State of Connecticut

DDS

Mortality

ANNUAL REPORT

FY 2015

This is the fourteenth 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: January 2017

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 2015 fiscal year (July 1, 2014- June 30, 2015) 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 149 deaths reviewed by the DDS nurse investigators, regional mortality review committees and Independent Mortality Review Board (IMRB) for the period of July 1, 2014 – June 30, 2015.

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, 2014 to June 30, 2015.
Data in this report was obtained from the CT DDS Database system.

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Executive Summary 2015 Report

- There were 249 deaths resulting in a crude **mortality rate of 15/1000**
- The strongest predictors of mortality were age, mobility status, and the need for special assistance when eating
- The average age of death for individuals with ID was 61.1 years
- Starting early in the fifth decade of life there was 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 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 (31%)
- Aspiration pneumonia/pneumonia accounted for 9.2% of all deaths
- The incidence of deaths related to cancer in the DDS population (10.4%) was lower than the national (22.5%) and state (22.7%) [13,14]
- Accidental deaths continue to occur at a rate below that of the general state and national population [13,14]
- The average age of death for people with Down syndrome was 57.9 years
- Cardiac Arrest was the leading cause of death for people with Down syndrome
- Hospice supports were provided in 33% of the reviewed deaths which allowed individuals to remain in their home residences in the final stages of a terminal illness

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

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 individuals?

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/IID.

Regional Mortality Review Committee
Criteria for Review

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

Independent Mortality Review Board
Criteria for Review

- Determined necessary by the regional mortality 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
- Private provider agency representative
- Family 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, 2014 – JUNE 30, 2015) NUMBER OF DEATHS REPORTED = 249

Overall Mortality Rate

During the 12 month time period between July 1, 2014 and June 30, 2015 a **total of 249** individuals supported by CT DDS passed away **resulting in a mortality rate of 15** (Figure 1 & 2 below). Both the number of deaths and mortality rate increased in FY 15.

Figure 1

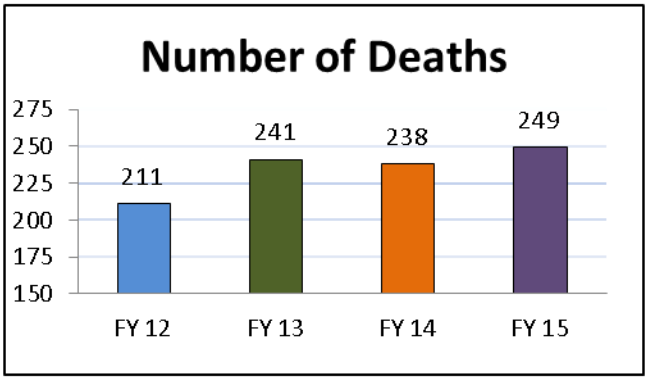
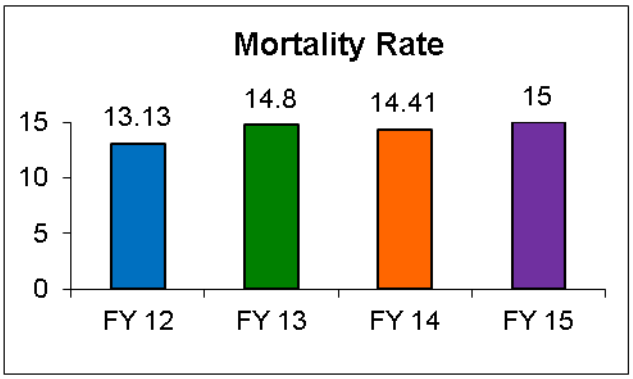


Figure 2



Mortality and Residence

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

	% Deaths	% DDS population
CLA	33	23
SNF	30	2
Family	19	46
STS	10	2
IHS	4	17
CRS	2	4
CCH	2	2
RC	1	1

SNF = skilled nursing facility; RC = regional center; STS = Southbury Training School; CLA = community living arrangement (group home); CCH = community companion home (formerly called CTH); IHS = individualized home supports; CRS = continuous residential supports, Family = live with family at home or independently.

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

Figure 3

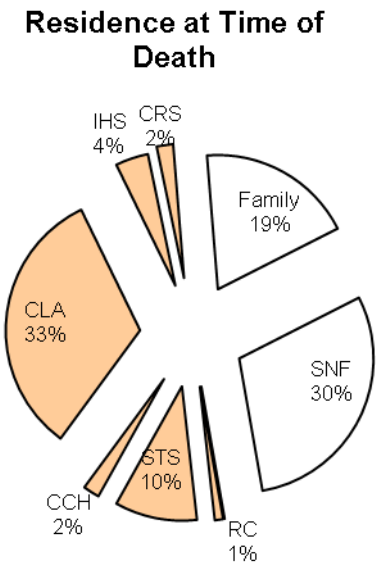
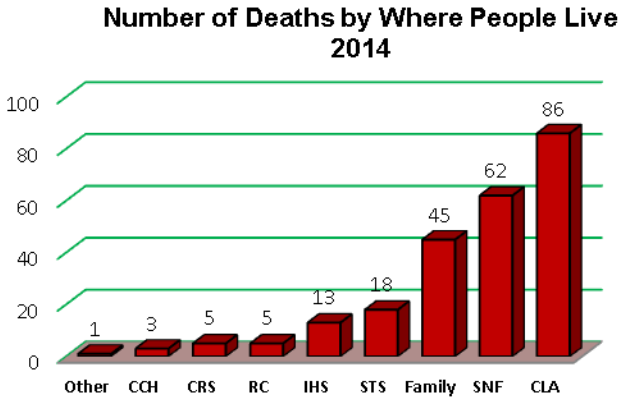


Figure 4



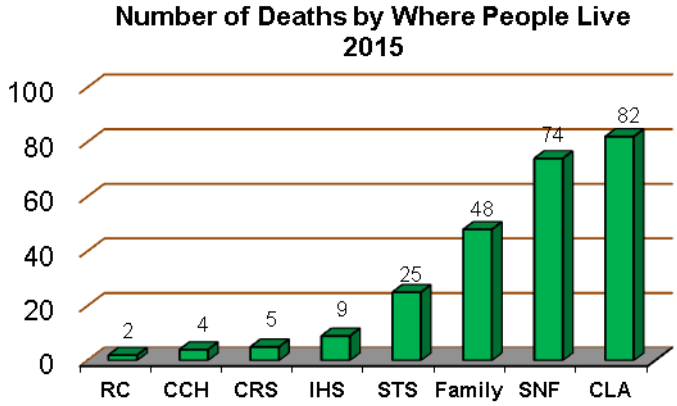


Figure 4 (above) depicts the actual number of deaths by where people live. As last year, the greatest number of deaths occurred in CLAs followed by skilled nursing facilities, family homes and STS. Of note: Sixty-four (64%) of the people DDS supports live in family homes or in their own home with individualized supports, 23% in group homes (CLA's) and only 2% in skilled nursing facilities.

Figure 5

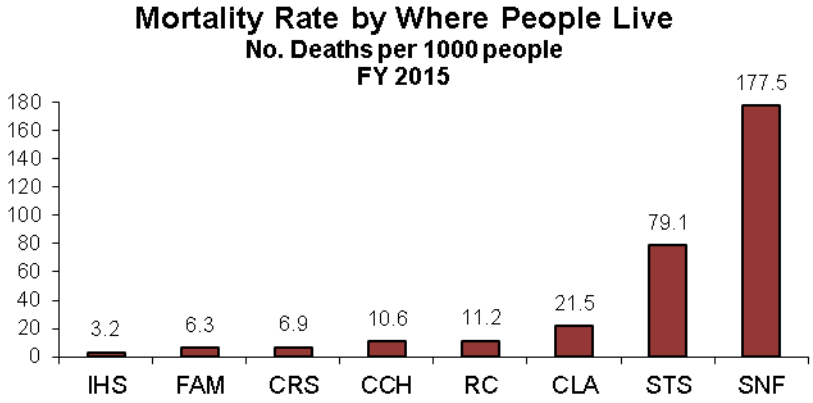


Figure 5 (left) depicts the number of people who died for every 1000 people served by type of support.

Of note: In general, individuals supported by DDS who live in skilled nursing facilities and at STS tend to be older. In addition, residents of skilled nursing facilities have considerable health co-morbidities.

Mortality and Residence Definitions

Family Home: People who live with their family without significant residential DDS supports or independently represent 46% of the DDS population. However, in FY 2015 only 48 deaths (19.3% of all deaths) occurred in a family home with an associated mortality rate of 6.3. All CT DDS deaths of children were for those who lived with their families. Twenty-five of the 48 people died in a hospital, hospital emergency department or SNF.

CLA: These settings serve people with varying levels of intellectual disabilities who require 24 hour supervision for their health and direct care supports. In FY 2015, 82 or 32.9% of all deaths occurred in CLA's compared to 33.6% in FY 14. Fifty of the 82 people died in a hospital, hospital emergency department, hospice or SNF.

CCH: There were 4 reported deaths in the community companion homes compared with 3 reported deaths in FY 2014. The CCH mortality rate of 10.6 was greater than the mortality rate for people living at home with their family or people living in their own home. People living in CCH's represent 2% of the DDS population and accounted for 1.6% of the reported deaths. Two of the people died in a hospital, hospital emergency department or SNF.

CRS: People receiving 24 hour supports in their own homes. People receiving continuous residential supports in their own homes, in most cases, are less medically involved than people living in other settings. Five or 2% of reported deaths occurred in this environment. Four of the people died in a hospital, hospital emergency department or hospice.

