

Mortality

ANNUAL REPORT

FY 2019

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

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CT DDS Mortality Report

SECTION ONE OF THIS REPORT:

CT DDS MORTALITY REVIEW PROCESS

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

SECTION TWO OF THIS REPORT:

DEMOGRAPHICS 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 were reported during the 2019 fiscal year (July 1, 2018 - June 30, 2019) including death rates and life expectancy.

SECTION THREE OF THIS REPORT:

CT DDS MORTALITY REVIEW PROCESS DATA OVERVIEW

This section includes information and analysis of data generated for the 169 deaths reviewed by the DDS nurse investigators, regional mortality review committees and Independent Mortality Review Board (IMRB) for the period of July 1, 2018 – June 30, 2019.

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, 2018 to June 30, 2019.
Data in this report was obtained from the CT DDS Database system.

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Executive Summary 2019 Report

- There were 319 deaths resulting in a crude **mortality rate of 18.3/1000**
- The strongest predictors of mortality were age, mobility status, and the need for special assistance when eating
- The average age of death for individuals receiving services from DDS was 59.1 years
- There was a progressive increase in mortality starting early in the people receiving services from DDS' 50's
- People receiving services from DDS 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 most common cause of death in the CT DDS population (27.9%)
- Aspiration pneumonia/pneumonia accounted for 4.4% of all deaths
- The percentage of deaths related to cancer in the DDS population (8.5%) was lower than the national (21.3%) and state (21.1%)^{13,17}
- Accidental deaths continue to occur at a rate below that of the general state and national population^{13,17}
- The average age of death for people with Down syndrome was 60.5 years. Cardiac Arrest was the leading cause of death for people with Down syndrome
- Hospice supports were provided in 43% of the reviewed deaths which allowed individuals to remain in their home residences in the final stages of a terminal illness

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CT DDS MORTALITY REVIEW

An important component of the quality and risk management systems present within DDS involves the analysis and review of deaths to identify important patterns and trends that may help increase knowledge about risk factors and provide information to guide systems enhancements. Consequently, CT DDS continues to embrace a planned organization wide approach to design performance measurement, analysis and improvement by collecting information pertaining to the deaths of all individuals served by the department. The CT DDS mortality review system has proven to be a valuable quality assurance mechanism providing information to trigger corrective action and reduce future risk.

The CT DDS mortality review process provides a retrospective analysis

THAT

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

AND GENERATES

- changes in policy 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 Abuse Investigation Division (AID) whether or not abuse or neglect is suspected or contributed to the individual's death.

The CT DDS death reporting requirements are a structured process that ensures that all deaths are immediately reported to the department within 24 hours of notification.

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SECTION ONE: CT DDS MORTALITY REVIEW PROCESS

CRITICAL COMPONENTS OF THE CT DDS MORTALITY PROCESS:

- Uniform death reporting system
- Collect standard information from every death report
- 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
- Publicly report and document mortality information (Annual CT DDS Mortality Report)

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Section One Continued

Connecticut law (which comprises statutes and executive order) currently requires CT DDS to review the death of anyone for whom it has direct or oversight responsibility for medical care. The review must cover the events, overall care, quality of life issues, and medical care preceding the death to assure that a vigorous and objective evaluation and review of the circumstances surrounding untimely deaths takes place. 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 postmortem examination. Individual was not a Class Member and did not reside in an 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
- Postmortem 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 AID 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.

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Section One Continued

Nurse Investigators Medical Desk Review

In addition to the regional mortality review committees and the Independent Mortality Review Board, the DDS death reporting and mortality review process requires that all deaths are reported to a **Nurse Investigator (NI)** who is assigned to the DDS Investigations Division. The Nurse Investigator conducts a **Medical Desk Review (MDR)**, an abbreviated mortality review to determine the need for an 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

Independent Mortality Review Board Membership

Members of the Independent Mortality Review Board (IMRB) are appointed by the CT DDS Commissioner 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 Department of Public Health representative
- 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, 2018 – JUNE 30, 2019) NUMBER OF DEATHS REPORTED = 319 *

Overall Mortality Rate

During the 12 month time period between July 1, 2018 and June 30, 2019 a total of **319** deaths of individuals supported by CT DDS were reported **resulting in a mortality rate of 18.3** (Figure 1 & 2 below).

Figure 1

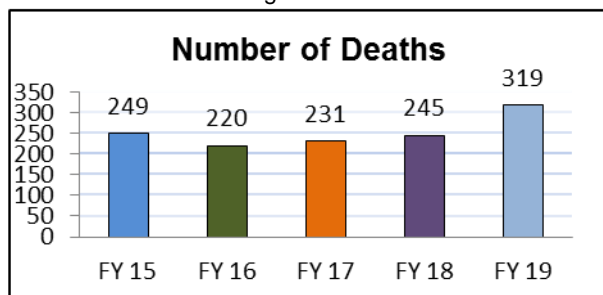
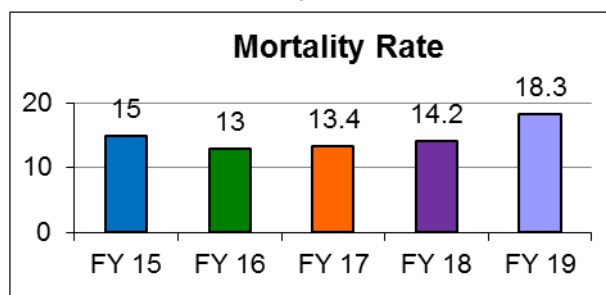


Figure 2



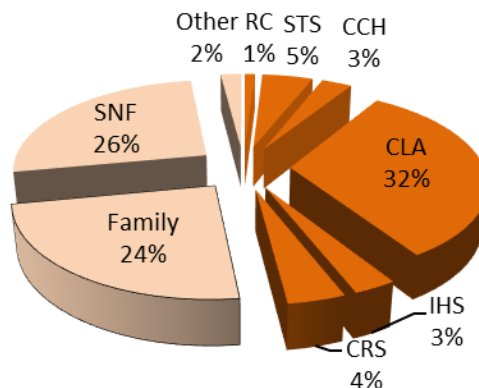
Mortality and Residence

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

Figure 3

Residence at Time of Death

	% Deaths	% DDS population
CLA	32	22
SNF	26	2
Family	24	50
STS	5	1
CRS	4	4
IHS	3	17
CCH	3	2
Other	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, HOSP = hospital.

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

* 35 individuals died in previous years, but their deaths were reported in FY2019.

