlike the previously mentioned leading causes of death, cancer in DDS occurs less frequently in the CT DDS population than in the CT (24%) and national (23.7%) general populations.

Aspiration Pneumonia: Is the fifth leading cause of death in the DDS population (12.3%) 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.

Pneumonia: Is the sixth leading cause of death accounting for 7.6% of CT DDS deaths compared to <3% in the general CT and US population. 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.

Accidental Deaths: In calendar year 2010 the percent of deaths resulting from accidents in the CT DDS system (4%) did not make the top 10 leading causes of death and once again was lower than the number of accidental deaths reported in the 2007 CT population (4.6%) 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. 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.[9]

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 2010. 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 (2007) calendar year.

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 21

Mortality Case Review Summary (FY 2010)

Death Reviewed By Regional Committees	*Cases Closed at Regional Level*	*Cases Referred and Reviewed By IMRB*	*QA Cases Closed by Region IMRB Review*	*Total Cases Reviewed By IMRB*
121 *	74 (61%)	47 (39%)	9 (7%)	56 (46%)

Table 25 above provides a summary of all deaths reviewed by the CT DDS Mortality Review Committees. Sixty-one percent of the 121 cases reviewed were closed by the local regional mortality committees. The regional committees referred 47 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 12% of cases closed by regional mortality committees.

Table 22

Cases Referred to IMRB (47)	
Medical/Health Care	24
Post mortem examination	14
Pending Abuse/Neglect Investigations	9

* Does not include Abridged Reviews

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.
- Training topics were identified from IMRB findings and have been implemented for nursing and direct care staff by provider agencies.
- 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.

References

1 CIA World Fact Book.

2 Sutherland, Georgina, Couch, Murray A. and Iacono, *Health Issues for Adults with Developmental Disabilities Research in Developmental Disabilities,* Vol 23, Issue 6 Nov-Dec 2002 422-445.

3 Gruman, C; Fenster, J; *A Report to the CT Department of Mental Retardation*: *1996-2002 Data Overview 2002*; April 2002.

4 Department of Public Health, 2004/2005 State of Connecticut: *Health Care Quality, Statistics, Analysis and Reporting.*

5 Coppus, A; Evenhuis, H; Verberne, G-J; Visser, F; van Gool, P; Eikelenboom, P; van Duin, C; *Dementia and Mortality in Persons with Down's Syndrome.* Journal of Intellectual Disability Research, v50 n10 p768-777 Oct 2006.

6 Thase, ME; *Longevity and Mortality in Down's Syndrome;* Journal of Mental Deficiency Research, v26 n3 p177-92 Sept 1982.

7 Day, Steven M; Strauss, David J; et al; *Life expectancy project mortality and causes of death in person's with Down Syndrome in California*; May 19, 2004.

8 Strauss, D; Eyman, RK; *Mortality with and without Down syndrome;* American Journal on MR 1996.

9 Horwitz, S.M., Kerker, B.D., Owens, P.L.,& Zigler, E. (2000). Physical Health Conditions Contributing to Morbidity and Mortality of Individuals with Mental Retardation. In *The Health Status and Needs of Individuals with Mental Retardation*. New Haven: Yale University School of Medicine. Published by Special Olympics, Inc.,March 2001.

10 Strauss, D., Eyman, R. & Grossman, H.J. (1996) *Predictors of mortality in children with severe mental retardation: The effect of placement*. American Journal of Public Health, 86, 1422-1429.

11 Mitchell S.L., Kiely DK, Lipsitz L.A., *The Risk Factors and Impact on Survival of Feeding Tube Placement in Nursing Home Residents with Severe Cognitive Impairment.* Arch Inter Med, 157: 327-332 1997.39.

12 Pick N., McDonald A., Bennett N., Litsche M., Dietsche, L., Legerwood, R., Spurgas, R., LaForce, F.M., *Analysis of Risk Factors.* Journal of the American Geriatrics Society, 44: 763-8 1996.

13 Finucane, T.E., Christmas, C., Travis, K., *Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence.* JAMA, Oct 13: 282 (14): 1365-70 1999.

14 Murphy, L.M., Lipman, T.O., *Percutaneous Endoscopic Gastrostomy Does Not Prolong Survival in Patients with Dementia.* Arch Intern Med, Vol 163, June 9, 2003.

15 *Artificial Nutrition and Hydration: Clinical Issues.* Journal of Hospice and Palliative Nursing 5(4): 221-230, 2003.