IHS: Similar to people living in CRS, however, this population does not require 24 hour support. As with CRS, people receiving individualized home supports in their own homes, in most cases, are less medically involved than people living in other settings. This year 9 or 3.6% of reported deaths occurred in this environment compared with 5.4% last year. Seven of the 9 died in the hospital, hospital emergency department, hospice or SNF.

STS: The higher mortality rate of 79.1 is not surprising as this larger campus setting serves a population of older adults (average age of 65.9 years). Twenty-five deaths were reported at STS this past fiscal year representing 10% of all DDS deaths. Last year the Training School accounted for 7.6% of all deaths. Twelve of the 25 people died in a hospital or hospital emergency department.

RC: Less than 2% of DDS consumers reside at DDS regional centers. Two RC residents died in FY 2015 accounting for 1% of all DDS deaths. One of the individuals 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 66.5 years) and medically fragile population accounted for 74 or 29.7% of all reported deaths. People living in licensed nursing facilities had the highest mortality rate 177.5 per thousand. Fourteen percent (13.6%) of all DDS consumers over 65 years of age live in a skilled nursing facility. It is important to note that 27 of the 74 people died in a hospital or hospital emergency.

- 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 Companion Home (CCH): A family setting that is not the consumer's own family. CCH provider has received training and is licensed by DDS to provide services. (Formerly known as CTH, Community Training Home.)
- Continuous Residential Supports (CRS): 24 hours of support for consumers to live in their own home.
- Individualized Home Supports (IHS): Less than 24 hours of support for consumers 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 individual.
- Southbury Training School (STS): 24 hour support is provided in a large campus setting serving a population of older adults.
- 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

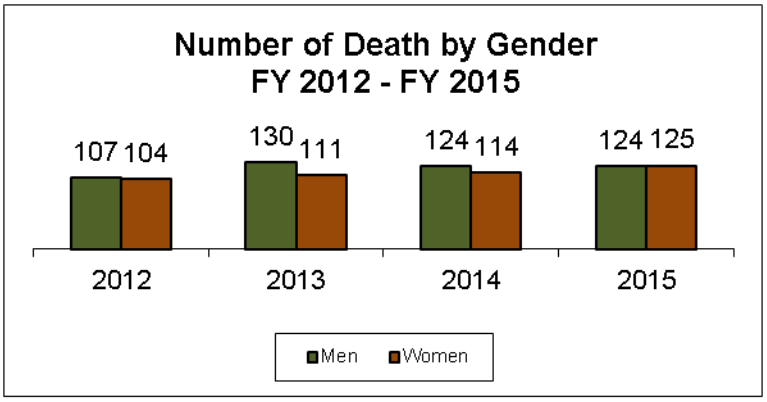
Table 1

Mortality Rate by Gender - 2015

GENDER	All Individuals Served by DDS	Total Number of Consumers	No. Deaths	Percentage of Deaths	Rate (No. Deaths Per 1000)
Men	58%	9,499	124	50%	13
Women	42%	6,829	125	50%	18
Total	**100%**	**16,328**	**249**	**100%**	**15**

In FY 2015 the number of females who died within the DDS was higher than the gender distribution served by the department and the number of males was lower.

Figure 6



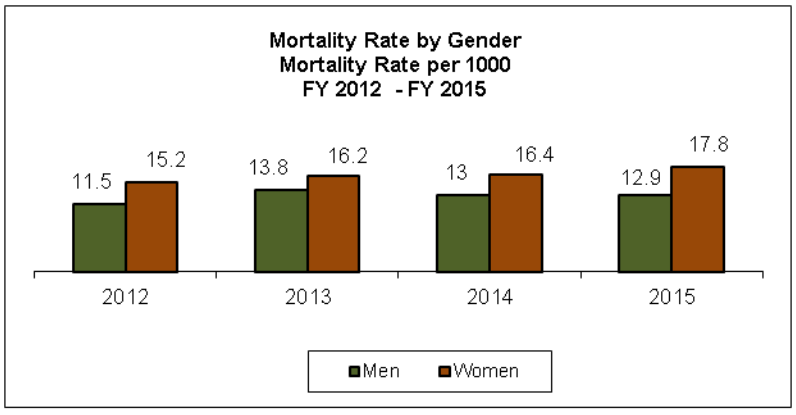


Figure 7

This year the number of women's deaths was slightly higher than the number of men's deaths and, as with past years, women have a higher mortality rate.

Mortality and Age

Table 2

Age of Death

Year	Men	Women	Average Age
CT DDS FY 2015	**60.7**	**61.4**	**61.1**
CT DDS FY 2014	57.9	60.4	59.1
CT DDS FY 2013	57.7	60.4	59
CT DDS FY 2012	59.6	62.1	60.8

Figure 8

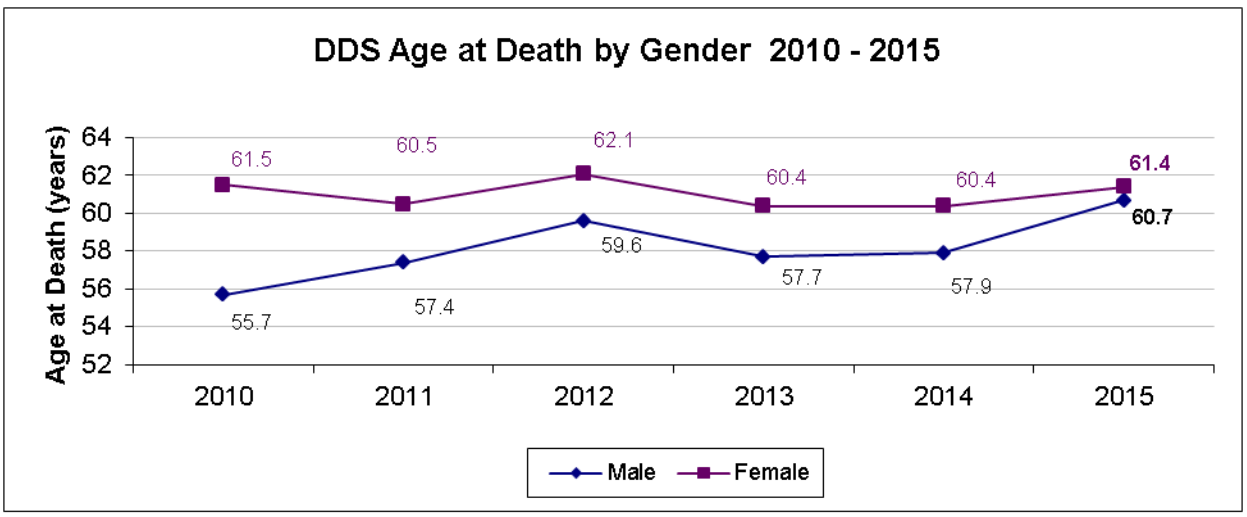
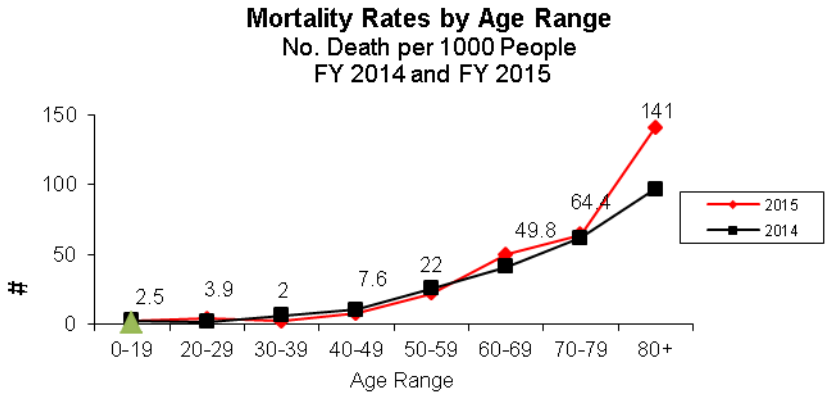


Figure 9



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.

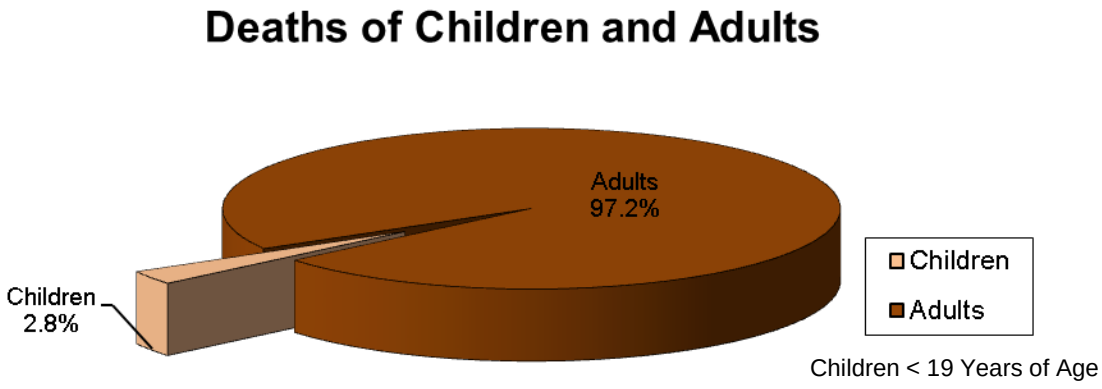
Table 3

Mortality Age Range Distribution Data
FY 2015

AGE RANGE	# OF DEATHS	% OF DEATHS	MORTALITY RATE
Age 0-19	8	3.2%	2.5
Age 20-29	15	6%	3.9
Age 30-39	5	2%	2
Age 40-49	16	6%	7.6
Age 50-59	55	22%	22
Age 60-69	79	31.7%	49.8
Age 70-79	39	15.7%	64.4
Age 80+	32	12.9%	141
TOTAL	**249**	**100%**	