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Figure 4

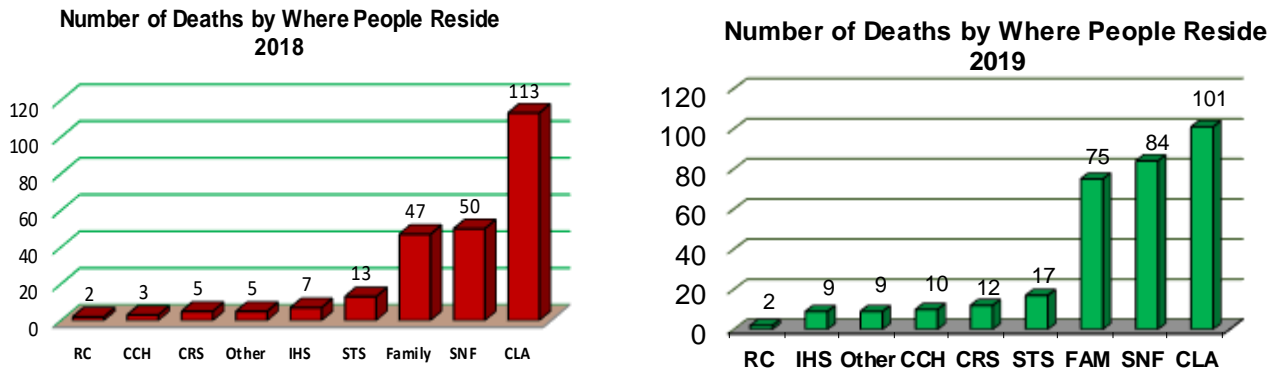


Figure 4 (above) depicts the actual number of deaths by where people reside. Similar to last year, the greatest number of deaths occurred in CLAs followed by skilled nursing facilities, family homes and STS. Of note: Sixty-six (66%) of the people DDS supports reside in family homes or in their own home with individualized supports, 22% in group homes (CLA's) and only 2% in skilled nursing facilities.

Figure 5

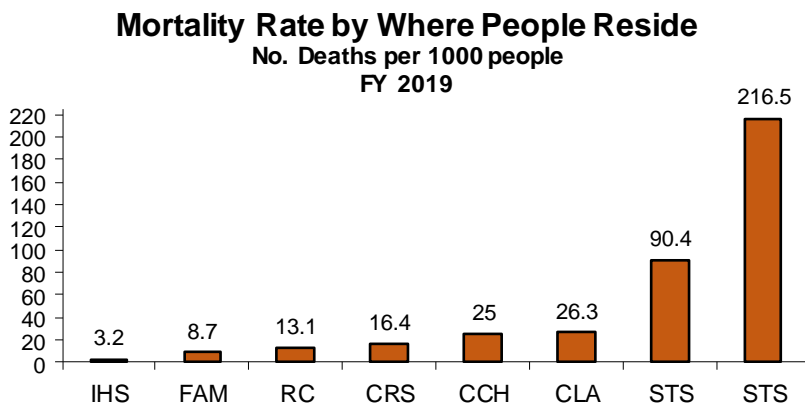


Figure 5 (left) depicts the number of people who died for every 1,000 people served by type of support.

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

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Mortality and Residence Definitions

Family Home: People who live with their family without significant residential DDS supports or independently represent 50% of the DDS population. However, in FY 2019 75 deaths (23.5% of all deaths) occurred in a family home with an associated mortality rate of 8.7. All but three CT DDS deaths of children were for those who lived with their families. Thirty-six of the 75 people died in a hospital or hospital emergency department.

CLA: These settings serve people with varying levels of intellectual disability who require 24-hour supervision for their health and direct care supports. In FY 2019, 101 or 31.7% of all deaths occurred in CLA's compared to 46% in FY 2018. Seventy of the 101 people died in a hospital, hospital emergency department, hospice or SNF.

CCH: There were 10 reported deaths in the community companion homes compared with 3 reported deaths in FY 2018. The CCH mortality rate of 25 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 3.1% of the reported deaths. Six of the 10 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. Twelve or 3.8% of reported deaths occurred in this environment. Seven of the 12 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 2.8% of reported deaths occurred in this environment compared with 3% last year. Six of the 9 people died in the hospital, hospital emergency department, hospice or SNF.

STS: The higher mortality rate of 90.4 is not surprising as this larger campus setting serves a population of older adults (average age of 70 years). Thirteen deaths were reported at STS this past fiscal year representing 5.3% of all DDS deaths. Last year the Training School accounted for 5% of all deaths. Twelve of the 13 people died in a hospital or hospital emergency department.

RC: One percent of DDS individuals reside at DDS regional centers. Two RC residents died in FY 2019 accounting for .3% 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 reside in a skilled nursing facility. This older (average age 65.3 years) and medically fragile population accounted for 84 or 26.3% of all reported deaths. People living in licensed nursing facilities had the highest mortality rate 216.5 per thousand. Eight percent (8.4%) of all DDS consumers over 60 years of age live in a skilled nursing facility. It is important to note that 19 of the 84 people died in a hospital, hospital emergency 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 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.

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Mortality and Gender

Table 1

Mortality Rate by Gender - 2019

GENDER	Total Number of Individuals Served by DDS	% of Individuals Served by DDS	Number of Deaths	% of Deaths	Rate (Deaths Per 1000 people)
Men	10,155	59%	172	54%	17
Women	6,972	41%	147	46%	20
Total	17,127	100%	319	100%	18.3

In FY 2019 both the number of males and females who died within the DDS was similar to the gender distribution of those people served by the department (Table 1).

Figure 6

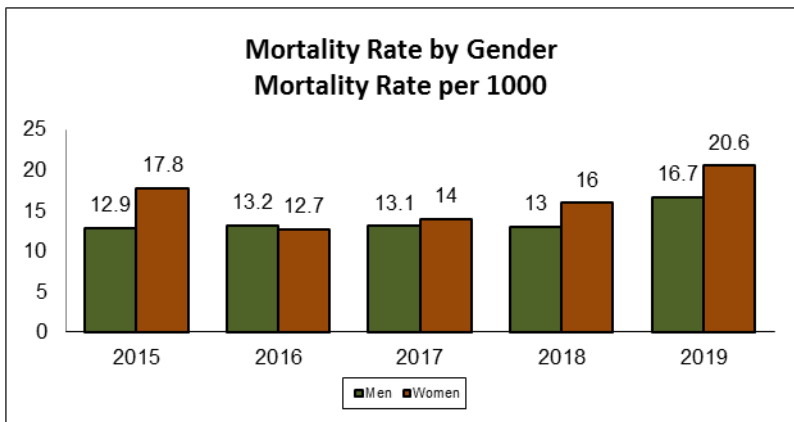
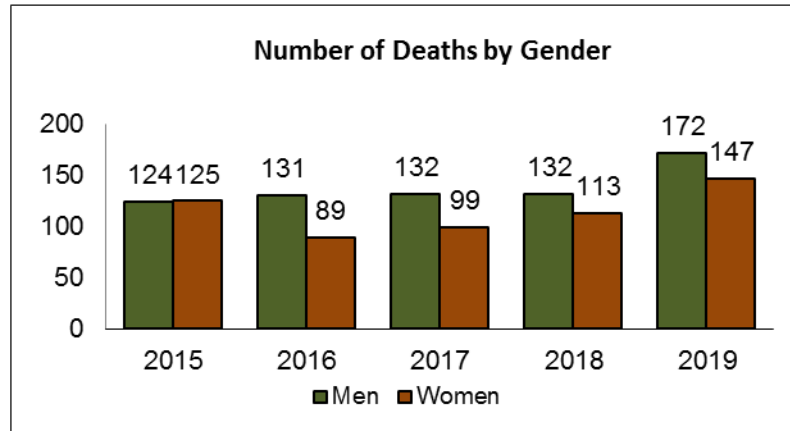


Figure 7

This year the number of men's deaths was higher than the number of women's deaths and women had a higher mortality rate. These results are similar to the general population of deaths by gender in the U.S. (<https://www.cdc.gov/nchs/data/databriefs/db395-H.pdf>)