16 *Clinical Goals of ANH: Rationale and Evidence.* Journal of Hospice and Palliative Nursing 5(4): 221-230, 2003.

17 Goodwin, R.S., *Prevention of Aspiration Pneumonia: A Research-Based Protocol.* www.pspinformation.com.

18 Meier, D.A., Ahronheim, J.C., Morris, J., Baskin-Lyons, S., Morrison, R.S., *High Short-Term Mortality in Hospitalized Patients with Advanced Dementia.* Arch Inter Med. Vol 161, February 26, 2001.

References (continued)

19 Heart Disease and Stroke Statistics 2010 Update American Heart Association.

20 Barlow, G.M. et al, *Down syndrome Congenital Heart Disease,* Genet Med. 2001 Mar-Apr;3(2): 91-101.

21 Gray, Sherian, D., Kimbell, D, *Enteral Tube Feeding and Pneumonia.* American Journal on MR Vol:111, Issue:2: 113-120, 2006.

22 Finucane, T.E., Bynum, J.P., *Database of Abstracts with Reviews of Effects (DARE); Use of Tube Feeding to Prevent Aspiration Pneumonia.*

23 Finucane, T.E., Mitchell, S.L., Christmas, C., McCann, R., *Tube Feeding for Elderly Patients. Caring for Older Adults: Innovations in Research and Practice.* Presented at the American Geriatrics Society Annual Scientific Meeting 2001; May 12, 2001, Chicago, IL, Symposium.

24 Grant, M.D., Rudberg, M.A., Brody, J.A., *Gastrostomy Placement and Mortality Among Hospitalized Medicare Beneficiaries;* Journal of American Medicine; 279:1973-1976.

25 CDC National Center for Health Statistics, Division of Vital Statistics; Deaths: Final Data for 2004, 2005, 2006, 2007.

26 State of Connecticut Department of Public Health, Health Care Quality, Health Statistics & Analysis 2006, 2007, 2008.

27 State of Connecticut Department of Public Health, Age Adjusted Mortality Rates 2008.

28 Noberto Alverez, MD; *Alzheimer Disease in Individuals with Down syndrome.*

The next Annual Mortality Report UPDATE will be issued in March of 2012

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Report prepared by Dory McGrath, MN, RN with special thanks to Julie Bouchard with assistance from Tim Deschanes-Desmond.

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APPENDICES

Appendix A: Overview of DDS Population

Appendix B: DDS Consumers by Residential Setting
DDS Population by Age

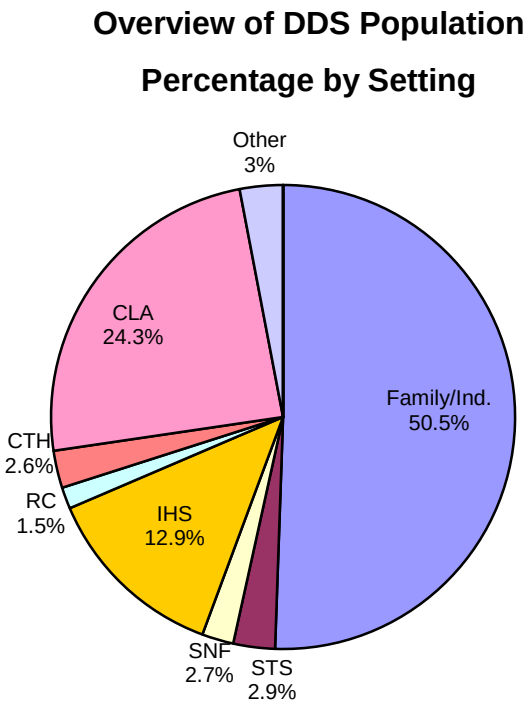
Appendix C: Percentage Population by Age Ranges
Level of Intellectual Disability

Appendix D: Age Category and Residence
Consumers by Program Type

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, 2010 **15,495** individuals with intellectual disability were being supported by the department.