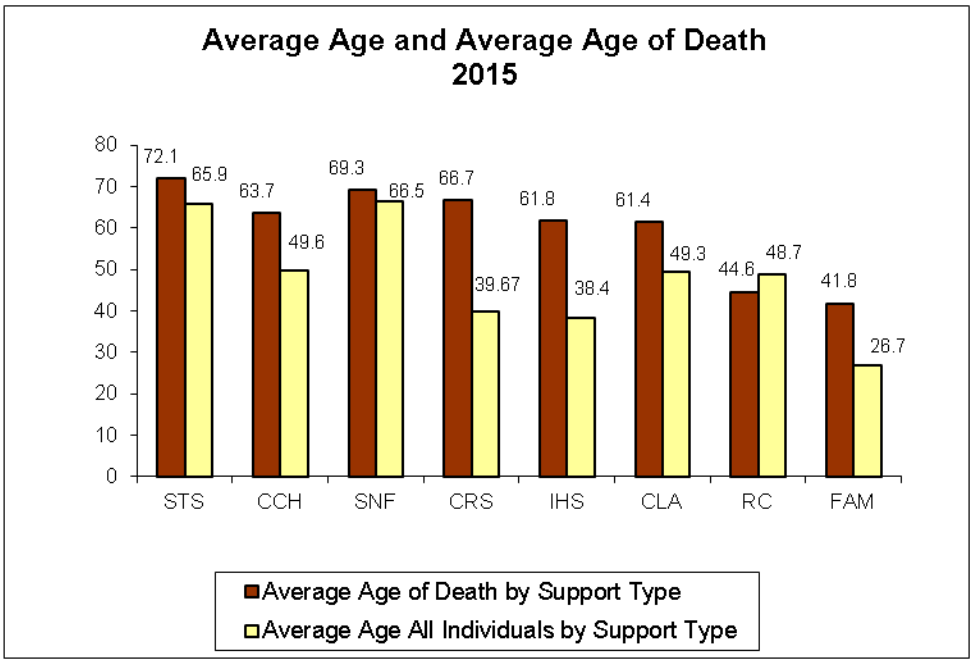
Mortality statistics for the DDS population in Table 3 reveal a progressive increase in the mortality rate as the age range increases.

Figure 10



In FY15 seven children died. All of the children lived at home with their family.

Figure 11



The average age of death in the CT DDS population is 61.1. 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 62.7 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 2015

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 = 149 cases (of total 249 deaths)

**** 54 of the 149 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 companion homes, continuous residential supports, individualized home 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-one individuals received hospice services: 58% lived in a community living arrangement, 13% lived at the training school, 19% lived in a nursing home, 3% lived in individual home support, and 3% lived in continuous residential support. The average age of death for people receiving hospice services was 70.

Thirty-one people (33% 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:	**8 (5.4% of reviewed deaths)**
Number of post mortem examination performed by CT OCME:	**6**

* Does not include Abridged Reviews

Predictability

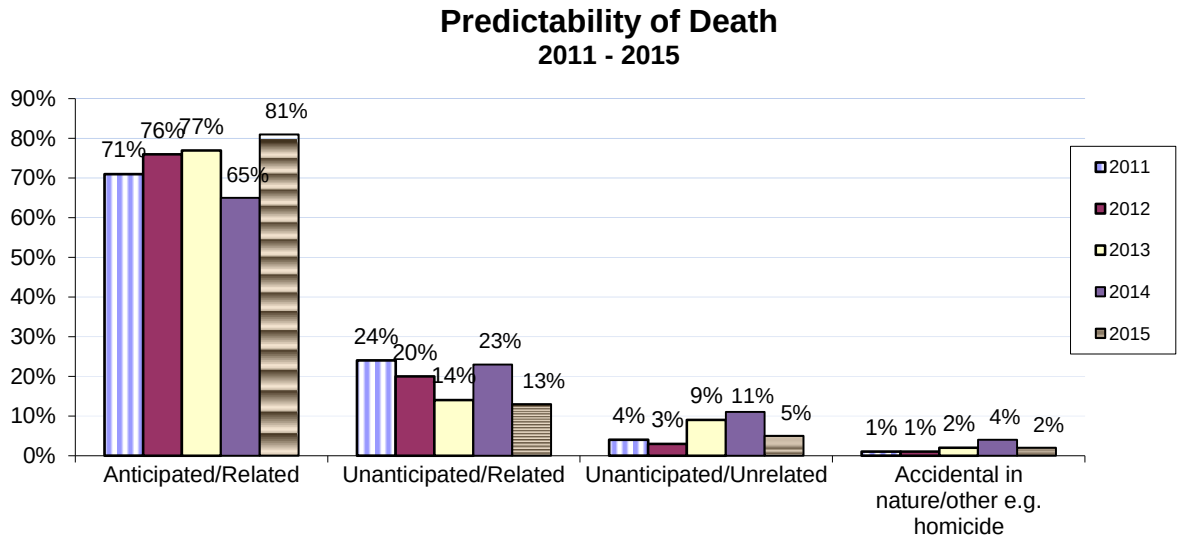
Analysis of the mortality review data indicates a relationship between an individual's pre-existing diagnosed medical condition(s) and his/her immediate cause of death (see Figure 12 below). In ninety-five percent of all deaths, an individual's immediate cause of death was related to a known or previously 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: 81%**
- **Death was unanticipated but related to a preexisting diagnosis: 13%**
- **Death was unanticipated and unrelated to a preexisting diagnosis: 5%**
- **Death was accidental in nature 2%**

Two of the accidental deaths were included in the "anticipated and related to a preexisting diagnosis" percentage.

One of the accidental deaths was included in the "unanticipated and related to a preexisting diagnosis" percentage.

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 97% 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 Connecticut 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 149 cases reviewed during FY 15, 146 (98%) were classified as **due to natural causes**. Three cases were determined to be the result of an accident.

Table 4

FY 15 Manner of Death

Manner of Death	*No.*	*Percent*
Natural	*146*	*98%*
Accident	*3*	*2%*
Total	*149*	*100%*

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

Fall	(2)
Neck Compression	(1)

UNANTICIPATED/UNRELATED DEATHS:

Of the 7 deaths that were unanticipated and not related to a known condition 4 were due to cardiac arrest, 1 was due to bronchopneumonia, 1 was due to hypoxia/hypotension and 1 was due to intra-abdominal hemorrhage/arterial hemorrhage anastomosis.

ACCIDENTAL DEATHS

Two cases of accidental death were the result of a fall, one case of accidental death was the result of neck compression.

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 149 mortality cases reviewed in FY 2015

125 cases had a DNR order in place

91% of the DNR orders were formally reviewed by DDS

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

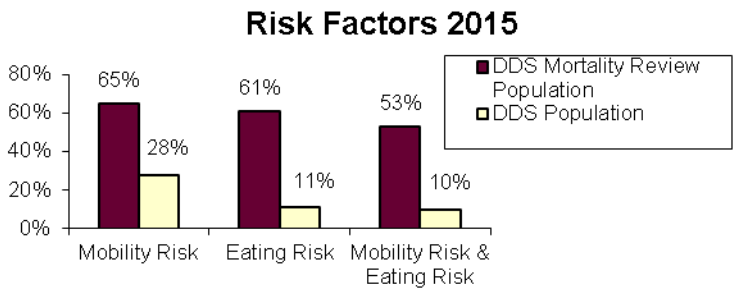
In 9% of all cases in which a DNR was ordered by a medical practitioner DDS was not notified prior to the implementation of the DNR order as is required by DDS procedure. However, the DDS mortality review process determined that in every case the medical criteria to support the decision to initiate the DNR was met. DDS continues to provide written education and support to those agencies that fail to notify of a DNR implementation.

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 2015 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 2015, 62 (65.3%) of the deceased did not ambulate independently.

* MORTALITY REVIEW POPULATION ONLY	* TOTAL DDS POPULATION
65% did not ambulate independently 61% did not eat independently * Does not include Abridged Reviews	28% do not ambulate independently 11% do not eat independently

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.

Level of Intellectual Disability and Mortality Rate

	2013	2014	2015	Percent of Population
Mild	4.1	5	**2.6**	45
Moderate	4.2	4.7	**3.9**	30
Severe	6.7	8.2	**12**	13
Profound	20.6	23.5	**22.9**	7

Table 5

Table 5 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.

Of note: Traditionally intellectual disabilities have been divided into four levels of severity based largely on IQ scores. Although this classification system is no longer used by CT DDS, data is included for longitudinal comparative purposes.