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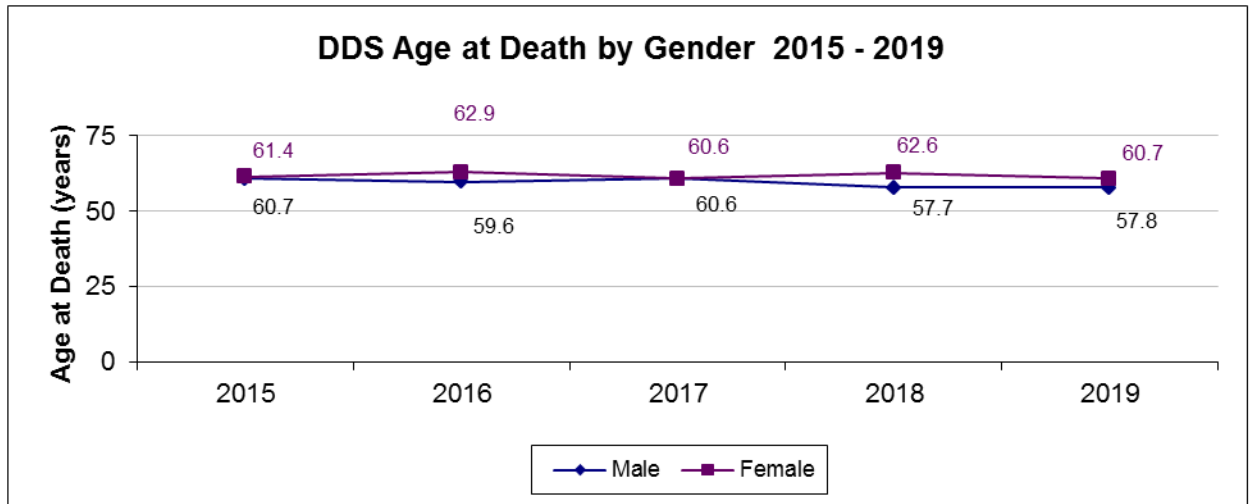
Mortality and Age

Table 2

Age of Death by Fiscal Year

Year	Men	Women	Average Age
FY2019	57.8	60.7	59.1
FY2018	57.7	62.6	60
FY2017	60.6	60.6	60.6
FY2016	59.6	62.9	60.9
FY2015	60.7	61.4	61.1

Figure 8



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Figure 9

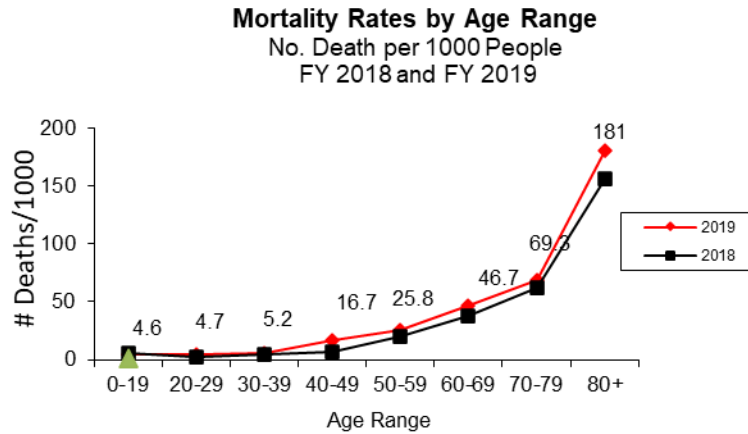


Figure 9 shows the relationship between age and mortality. As expected, when age increases mortality rates also increase. There is an increase in the mortality rate that begins early in the individual's fifties that continues to increase with advancing age. This finding is consistent with previous CT DDS mortality rate by age data.

Table 3

Mortality Age Range Distribution Data
FY 2019

AGE RANGE	# OF DEATHS	MORTALITY RATE
Age 0-19	15	4.6
Age 20-29	20	4.7
Age 30-39	15	5.2
Age 40-49	33	16.7
Age 50-59	61	25.8
Age 60-69	81	46.7
Age 70-79	54	69.3
Age 80+	40	181
TOTAL	319	

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

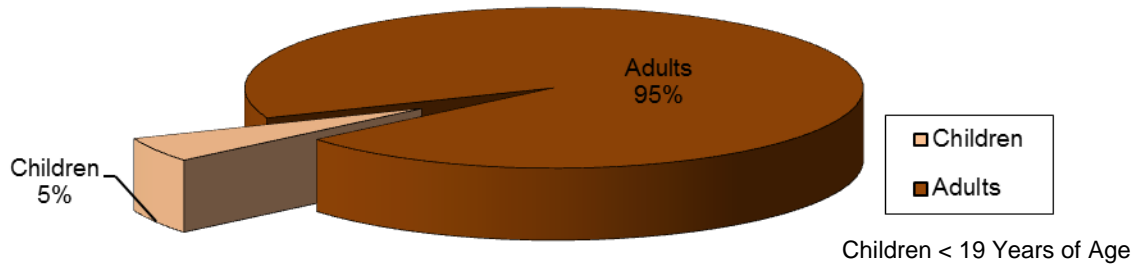
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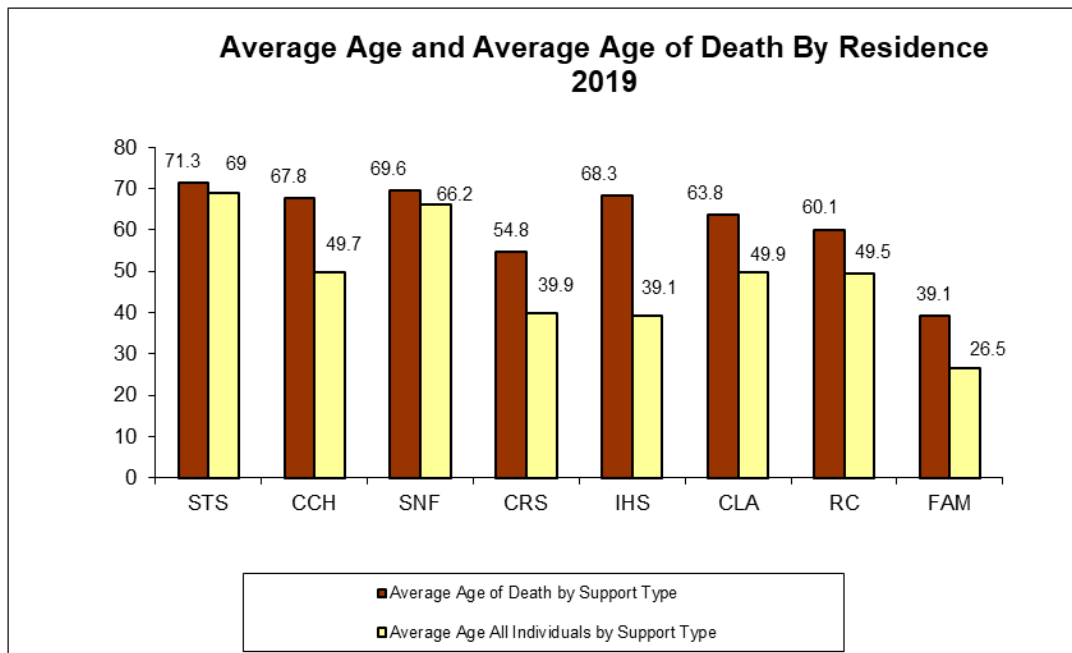
Figure 10

Deaths of Children and Adults



In FY19 fifteen children 's deaths were reported. Twelve of the children lived at home with their family , two children resided in a hospital and one child resided in a CLA.