Half of the people served by CT DDS live at home with their family. One third receive support services provided in community living arrangements (CLAs), community training homes (CTH), regional centers (RC) and a campus program, Southbury Training School (STS). Approximately 13% of the DDS population receive individualized home supports (OH/IS). The remainder (5%) 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 2009 - FY 2010

	2010	2010	2009	2009	2009-2010
Type of Support	# of Consumers	Percent	# of Consumers	Percent	**% Change**
Family	7,831	51%	7,758	50%	1.0%
CLA (Group Home)	3,763	24%	3,781	24%	(-0.5%)
Individualized Home Supports (IHS)	1,992	13%	1,945	13%	2.4%
Training School	450	3%	480	3%	(-6.25%)
Other	471	3%	353	2%	33.40%
Community Training Home (CTH)	409	3%	413	3%	(-1.0%)
SNF	382	2%	417	3%	(-8.4%)
Regional Center (RC)	236	2%	243	2%	(-2.9)
TOTAL	**15,534**	**100%**	**15,390**	**100%**	

DDS Resident Population by Age

2005 - 2010

	2010	**2009**	**2008**	**2007**	**2006**	**2005**
Children (0-19)	3,456	3,576	3,594	3,575	3,663	3,766
Adults (20 - over)	12,039	11,814	11,676	11,573	11,355	11,177
TOTAL ALL AGES	**15,495**	**15,390**	**15,270**	**15,148**	**15,018**	**14,943**

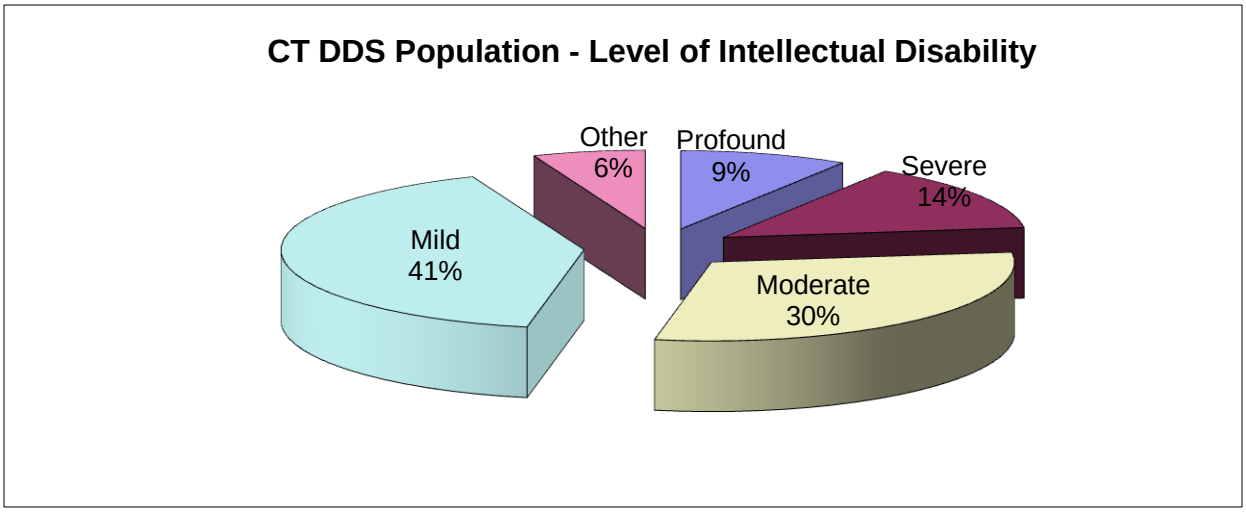
Adults (55 - over)	**2,893**	**2,779**	**2,628**	**2,587**	**2,470**	**2,397**
Adults (65 - over)	**1,105**	**1,050**	**1,005**	**991**	**957**	**954**

APPENDIX C

Percent Population by Age Ranges

FY 2010

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,456	22.3%
Age 20-29	3,278	21.2%
Age 30-39	2,078	13.4%
Age 40-49	2,541	16.4%
Age 50-59	2,263	14.6%
Age 60-69	1,244	8.0%
Age 70-79	443	2.9%
Age 80+	192	1.2%
TOTAL	**15,495**	**100%**



APPENDIX D

AGE CATEGORY AND RESIDENCE
FY 2010

Restype	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
CLA (Group Home)	108	3,252	403	3,763
SNF	1	190	191	382
Campus	0	292	158	450
Own Home/Individualized Services	4	1,519	162	1,685
Other	198	482	59	739
Family Home	3,132	4,622	77	7,831
CTH (Community Training Home)	13	345	51	409
Regional Center	0	232	4	236
TOTAL	**3,456**	**10,934**	**1,105**	**15,495**
PERCENT	**22%**	**71%**	**7%**	**100%**

Consumers Age 19 - 64 Years
By Program Type

SNF	89%
STS	65%
CTH	88%
CLA	89%
OH/IS	90%
Family/Independent	99%
RC	98%

Consumers over the Age of 65
By Program Type

SNF	11%
STS	35%
CTH	13%
CLA	11%
OH/IS	10%
Family/Independent	1%
RC	2%