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 149 mortality cases reviewed by DDS, 8 cases were investigated by either the OPA/AID or the DDS through its Investigations Division when 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	***1***
Neglect not substantiated	***0***
Cases still open	***7***

In the 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 2015 seven (7) 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

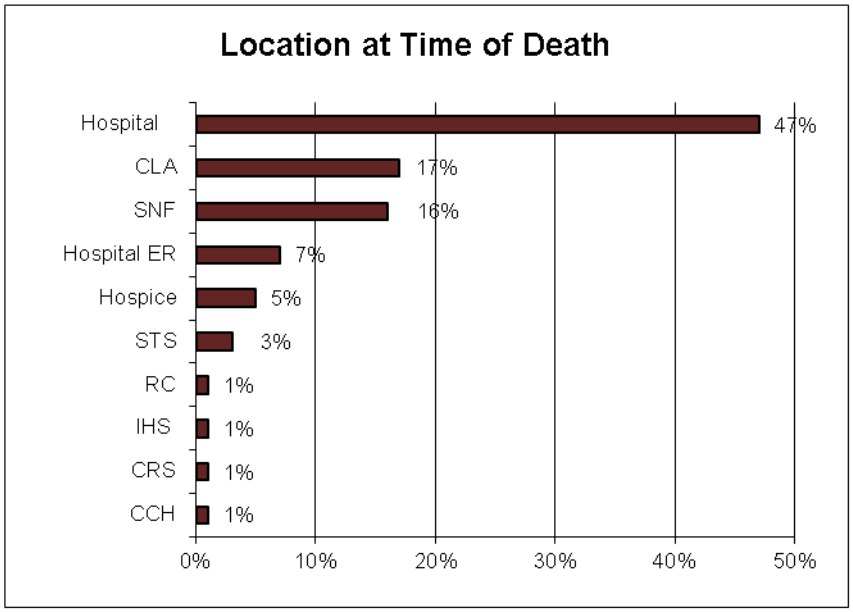
Practitioner Division Referrals– (0)
cases open – 0
cases closed - 0
citations, violations found - 0

Facility Division Investigations – (7)
cases open – 2
cases closed - 5
citations, violations found – 4

Pronouncement of Death (Location at Time of Death)

Figure 14 below depicts the location where death was pronounced.

Figure 14



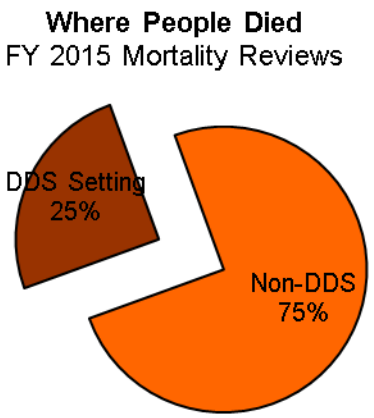
KEY: Location of Death

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



As can be seen in Figure 15 to the right, 75% of all deaths reviewed by the mortality review committee during FY 15 occurred outside of a DDS operated, licensed or funded residential setting, this represents an decrease in the number of people dying outside of a DDS setting compared to FY 14 (79%).

SUMMARY OF MORTALITY DATA

for the 149deaths that were reviewed in FY15

- **100%** of required cases were reviewed **Regionally**.
- **24%** of all cases were reviewed by the **IMRB**.
- **33%** of the individuals received **Hospice** supports prior to their deaths. *
- **5%** of the individuals had **Autopsies** performed.
- **94%** of all deaths were **Related** to an existing medical diagnosis.
- **84%** of the individuals had a **DNR** order in place at the time of death.
- **53%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance). *
- **98%** of the deaths reviewed were due to **Natural** causes.
- **3** number of deaths that were classified as **Accidental**.
- **7** number of referrals to **Department of Public Health**.
- **8** number of referrals to **Office of Protection & Advocacy Abuse Investigation Division**.
- **1** number of cases **Neglect** was substantiated by OPA or DDS.

* Does not include Abridged Reviews

SECTION FOUR: MORTALITY TRENDS CT DDS

For the past fourteen 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

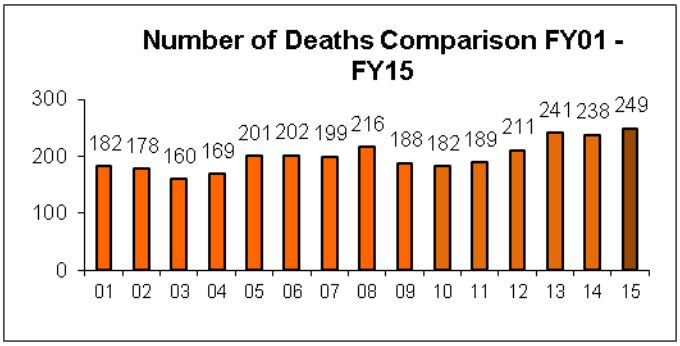
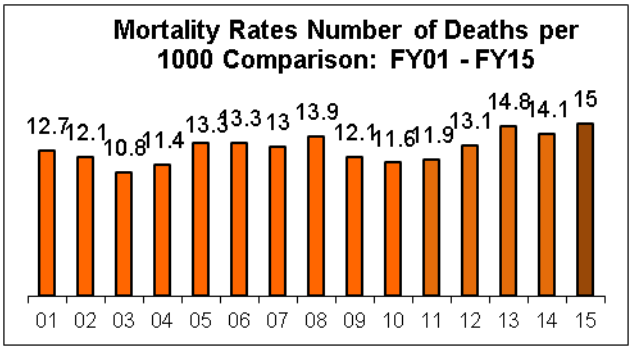
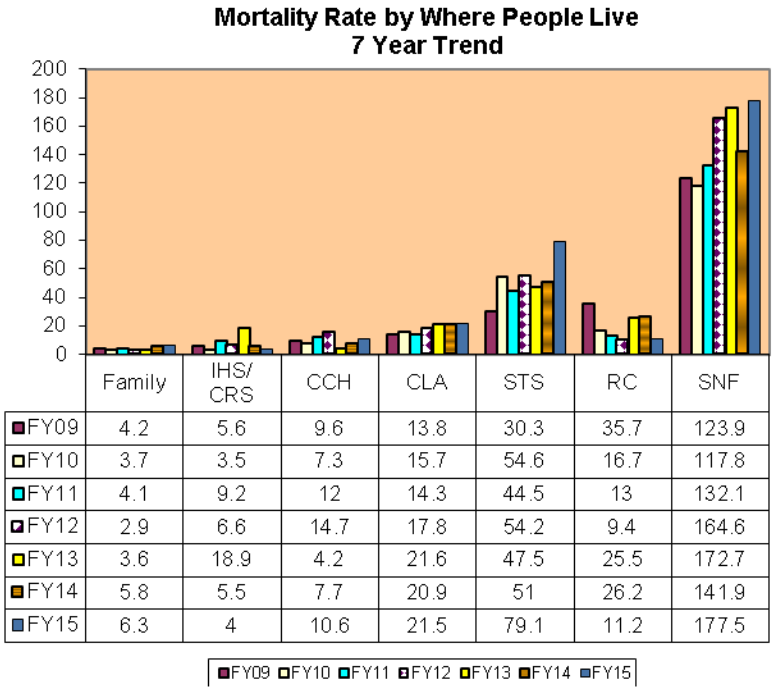


Figure 17



Figures 16 and 17 depict on an annual basis the number of deaths and the average death rate for FY 2001 – 2015 within the population served by DDS. The death rate average over the fifteen year period of time is 12.87/1000 people.

Figure 18



	Family	IHS/ CRS	CCH	CLA	STS	RC	SNF
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
FY11	4.1	9.2	12	14.3	44.5	13	132.1
FY12	2.9	6.6	14.7	17.8	54.2	9.4	164.6
FY13	3.6	18.9	4.2	21.6	47.5	25.5	172.7
FY14	5.8	5.5	7.7	20.9	51	26.2	141.9
FY15	6.3	4	10.6	21.5	79.1	11.2	177.5

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.

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

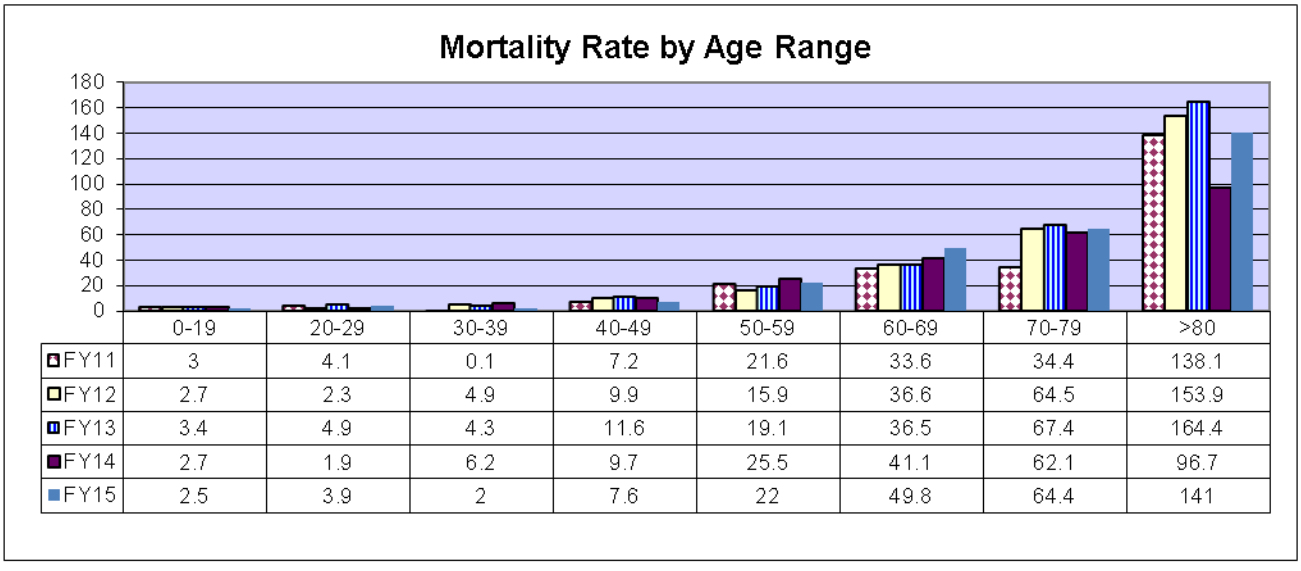
Table 6

Mortality and Gender
(2006 - 2015)

Year	# Deaths Men	# Deaths Women	Mortality Rate Men	Mortality Rate Women
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
2011	108	81	11.88	12.01
2012	107	104	11.57	15.23
2013	130	111	13.82	16.16
2014	124	114	13	16.4
2015	**124**	**125**	**12.9**	**17.8**

With the exception of this year, over the past nine years more men died annually than women and the mortality rate for women exceeded the mortality rate for men.