Figure 11



The average age of death in the CT DDS population is 59.1. 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 for that residence type. Excluding children the average age of death in the CT DDS population is 61.4 years.

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

IMPORTANT PLEASE NOTE:

THE INFORMATION PRESENTED IN THIS SECTION SUMMARIZES ONLY THOSE DEATHS THAT WERE REVIEWED BY THE NURSE INVESTIGATORS, REGIONAL COMMITTEE AND/OR STATE INDEPENDENT MORTALITY REVIEW BOARD IN FY 2019 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 = 169 cases (of total 319 deaths)

** 83 of the 169 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-seven individuals received hospice services: 65% lived in a community living arrangement or received continuous residential supports, 22% lived in a training school, 11% lived in a nursing home, and 3% lived in community companion home. The average age of death for people receiving hospice services was 67.

Thirty-seven people (43% of all reviewed deaths) received hospice supports *

Autopsies/Postmortem 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 postmortem examinations performed:	8 (4.7% of reviewed deaths)
Number of postmortem examination performed by CT OCME:	8

* Does not include Abridged Reviews

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Predictability

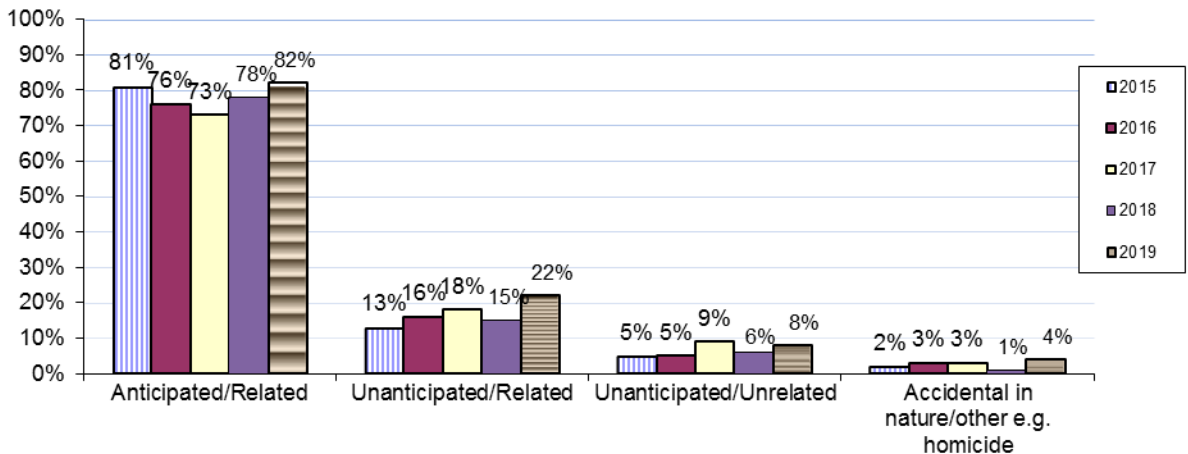
Analysis of the mortality review data indicates a relationship between an individual’s pre-existing diagnosed medical condition(s) and his/her immediate cause of death (see Figure 12 below). In ninety-five percent of all deaths, an individual’s immediate cause of death was related to a known or previously 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:	82%
❖ Death was unanticipated but related to a preexisting diagnosis:	13%
❖ Death was anticipated but unrelated to a preexisting diagnosis:	1%
❖ Death was unanticipated and unrelated to a preexisting diagnosis:	4%
❖ Death was accidental/homicidal/undetermined in nature	4%

Of the 7 deaths that were accidental/homicidal/undetermined in nature, 4 were included in the “unanticipated and unrelated to a preexisting diagnosis” percentage, 1 was included in the “anticipated and related to a preexisting diagnosis” percentage, and 1 was included in the “anticipated but unrelated to a preexisting diagnosis” percentage.

Figure 12

Predictability of Death 2015 - 2019



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 95% of the time.

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Section Three Continued

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 169 cases reviewed during FY 19, 162 (96%) were classified as **due to natural causes**. Five cases were determined to be the result of an accident, one case was a homicide and one case was undetermined.

Table 4

FY 19 Manner of Death

<i>Manner of Death</i>	<i>No.</i>	<i>Percent</i>
<i>Natural</i>	<i>162</i>	<i>96%</i>
<i>Accident</i>	<i>5</i>	<i>3%</i>
<i>Homicide</i>	<i>1</i>	<i>.5%</i>
<i>Undetermined</i>	<i>1</i>	<i>.5%</i>
<i>Total</i>	<i>169</i>	<i>100%</i>

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

Fall	(4)
Car Accident	(1)

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Section Three Continued

UNANTICIPATED/UNRELATED DEATHS:

Of the 7 deaths that were unanticipated and not related to a known condition 1 was due to cardiac arrest, 1 was due to hypertension and atherosclerotic cardiovascular disease, 1 was due to saddle pulmonary embolism, 1 was due to blunt injuries of head torso and extremities, 1 was due to right frontotemporal parietal subdural hematoma, 1 was due to sharp force injury of head neck torso and extremities and 1 was due to complications of blunt head injury

ACCIDENTAL DEATHS

Falls were the reason for 3 of the 4 accidental deaths. A car accident was the reason for 1 accidental death.

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 169 mortality cases reviewed in FY 2019

137 cases had a DNR order in place
96% of the DNR orders were formally reviewed by DDS
99% 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 all but one 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 which fail to comply with the DDS DNR review process in accordance with CGS17a-238(g).

OF NOTE: ninety percent (90%) of DDS consumers residing in *skilled nursing facilities* had a DNR order in place at the time of their death.

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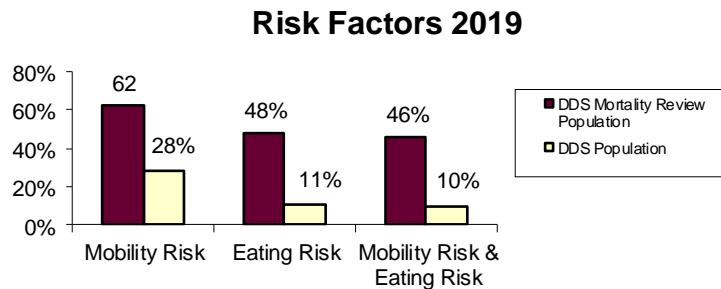
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Section Three Continued

Risk Factors

Mobility impairments and dysphagia/swallowing risks are well known risk indicators that place individuals at significantly higher risk of morbidity and mortality. CT DDS mortality data has consistently demonstrated that people who require the need for special assistance when eating and those who cannot ambulate without assistance have a greater mortality rate. Therefore, the CT DDS mortality review process carefully analyzes the presence or absence of these two risk indicators. Once again, the FY 2019 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 2019, 53 (62%) of the deceased did not ambulate independently.

<p>* MORTALITY REVIEW POPULATION ONLY</p> <p>62% did not ambulate independently 48% did not eat independently</p> <p><small>* Does not include Abridged Reviews</small></p>	<p>* TOTAL DDS POPULATION</p> <p>28% do not ambulate independently 11% do not eat independently</p>
--	--

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

	2015	2016	2017	2018	2019	Percent of Population
Mild	2.6	3	1.9	3.1	3	48
Moderate	3.9	3.8	3.3	3.7	4.2	29
Severe	12	8.9	4.3	4.3	5.3	12
Profound	22.9	32.6	31.2	17.5	25.5	6

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.

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Section Three Continued

Investigations

Department of Developmental Services / Abuse Investigations Division

CT DDS must report all deaths to the Abuse Investigations Division (AID) which determines if abuse or neglect was involved in the death.

Of the 169 mortality cases reviewed by DDS, 11 cases were investigated by the AID when abuse or neglect was suspected to have contributed to the person's death. In several cases, deaths that were investigated by the AID were also referred to and investigated by the CT Department of Public Health.

<u>Disposition of DDS/AID Cases</u>	
<i>Neglect substantiated</i>	3
<i>Neglect not substantiated</i>	1
<i>Cases still open</i>	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 2019 eight (8) mortality cases were referred by the regional mortality committee or IMRB to the **State of Connecticut Department of Public Health** (DPH) Health Systems Regulation Division for further investigation by the Facilities and/or the Practitioner and Licensing Section.

Disposition of DPH Investigations

<u>Practitioner Division Referrals– (0)</u>
cases open – 0
cases closed - 0
citations, violations found - 0

<u>Facility Division Investigations – (8)</u>
cases open – 6
cases closed - 2
citations, violations found – 1

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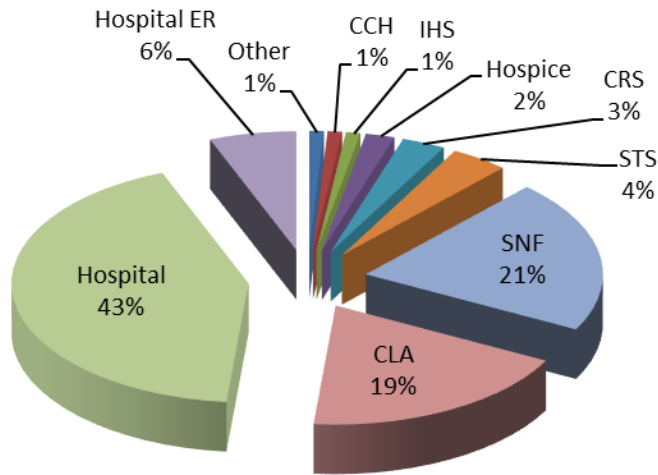
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Pronouncement of Death (Location at Time of Death)

Figure 14 below depicts the location where death was pronounced.

Figure 14



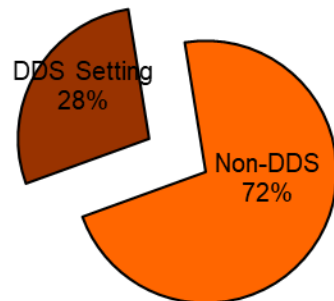
KEY: Location of Death

- 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 2019 Mortality Reviews

As can be seen in Figure 15 to the right, 72% of all deaths reviewed by the mortality review committee during FY 19 occurred outside of a DDS operated, licensed or funded residential setting. This represents no change in the percent of people dying outside of a DDS setting compared to FY 18 (72%).



SUMMARY OF MORTALITY DATA ***for the 169 deaths that were reviewed in FY19***

- **100%** of required cases were reviewed **Regionally**.
- **42%** of all cases were reviewed by the **IMRB**.
- **43%** of the individuals received **Hospice** supports prior to their deaths. *
- **5%** of the individuals had **Autopsies** performed.
- **95%** of all deaths were **Related** to an existing medical diagnosis.
- **81%** of the individuals had a **DNR** order in place at the time of death.
- **48%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance). *
- **96%** of the deaths reviewed were due to **Natural** causes.
- **4** deaths that were classified as **Accidental**.
- **7** referrals to **Department of Public Health**.
- **11** referrals to **Abuse Investigation Division**.
- **3** **Neglect** cases were substantiated by **Abuse Investigation Division**

* Does not include Abridged Reviews

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SECTION FOUR: MORTALITY TRENDS CT DDS

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

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

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

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Figure 16

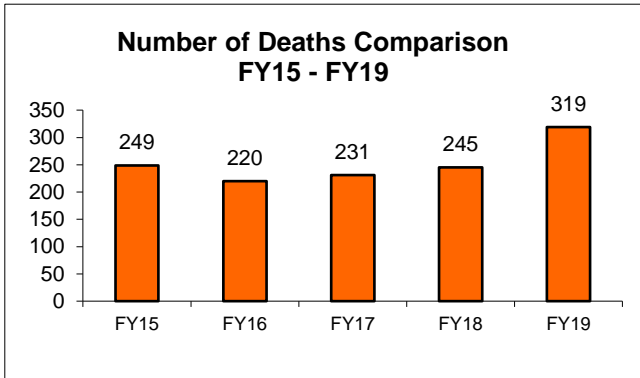
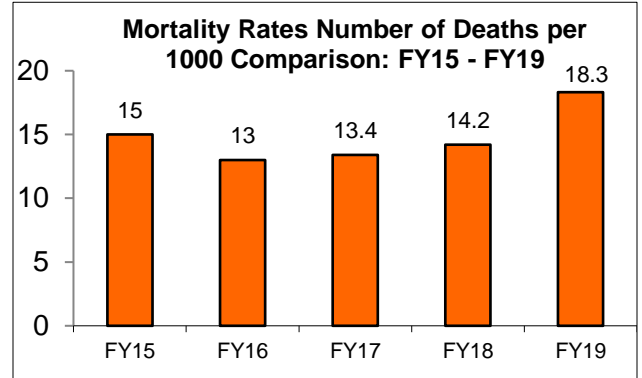


Figure 17



Figures 16 and 17 depict on an annual basis the number of deaths and the average death rate for FY 2015 – 2019 within the population served by DDS. The death rate average over the five year period of time is 14.8/1000 people.

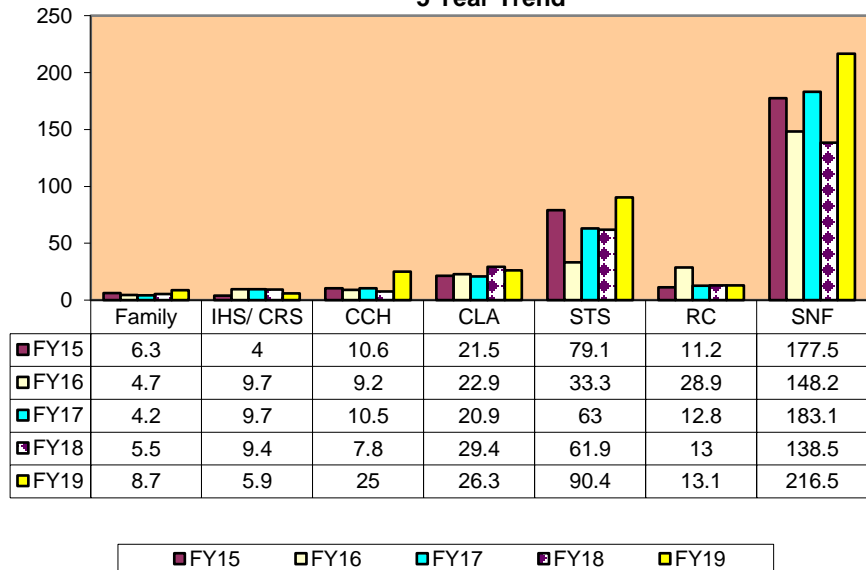
Figure 18 (below) compares the rate of death (the number of deaths per 1000 persons served) for the past five (5) fiscal years by type of support.