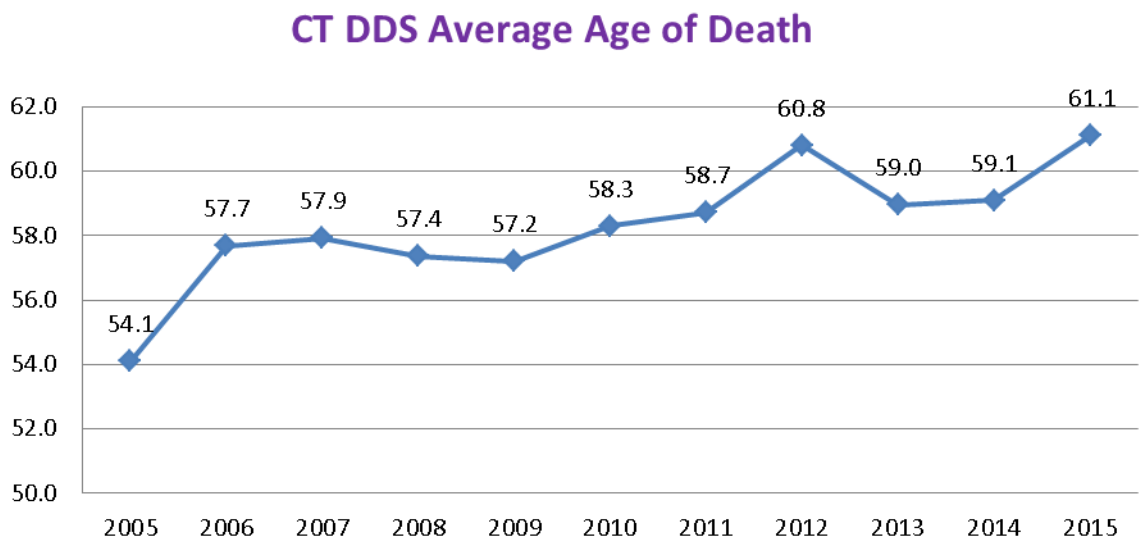
Figure 19



	0-19	20-29	30-39	40-49	50-59	60-69	70-79	>80
FY11	3	4.1	0.1	7.2	21.6	33.6	34.4	138.1
FY12	2.7	2.3	4.9	9.9	15.9	36.6	64.5	153.9
FY13	3.4	4.9	4.3	11.6	19.1	36.5	67.4	164.4
FY14	2.7	1.9	6.2	9.7	25.5	41.1	62.1	96.7
FY15	2.5	3.9	2	7.6	22	49.8	64.4	141

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 8 out of the last 10 fiscal years the average age of death has held in a tight range within the fifth decade of life. This is lower than the national life expectancy (79.7) [1] and the Connecticut life expectancy (80.8). [11,15]

Figure 21

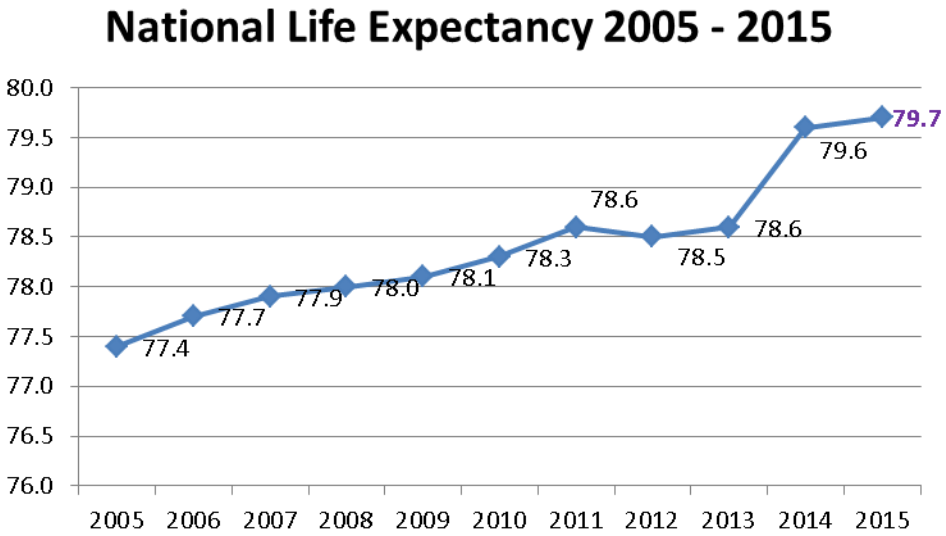


Table 7

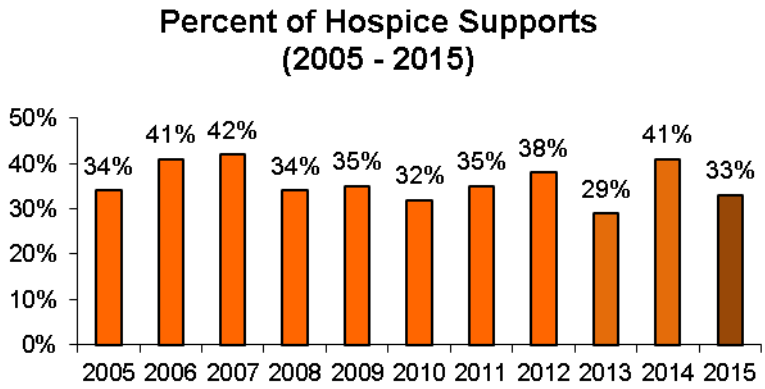
RESIDENCE AT TIME OF DEATH TRENDS
(2006 - 2015)

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
SNF	33%	33%	30%	31%	28%	31%	32%	34%	26%	**30%**
CLA	31%	29%	26%	28%	33%	29%	33%	34%	36%	**33%**
Family	18%	17%	20%	18%	18%	19%	12%	14%	19%	**19%**
STS	10%	10%	13%	8%	14%	11%	11%	8%	8%	**10%**
IHS/CRS	4%	7%	5%	6%	2%	5%	6%	5%	7%	**5%**
RC	2%	2%	2%	5%	2%	1%	1%	2%	2%	**1%**
CCH	1%	1%	2%	2%	2%	3%	3%	1%	1%	**2%**
Other	0%	1%	2%	2%	1%	1%	2%	2%	1%	**0%**
	100%	100%	100%	100%	100%	100%	100%	100%	100%	**100%**

Table 7 depicts the percentage of deaths within various support types over a ten 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 22



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.

SECTION FIVE: LEADING CAUSES OF DEATH

This section discusses cause of death data for people served by the CT DDS. 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 8

Leading Cause of Death Data CT DDS
(based on the 2015 fiscal year)

30.9%	*of deaths were due to*	**Heart Disease**	*including*	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
21.2%	*of deaths were due to*	**Respiratory Disease**	*including*	Respiratory Failure, Pulmonary Embolism, Influenza, Multi-System Failure, COPD, ARDS, Asthma
10.4%	*of deaths were due to*	**Cancer**	*including*	Wide variety of primary origin sites
6.4%	*of deaths were due to*	**Sepsis**	*including*	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
5.6%	*of deaths were due to*	**Aspiration Pneumonia**	*including*	Aspiration Pneumonia
4.4%	*of deaths were due to*	**Alzheimer's Disease**	*including*	Dementia
3.6%	*of deaths were due to*	**Pneumonia**	*including*	Pneumonia
2.4%	*of deaths were due to*	**Brain Disorders**	*including*	TBI, Subdural Hematoma
1.6%	*of deaths were due to*	**Digestive System**	*including*	Intestinal Obstruction, Volvulus
1.6%	*of deaths were due to*	**Renal/Kidney**	*including*	Renal Failure chronic and acute

The 10 leading causes of death in 2015 (Table 8) are noted above. Heart disease remains the leading cause of death for the DDS population with respiratory disease, cancer, sepsis and aspiration pneumonia rounding out the top five.

Heart Disease

According to the Centers for Disease Control[16] "The term 'heart disease' refers to several types of heart conditions. The most common type in the United States is coronary artery disease, which can cause heart attack, angina, heart failure, and arrhythmias."

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

Table 9

Location Where Death Pronounced

(FY 2006 - 2015)

Location	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	10 Year Total
Hospital	58	63	71	71	61	49	56	67	87	70	**653**
SNF	30	28	26	14	18	21	33	36	34	24	**264**
CLA	17	15	7	10	12	15	21	22	24	26	**169**
Hospital ER	14	16	9	13	12	9	10	17	16	11	**127**
STS	14	6	11	10	13	13	13	8	5	5	**98**
RC	2	1	0	1	1	1	0	2	4	1	**13**
IHS	5	3	3	5	3	3	5	2	1	2	**32**
Hospice	2	2	1	5	0	5	7	7	2	7	**38**
Other	3	3	5	4	1	1	2	1	5	3	**28**

Table 10

Number of Autopsies (FY 2007 – FY 2015)

FY 07	11	8%
FY 08	17	13%
FY 09	14	11%
FY 10	14	10%
FY 11	6	5%
FY 12	13	9%
FY 13	3	2%
FY 14	6	3%
FY 15	**8**	**5%**

As noted in Table 9 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 2015 increased from FY 2014 (5% vs. 3%).