Historically, individuals residing in residences that require more intensive nursing supports and medical oversight due to their compromised health status (SNF, campus) 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.

Mortality Rate by Where People Live
5 Year Trend

Figure 18



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Table 6

**Mortality and Gender
(FY2015 - 2019)**

Year	# Deaths Men	# Deaths Women	Mortality Rate Men	Mortality Rate Women
FY15	124	125	12.9	17.8
FY16	131	89	13.2	12.7
FY17	132	99	13.1	14
FY18	132	113	13	16
FY19	172	147	16.7	20.6

With one exception (FY15), over the past five years more men died annually than women. However, (except in FY 16) the mortality rate for women exceeded the mortality rate for men.

Figure 19

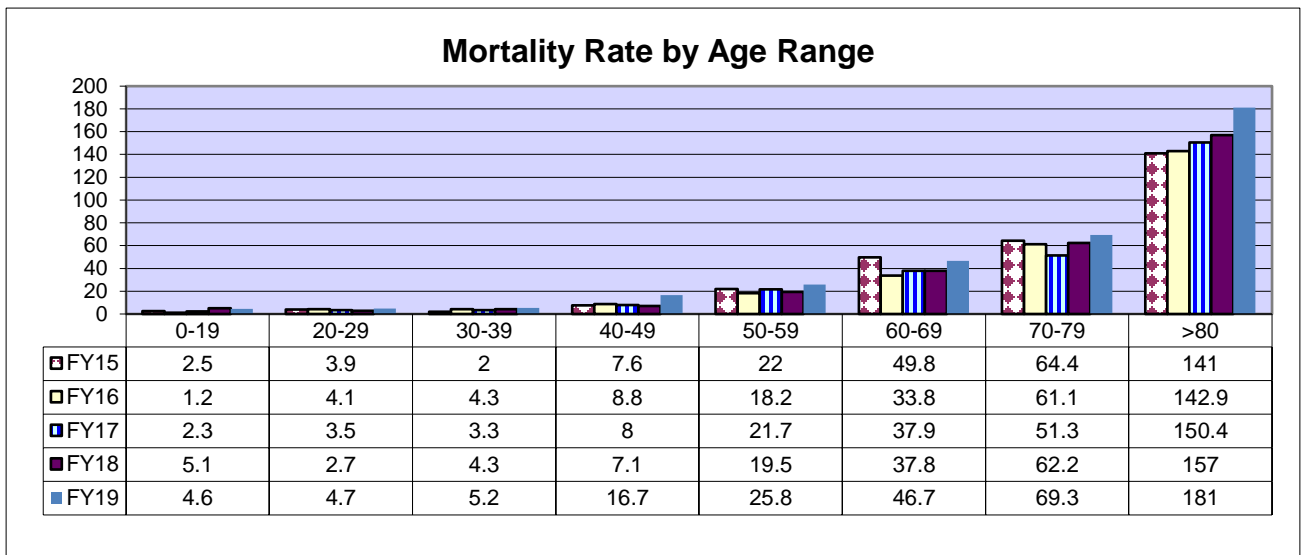


Figure 19 (above) illustrates mortality rate by age range. The data over the past five fiscal years reveals a consistent pattern of increasing mortality rates with each age range. The mortality rates increase markedly for adults who are in their 50s. The data also demonstrates that within each age range there is some fluctuation in mortality rates from one year to the next.

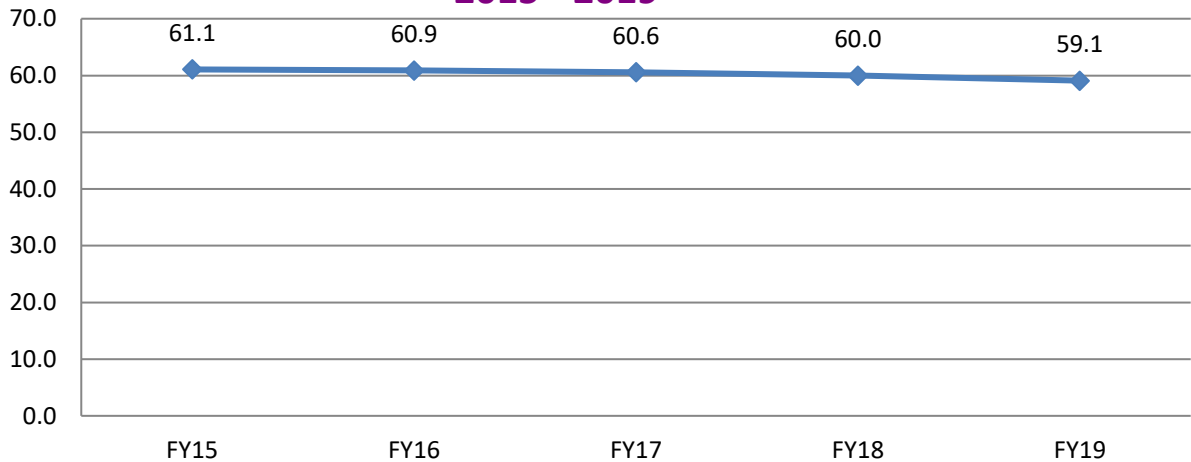
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Figure 20

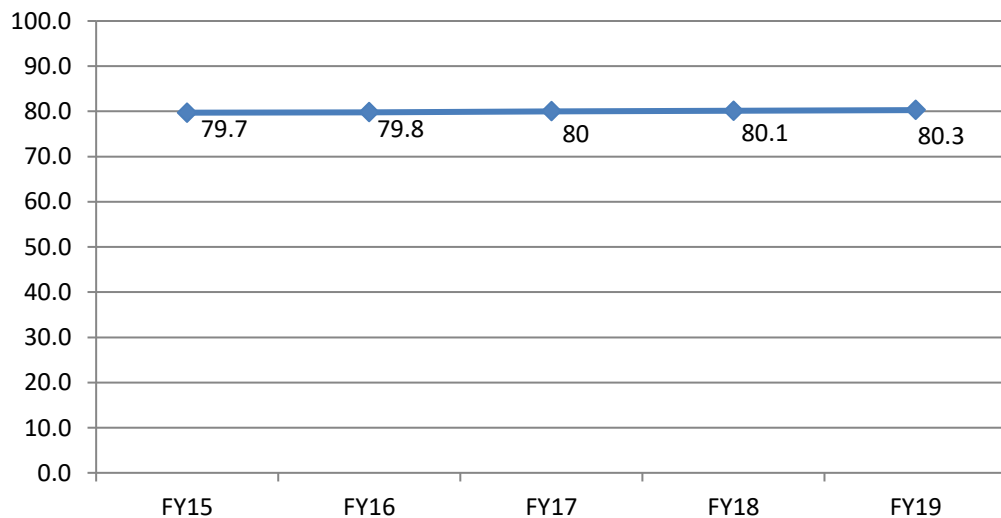
CT DDS Average Age of Death 2015 - 2019



For the last five fiscal years the average age of death was within the individual's late fifties/early sixties. This is lower than the national life expectancy (80.3)¹ and the Connecticut life expectancy (80.8).¹⁵