Table 11 provides an in-depth analysis of the cardiac deaths that were reviewed as part of the DDS mortality review process.* In FY 15 more men died as a result of heart disease than women and women lived longer than men.

Table 11

Deaths Due to Heart Disease

Year	Number of Male Deaths	Number of Female Deaths	Average Age Male	Average Age Female	Average Age
FY 13	28	17	62.7	62.5	62.6
FY 14	32	15	60.8	66.6	62.7
FY 15	**18**	**13**	**62.7**	**67**	**64.5**

As in the general population, many of the individuals served by DDS 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 80% of people who die of coronary heart disease are 65 or older [17] as compared with only 42% of individuals in the CT DDS population. Of the remaining cardiac related deaths in the DDS population group: Fourteen percent (14%) of the cardiac deaths occurred prior to the age of 50 years and 43% 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.[12] CT DDS data reveals that the incidence of cardiac deaths reported for people with Down syndrome was higher than that of the DDS population.

Respiratory Disease

The 2015 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 they had a lower age of death.*

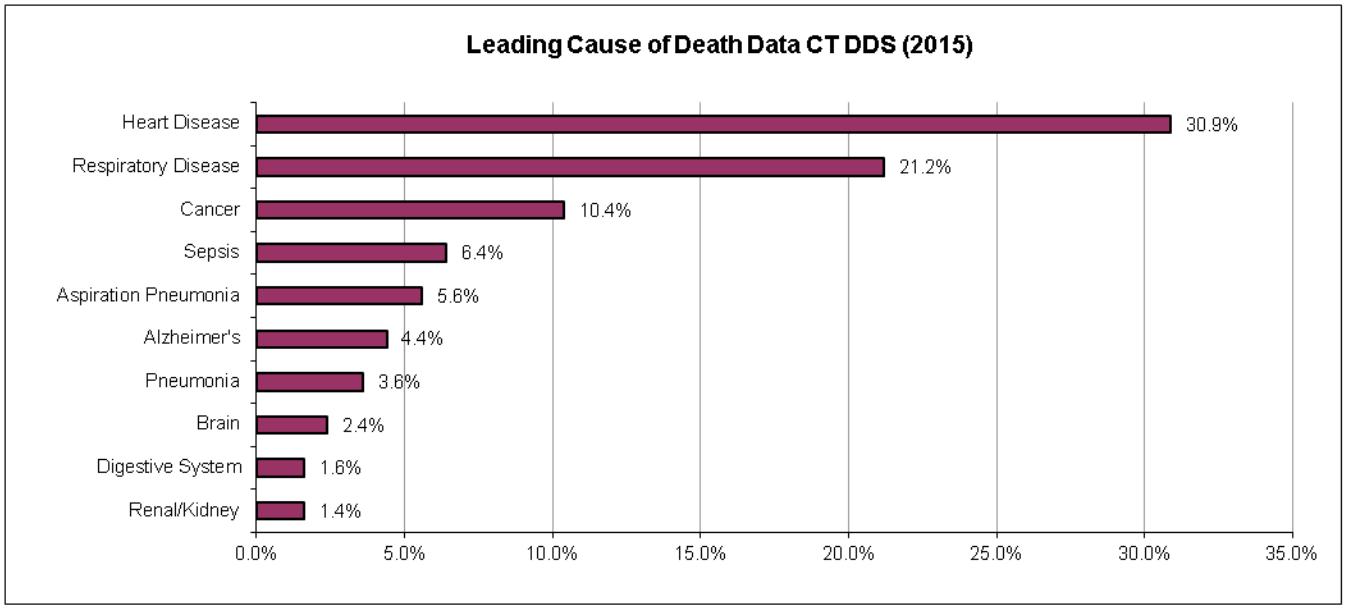
Table 12

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 13	14	16	64.9	71.9	68.6
FY 14	21	20	64.4	64.4	64.4
FY 15	**22**	**19**	**58.4**	**64.6**	**61.3**

* Abridged Reviews Excluded

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 30.5 of all deaths in 2015 which was slightly lower than the deaths caused by cardiac disease (30.9%).

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 the sixth leading cause of death (4%) in the CT DDS leading cause of death statistics. During the mortality review process it was determined that in 21% of the 95 deaths*, the person had a diagnosis of Alzheimer's disease at the time of their death.

* Abridged Reviews excluded

Table 13

Leading Causes of Death CT DDS

Rank	CT DDS 2015	CT DDS 2014	CT DDS 2013	CT DDS 2012	CT DDS 2011	CT DDS 2010	CT DDS 2009
1	**Heart Disease 30.9%**	Heart Disease 29.8%	Heart Disease 28.6%	Heart Disease 21.8%	Heart Disease 22.5%	Heart Disease 28%	Heart Disease 29.9%
2	**Respiratory Disease 21.2%**	Respiratory Disease 25.2%	Respiratory Disease 22.4%	Aspiration Pneumonia 17.1%	Cancer 13.5%	Respiratory Disease 14.6%	Respiratory Disease 13.7%
3	**Cancer 10.4%**	Cancer 11%	Cancer 10%	Respiratory Disease 14.2%	Aspiration Pneumonia 8.2%	Sepsis 12.9%	Pneumonia 12.8%
4	**Sepsis 6.4%**	Aspiration Pneumonia 6.7%	Aspiration Pneumonia 7.9%	Cancer 13.3%	Respiratory Disease 11.1%	Cancer 12.9%	Aspiration Pneumonia 10.3%
5	**Aspiration Pneumonia 4.4%**	Sepsis 5.0%	Sepsis 7.9%	Pneumonia 8.5%	Pneumonia 8.2%	Aspiration Pneumonia 12.3%	Sepsis 9.8%
6	**Alzheimer's Disease 4.4%**	Pneumonia 4.6%	Pneumonia 7.5%	Sepsis 3.3%	Sepsis 5.3%	Pneumonia 7.6%	Cancer 7.4%
7	**Pneumonia 3.6%**	Alzheimer's Disease 2.9%	Alzheimer's Disease 3.7%	Kidney/ Renal 3.3%	Alzheimer's Disease 4.4%	Stroke 4%	Stroke 3.4%
8	**Brain 2.4%**	Stroke 2.5%	Seizures 1.7%	Alzheimer's Disease 1.9%	Digestive System 3.4%	Digestive System 3%	Kidney/ Renal 2.5%
9	**Digestive System 1.6%**	Digestive System 1.7%	Kidney/ Renal 1.2%	Accident 1.9%	Kidney/ Renal 3.4%	Kidney/ Renal 2%	Digestive System 2.5%
10	**Kidney/ Renal 1.6%**	Brain 1.3%	Digestive System 0.8%	Digestive System 1.4%	Stroke 2.4%	Genetic Disorder 2%	Genetic Disorder 2.5%

Based on 2015 Fiscal Year Data

Table 13 compares the top ten leading causes of death with CT DDS data from previous years.* Heart disease remained as the leading cause of death in the CT DDS population. There were some changes in the cause of death rankings compared to the 2014 data. For example: Sepsis has become the forth leading cause of death with aspiration pneumonia falling to the fifth leading cause of death and pneumonia falling to seventh leading cause of death. Brain disorders is the eighth leading cause of death followed by digestive system and kidney/renal tied for ninth and tenth leading 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.

* 2014, 2013 and 2012 data is based on fiscal year data – the previous years' data was based on calendar year data.

Leading Causes of Death for People with Down Syndrome *

Table 14

FY15
Primary Cause of Death/Down Syndrome

Cardiac Arrest	3
Alzheimer's Disease	2
Respiratory Failure	1
Aspiration Pneumonia	1
Pneumonia	1
Sepsis	1
Total	**9**

This year cardiac arrest was the leading cause of death for persons with Down syndrome (33%). (Table 14)

Since 2006 aspiration pneumonia and respiratory failure have accounted for 49% of all deaths for people with Down syndrome. (Table 15)

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 57.9.

Based on the DDS Down syndrome and death data (Table 16) 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 (67%). This data supports other research studies that found increased prevalence of Alzheimer's disease in people with Down syndrome.[4,5]

Table 15

FY 06 - FY 15
Primary Cause of Death/Down Syndrome

Respiratory Failure	68
Cardiac Arrest	63
Aspiration Pneumonia	30
Sepsis	6
Alzheimer's Disease	5
Pneumonia	4
Renal Failure	4
Cancer	3
Anoxic Brain Damage	2
Failure to Thrive	2
Gastrointestinal Hemorrhage	2
Liver Disease	2
Subdural Hematoma	2
Asphyxia	1
CVA	1
Intracranial Hemorrhage	1
Lymphoma	1
Mucus Plug	1
Seizure Disorder	1
Total	**199**

Table 16

Average Age of Death Data

	2014	2015
Down syndrome:	60.6	**57.9**
Down syndrome & Alzheimer's disease:	59.3	**60.4**
Down syndrome without Alzheimer's disease:	62.2	**53.1**

* Does not include accidental deaths

Analysis of Cancer Deaths

Table 17

FY 15
Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Pancreas	4	74.9
Colon	3	64.2
Leukemia	3	80.9
Lymphoma	3	44.8
Liver	2	65.7
Lung	2	51
Stomach	2	52.9
Bladder	1	38.4
Breast	1	47
Cholangio	1	65.4
Endometrial	1	53.4
Esophagus	1	59.5
Unknown Origin	1	84.8
Urethra	1	64.4
TOTAL	**26**	**61.7**

In FY 2015 cancer was the third leading cause of death for people supported by the CT DDS

For FY 15 the distribution of cancers in men were: Leukemia (3), colon (2), lung (2), lymphoma (2), esophagus (1), pancreas (1), stomach (1), urethra (1).

The FY 15 distribution of cancers in women were: Pancreas (3), liver (2), bladder (1), breast (1), cholangio (1), colon (1), endometrial (1), non-Hodgkins lymphoma (1), stomach (1), unknown origin (1).

The average age of death for all cancer victims (62.4 years) was above the average age of death for all CT DDS deaths (61.1 years).

The rate of death due to cancer in the CT DDS population (1.6/1000) is lower than the rate in the state of CT and nationally.[13,14]

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

Table 18

FY 06 - FY15
Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	30	57.1
Pancreas	21	71.8
Breast	18	51.6
Colorectal	17	64.6
Stomach	12	51.4
Leukemia	11	74.6
Brain	9	55
Renal	9	67.9
Bladder	8	53.3
Ovary	8	67.3
Endometrial	7	59.4
Liver	7	62.3
Unknown Origin	7	73.6
Esophagus	6	60.2
Lymphoma non-Hodgkins	6	57.2
Myeloma	6	55.9
Prostate	5	79.7
Lymphoma	4	47.4
Cholagio	3	66.8
Gallbladder	2	57.2
Larynx	2	51.5
Neck	2	64
Parotid Gland	2	54.2
Thyroid	2	64.5
Vulva	2	58.6
Adeno Carcinoma	1	46
Angiosarcoma	1	53
Aplastic Anemia	1	23
Bone	1	80.2
Cervical	1	66.3
Chrondroblastic	1	36.7
Duodenum	1	90.4
Endocrine/Adrenal Gland	1	61
Ethmoid Sinus	1	48
Lymphatic/Hemotopoietic	1	73
Nasopharyngeal	1	63.2
Oral/pharynx	1	68
Testicular	1	63
Trachael/Bronchus	1	81
Urethra	1	64.4
TOTAL	**221**	**62.7**

SECTION SIX: BENCHMARKS

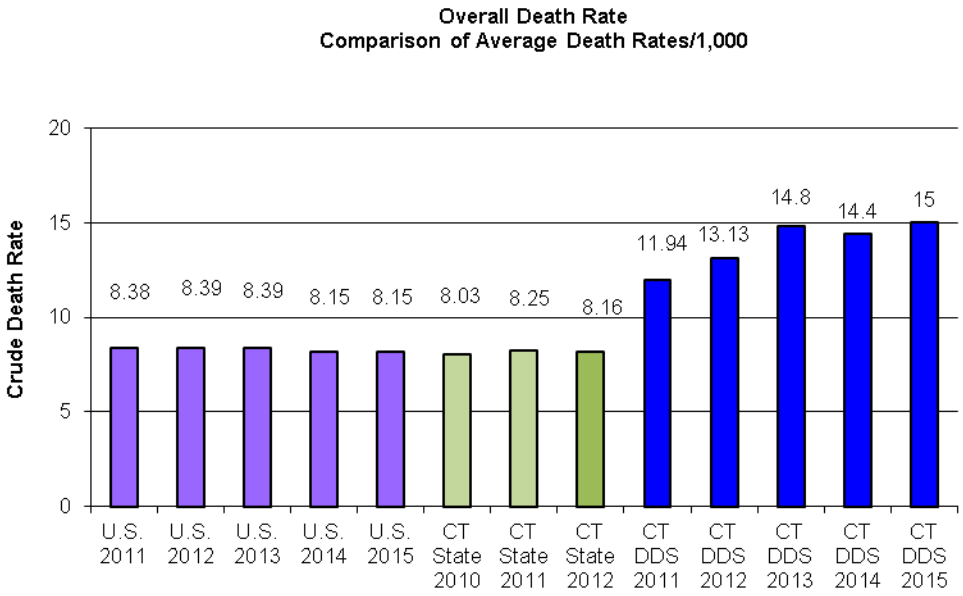
Mortality Rate Comparison

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.

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 15/1000 is higher than the rate of 8.16 in Connecticut (2012) and the rate of 8.15 in the general United States population (2015).[1,13] This would be expected due to the many health and functional complications associated with intellectual disabilities.

Figure 24



While comparison of CT DDS mortality data with benchmarks from the general population (state and national) are of interest, the comparison should be made with caution recognizing there are differences in population characteristics, adjusted age and statistical methods etc.[1,13,14]

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 19

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

(based on calendar year)

Rank	US 2013	US 2012	State CT 2013	State CT 2012	**CT DDS 2015**	CT DDS 2014	CT DDS 2013	CT DDS 2012
1	Heart Disease 23.5%	Heart Disease 23.6%	Heart Disease 23.9%	Heart Disease 24.8%	**Heart Disease 27.4%**	Heart Disease 29.8%	Heart Disease 25.6%	Heart Disease 28.2%
2	Cancer 22.5%	Cancer 22.9%	Cancer 22.3%	Cancer 22.8%	**Respiratory Disease 24.9%**	Respiratory Disease 25.2%	Respiratory Disease 17.8%	Respiratory Disease 18.1%
3	Respiratory Disease 5.7%	Respiratory Disease 5.6%	Accidents 5.3%	Respiratory Disease 4.7%	**Cancer 7.9%**	Cancer 10.5%	Cancer 12%	Aspiration Pneumonia 12.5%
4	Stroke 5%	Stroke 5.1%	Stroke 4.5%	Accidents 4.7%	**Sepsis 6.6%**	Aspiration Pneumonia 6.7%	Aspiration Pneumonia 9.7%	Cancer 10.7%
5	Accidents 5%	Accidents 5%	Respiratory Disease 4.5%	Stroke 4.3%	**Aspiration Pneumonia 6.2%**	Sepsis 5%	Pneumonia 8.9%	Sepsis 5.6%
6	Alzheimer's Disease 3.3%	Alzheimer's Disease 3.3%	Alzheimer's Disease 2.8%	Alzheimer's Disease 2.9%	**Pneumonia 4.1%**	Pneumonia 4.6%	Sepsis 6.9%	Pneumonia 4.6%
7	Diabetes Mellitus 2.9%	Diabetes Mellitus 2.9	Diabetes Mellitus 2.2%	Diabetes Mellitus 2.2%	**Alzheimer's Disease 3.3%**	Alzheimer's Disease 2.9%	Alzheimer's Disease 3.9%	Accidents 1.9%
8	Influenza/ Pneumonia 2.2%	Influenza/ Pneumonia 2.0%	Influenza/ Pneumonia 2.0%	Nephritis/ Kidney 1.9%	**Stroke 2.5%**	Stroke 2.5	Digestive System 1.2%	Digestive System 1.4%
9	Nephritis/ Kidney 1.8%	Nephritis/ Kidney 1.8%	Sepsis 1.9%	Influenze/ Pneumonia 1.9%	**Seizure Disorder 2.1%**	Digestive System 1.7%	Genetic Disorder 1.2%	Kidney/ Renal 1.4%
10	Intential Self-Harm 1.6	Intentional Self-Harm 1.6%	Nephritis/ Kidney 1.9%	Sepsis 1.9%	**Kidney/ Renal 1.7%**	Brain 1.3%	Accident 1.2%	Stroke 1.4%

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

Table 19 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. [1,13,14]

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 27.4% versus 23.9% in the CT general population and 23.5% nationally.

Respiratory Diseases: Is the second leading cause of death in the CT DDS population (24.9%). This category which includes influenza causes death in the CT DDS population at a rate 4 times the rates reported in the CT and national vital statistics data base (4.5%) and (5.7%) respectively .

Cancer: Is the third leading cause of death in the CT DDS population responsible for 9.9% of deaths. Unlike the other mentioned leading causes of death, cancer in DDS occurs less frequently in the CT DDS population than in the CT (22.3%) and national (22.5) general populations.

Septicemia: Originating from various sites and usually acute in onset is the forth leading cause of death in the CT DDS population resulting in 6.6% of deaths . Septicemia is the ninth leading cause of death in the CT general population (1.9%) and not reflected in the national vital statistics as one of the top ten leading causes of death.

Aspiration Pneumonia: Is the fifth leading cause of death in the DDS population (6.2%) 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 4.1% of CT DDS deaths compared to <3% in the 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.

Alzheimer's Disease: In calendar year 2015 the percent of deaths resulting from Alzheimer's Disease in the CT DDS system (3.3%) was the seventh leading causes of death and was higher than the percentage of Alzheimer's Disease deaths in the CT general population (2.8%) and the same as in the 2013 US population (3.3%).

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 added medical 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 gastro esophageal 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/DD population.[2,9]

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 2015. 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 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 20

Mortality Case Review Summary (FY 2015)

*Death Reviewed by Regional Committees **	*Cases Closed at Regional Level **	*Cases Closed at Regional Level ***	*Cases Referred and Reviewed by IMRB ***	*QA Cases Closed by Region ***	*Total Cases Reviewed by IMRB ***
149	135 (76%)	70 (62%)	36 (32%)	7 (10%)	43 (38%)

The table above, provides a summary of all deaths reviewed by the CT DDS Mortality Review Committees. Seventy-six percent of the 149 cases reviewed were closed by the local regional mortality committees. The regional committees referred 43 mortality cases to the state Independent Mortality Review Board for further review. The reasons for the case referrals are noted in Table 21 (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 10% of cases closed by regional mortality committees.