Figure 21

National Life Expectancy 2015 - 2019



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Section Four Continued

Table 7

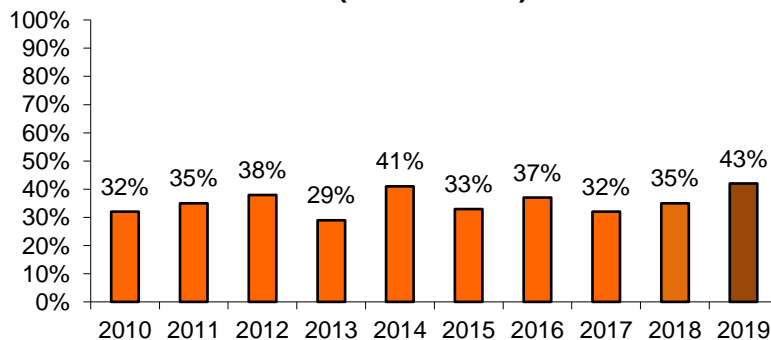
RESIDENCE AT TIME OF DEATH TRENDS (2010 - 2019)

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
SNF	28%	31%	32%	34%	26%	30%	27%	33%	20%	26%
CLA	33%	29%	33%	34%	36%	33%	40%	35%	46%	32%
Family	18%	19%	12%	14%	19%	19%	17%	18%	19%	23%
STS	14%	11%	11%	8%	8%	10%	4%	6%	5%	5%
IHS/CRS	2%	5%	6%	5%	7%	5%	6%	4%	5%	7%
RC	2%	1%	1%	2%	2%	1%	2%	1%	1%	1%
CCH	2%	3%	3%	1%	1%	2%	2%	2%	1%	3%
Other	1%	1%	2%	2%	1%	0%	2%	1%	3%	3%

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

Percent of Hospice Supports (2010 - 2019)



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.

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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 2019 fiscal year)

27.9%	<i>of deaths were due to</i>	Heart Disease	<i>including</i>	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
22.3%	<i>of deaths were due to</i>	Respiratory Disease	<i>including</i>	Respiratory Failure, Pulmonary Embolism, Influenza, Multi-System Failure, COPD, ARDS, Asthma
8.5%	<i>of deaths were due to</i>	Cancer	<i>including</i>	Wide variety of primary origin sites
4.4%	<i>of deaths were due to</i>	Aspiration Pneumonia	<i>including</i>	Aspiration Pneumonia
3.4%	<i>of deaths were due to</i>	Sepsis	<i>including</i>	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
2.5%	<i>of deaths were due to</i>	Pneumonia	<i>including</i>	Pneumonia
2.2%	<i>of deaths were due to</i>	Alzheimer's Disease	<i>including</i>	Dementia
2.2%	<i>of deaths were due to</i>	Asphyxia	<i>including</i>	Choking, Drowning, Smoke Inhalation
2.2%	<i>of deaths were due to</i>	Brain Disorders	<i>including</i>	TBI, Subdural Hematoma
1.9%	<i>of deaths were due to</i>	Digestive System	<i>including</i>	Intestinal Obstruction, Volvulus

The 10 leading causes of death in 2019 (Table 8) are noted above. Heart disease remains the leading cause of death for the DDS population with respiratory disease, cancer, aspiration pneumonia, and sepsis rounding out the top five.

Heart Disease

According to the Centers for Disease Control¹⁶ "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.

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Section Five Continued

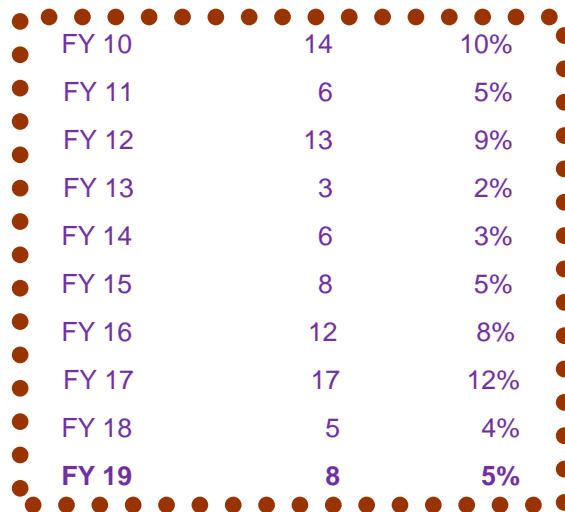
Table 9

Location Where Death Pronounced (FY 2010 - 2019)

Location	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	10 Year Total
Hospital	61	49	56	67	87	70	73	61	49	72	645
SNF	18	21	33	36	34	24	15	31	31	35	278
CLA	12	15	21	22	24	26	31	24	32	32	239
Hospital ER	12	9	10	17	16	11	12	11	10	10	118
STS	13	13	13	8	5	5	9	4	2	6	78
RC	1	1	0	2	4	1	3	3	0	0	15
IHS	3	3	5	2	1	2	1	3	3	2	25
Hospice	0	5	7	7	2	7	9	8	7	4	56
Other	1	1	2	1	5	3	5	1	4	8	31

Table 10

Number of Autopsies (FY 2010 – FY 2019)



As noted in Table 10 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 postmortems by family members. The number of postmortem examinations during FY 2019 increased from FY 2018 (5% vs 4%).

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Table 11 provides detail of the cardiac deaths that were reviewed as part of the DDS mortality review process.* In FY 19 more men died as a result of heart disease than women. When considering cardiac/heart deaths, women died later in life.

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 15	18	13	62.7	67	64.5
FY 16	23	18	62	69.7	65.4
FY 17	16	13	64.8	63.2	64.1
FY 18	16	12	69.4	73.6	71.2
FY 19	22	18	63.2	67.3	65

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 82% of people who die of coronary heart disease are 65 or older¹¹ as compared with only 54% of individuals in the CT DDS population. Of the remaining cardiac related deaths in the DDS population group, 61% percent of the cardiac deaths occurred between the ages of 50 - 65.

Respiratory Disease

The 2019 cause of death data demonstrates the impact of respiratory disease in the CT DDS population.