* Includes Abridged Reviews.

** Does not include Abridged Reviews

Table 21

Cases Referred to IMRB (36)	
Medical/Health Care	23
Pending Abuse/Neglect Investigations	7
Post Mortem Examination	5
Unexplained Death	1

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

I. Findings and Quality Enhancement Action

Mortality Review Finding	DDS Quality Enhancement Action
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.	• The department chaired a workgroup of private providers, nurse consulting agencies and DDs providers and created a Healthcare Coordination Fact Sheet to better facilitate the enhanced implementation of the waiver service.
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.	• Offered a number of health promotion oriented educational opportunities to providers • Implemented a Healthy Living Community of Practice Subcommittee focused on identify and enhancing health and wellness supports for families
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.	• Connecticut DDS will continue its **protocol** for the monitoring of all contemplated or existing **Do Not Resuscitate** (DNR) orders for all adjudicated individuals treated under the direction of the Commissioner of the Department of Developmental Services (DDS).
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.	• Reinforced commitment to ensuring individuals remain in their homes and communities regardless of their ability or age represented in Health services collaboration in the **Aging Conference, facilitating a Hospice end of Life Panel presentation** • Individuals are supported to **die with dignity where they have lived**. This policy and philosophical position applies to all individuals for whom the department bears direct or oversight responsibility for medical care.
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 continues to **foster partnerships** with Department of Public Health, PH, Office of Protection and Advocacy and other health care systems and facilities.
Fall risk has been identified as a consistent area of concern through our mortality review process	• The department's **Fall Prevention Protocol**, is currently under consideration for modification based on this year's fall data.

II. General Community Awareness Findings

These are general findings that we believe the community at large should be aware of.

1. Individuals living in their own home or receiving individualized supports benefit from health education and training that focuses on health promotion and disease prevention.
2. 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.
3. As individuals age, 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, but must be embraced through creative solutions and strengthened partnerships.
4. The aging Down syndrome population requires specialized and comprehensive supports.
5. CT DDS has sustained quality in the area of water temperature safety. There have been no mortality events related to scalding. The anti scalding devices continue to assist in ensuring maximum water temperature safety practices.

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

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 US Census Bureau, *Statistical Abstract of the United States 2012*

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

13 CDC National Center for Health Statistics, Division of Vital Statistics; *Deaths Final Data ,* 2007, 2008, 2009, 2010, 2011, 2012, 2013.

14 State of Connecticut Department of Public Health, Health Care Quality, *Health Statistics & Analysis ,* 2007, 2008, 2009, 2010, 2011.

15 American Human Development Project, *Measure of America 2012-2014. Mapping Risks and Resilience.*

16 CDC National Center for Disease Control and Prevention, *Heart Disease*.

17 American Heart Association, *Statistical Fact Sheet 2013 Update*.

The next Annual Mortality Report UPDATE will be issued in March of 2017

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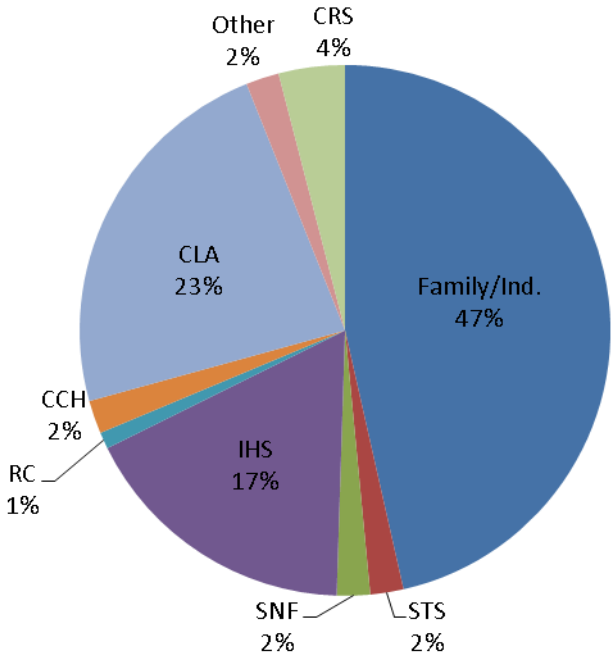
APPENDIX A

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, 2015 **16,328** individuals with intellectual disability were being supported by the department.

Overview of DDS Population

Percentage by Setting



Almost half of the people served by CT DDS live at home with their family. Almost one third receive support services provided in community living arrangements (CLAs), community companion homes (CCH), regional centers (RC) and a campus program, Southbury Training School (STS). Approximately 19% of the DDS population receive individualized home supports (IHS) or continuous residential supports (CRS). The remainder (4%) 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

	2015	2015	2014	2014	2014-2015
Type of Support	# of Consumers	Percent	# of Consumers	Percent	% Change
Family	7,573	46%	7,706	48%	-2%
CLA (Group Home)	3,738	23%	3,742	23%	-0.1%
IHS, CRS	3,530	22%	3,231	20%	9%
Training School	291	2%	335	2%	-13%
Other	300	2%	311	2%	-33%
Community Companion Home (CCH)	376	2%	388	2%	-3%
SNF	343	2%	375	2%	8%
Regional Center (RC)	177	1%	186	1%	-5%
TOTAL	**16,328**	**100%**	**16,274**	**100%**	

DDS Resident Population by Age
2010 - 2015

	2015	2014	2013	2012	2011	2010
Children (0-19)	3,249	3,308	3,226	3,281	3,322	3,456
Adults (20 - over)	13,079	12,966	12,811	12,577	12,318	12,039
TOTAL ALL AGES	**16,328**	**16,274**	**16,037**	**15,858**	**15,640**	**15,495**

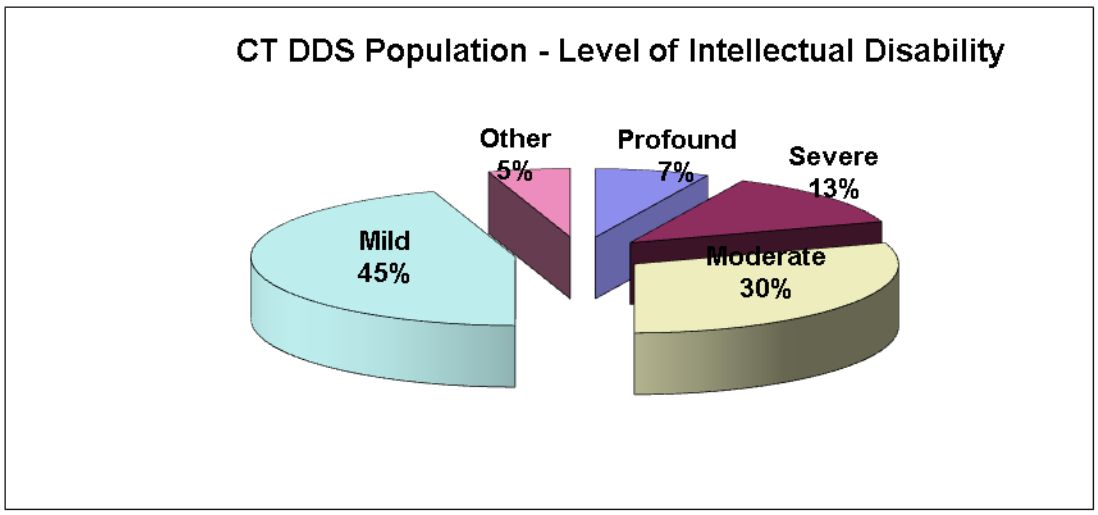
Adults (55 - over)	**3,420**	**3,214**	**3,121**	**3,019**	**2,893**	**2,779**
Adults (65 - over)	**1,401**	**1,307**	**1,243**	**1,156**	**1,105**	**1,050**

APPENDIX C

Percent Population by Age Ranges

FY 2015

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,249	20%
Age 20-29	3,827	23%
Age 30-39	2,460	15%
Age 40-49	2,078	13%
Age 50-59	2,445	15%
Age 60-69	1,507	9%
Age 70-79	567	4%
Age 80+	195	1%
TOTAL	**16,328**	**100%**



APPENDIX D

AGE CATEGORY AND RESIDENCE
FY 2015

Restype	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
CLA (Group Home)	67	3,084	587	3,738
CRS (Continuous Residential Suports)	16	660	47	723
CCH (Community Companion Home)	2	306	68	376
Family Home/Independent Living	2,627	4,816	130	7,573
IHS (Individualized Home Suports)	424	2,201	182	2,807
RC (Regional Center)	0	164	13	177
SNF (Skilled Nursing Facility)	0	153	190	343
STS (Southbury Training School)	0	134	157	291
Other	113	160	27	300
TOTAL	**3,249**	**11,678**	**1,401**	**16,328**
PERCENT	**20%**	**72%**	**8%**	**100%**

Consumers Age 19 - 64 Years By Program Type

CLA	81%
CRS	91%
CCH	81%
Family/Independent	64%
IHS	78%
RC	93%
SNF	45%
STS	46%

Consumers over the Age of 65 By Program Type

CLA	16%
CRS	7%
CCH	18%
Family/Independent	2%
IHS	6%
RC	7%
SNF	55%
STS	54%