More men died as a result of respiratory disease/aspiration pneumonia/pneumonia than women and men had a lower average 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 15	22	19	58.4	64.6	61.3
FY 16	20	14	66.9	69.3	67.9
FY 17	21	10	61.4	62.3	61.4
FY 18	19	6	61.3	77.8	65.3
FY 19	16	13	66.5	69.2	67.7

* Abridged Reviews Excluded

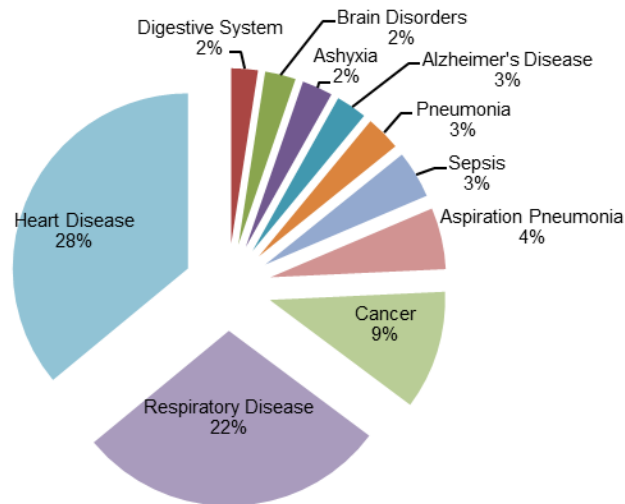
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Figure 23

Leading Cause of Death Data CT DDS (2019)



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 29.2% of all deaths in 2019 which was higher than the deaths caused by cardiac disease (27.9%).

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 seventh leading cause of death (2.2%) in the CT DDS leading cause of death. During the mortality review process, it was determined that in 25% of the 85 deaths*, the person had a diagnosis of Alzheimer's disease at the time of their death.

* Abridged Reviews excluded

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Table 13

Leading Causes of Death CT DDS

Rank	CT DDS 2015	CT DDS 2016	CT DDS 2017	CT DDS 2018	CT DDS 2019
1	Heart Disease 30.9%	Heart Disease 31.4%	Heart Disease 25.9%	Heart Disease 32.2%	Heart Disease 27.9%
2	Respiratory Disease 21.2%	Respiratory Disease 25.5%	Respiratory Disease 23.8%	Respiratory Disease 20.8%	Respiratory Disease 22.3%
3	Cancer 10.4%	Cancer 6.8%	Cancer 8.2%	Cancer 6.1%	Cancer 8.5%
4	Sepsis 6.4%	Pneumonia 5.9%	Alzheimer's Disease 5.2%	Aspiration Pneumonia 4.5%	Aspiration Pneumonia 4.4%
5	Aspiration Pneumonia 4.4%	Sepsis 5%	Pneumonia 4.8%	Brain 3.7%	Sepsis 3.4%
6	Alzheimer's Disease 4.4%	Aspiration Pneumonia 4.5%	Sepsis 4.8%	Sepsis 3.7%	Pneumonia 2.5%
7	Pneumonia 3.6%	Alzheimer's Disease 3.2%	Brain 2.6%	Alzheimer's Disease 3.3%	Alzheimer's Disease 2.2%
8	Brain 2.4%	Brain 3.2%	Kidney/ Renal 2.2%	Pneumonia 2%	Asphyxia 2%
9	Digestive System 1.6%	Kidney/ Renal 1.8%	Aspiration Pneumonia 1.7%	Digestive System 1.6%	Brain 2.2
10	Kidney/ Renal 1.6%	Stroke 1.8%	Digestive System 1.3%	Kidney/ Renal 1.6%	Digestive System 1.9%

Based on 2019 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 2018 data. For example: Sepsis has become the fifth leading cause of death with pneumonia as the sixth leading cause of death. Alzheimer's disease remained as the seventh leading cause of death tied with asphyxia and brain disorders. Digestive system fell to the tenth leading cause of death.

Respiratory disease, aspiration pneumonia and pneumonia as a cause of death once again represented almost 1/3 of all CT DDS deaths.

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Leading Causes of Death for People with Down Syndrome *

Table 14

FY19
Primary Cause of Death/Down Syndrome

Cardiac Arrest	5
Respiratory Failure	4
Pneumonia	1
Blunt Impact Injury	1
Total	11

This year cardiac arrest was the leading cause of death for persons with Down syndrome (45%). (Table 14)

Since 2006 aspiration pneumonia and respiratory failure have accounted for 48% 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.^{5,6,7,8,12} The average age of death for people with Down syndrome in the CT DDS system is 60.5.

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 (55%). 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 19
Primary Cause of Death/Down Syndrome

Cardiac Arrest	80
Respiratory Failure	78
Aspiration Pneumonia	32
Alzheimer's Disease	6
Sepsis	6
Pneumonia	5
Renal Failure	4
Cancer	3
Anoxic Brain Damage	2
Asphyxia	2
Failure to Thrive	2
Gastrointestinal Hemorrhage	2
Liver Disease	2
Subdural Hematoma	2
Blunt Impact Injury	2
CVA	1
Dehydration	1
Intracranial Hemorrhage	1
Lymphoma	1
Mucus Plug	1
Seizure Disorder	1
Total	234

Table 16

Average Age of Death Data

	2018	2019
Down syndrome:	63.1	60.5
Down syndrome & Alzheimer's disease:	64.2	61.3
Down syndrome without Alzheimer's disease:	60	59.6

* Does not include abridged reviews

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Analysis of Cancer Deaths

Table 17

FY 19 Analysis of Cancer Deaths		
Primary Site	Number of Deaths	Average Age at Death
Unknown Origin	4	55.9
Brain	3	63.5
Breast	3	55.8
Lung	3	61.8
Colon	2	74.7
Esophagus	2	59.1
Liver	2	76.5
Bladder	1	60.1
Cholangio	1	52.1
Gallbladder	1	49.8
Myeloma	1	69.1
Pancreas	1	46.2
Ovarian	1	64.6
Rectal	1	60.1
Uterine	1	61.3
TOTAL	27	61.1

In FY 2019 cancer was the third leading cause of death for people supported by the CT DDS

For FY 19 the distribution of cancers in men were: Unknown origin (3), esophagus (2), lung (2), bladder (1), brain (1), colon (1), liver (1), myeloma (1), pancreas (1)

The FY 19 distribution of cancers in women were: Breast (3), brain (2), cholangio (1), colon (1), gallbladder (1), liver (1), lung (1), ovary (1), rectal (1), unknown origin (1), uterine (1)

The average age of death for all cancer victims (61.1 years) was above the average age of death for all CT DDS deaths (59.1 years).

The rate of death due to cancer in the CT DDS population (0.8/1000) is lower than the rate in the state of CT and nationally.^{13,17}

Table 18

FY 06 - FY19 Analysis of Cancer Deaths	
Primary Site	Number of Deaths
Lung	36
Breast	26
Pancreas	24
Colorectal	22
Leukemia	17
Stomach	15
Brain	14
Unknown Origin	14
Liver	13
Esophagus	12
Ovary	11
Renal	11
Bladder	10
Myeloma	9
Endometrial	8
Lymphoma non-Hodgkins	6
Prostate	6
Cholangio	5
Gallbladder	4
Lymphoma	4
Angiosarcoma	3
Larynx	2
Neck	2
Parotid Gland	2
Thyroid	2
Vulva	2
Adeno Carcinoma	1
Aplastic Anemia	1
Bone	1
Cervical	1
Chondroblastic	1
Duodenum	1
Endocrine/Adrenal Gland	1
Ethmoid Sinus	1
Lymphatic/Hematopoietic	1
Mesothelioma	1
Nasopharyngeal	1
Oral/pharynx	1
Squamous	1
Testicular	1
Tracheal/Bronchus	1
Urethra	1
TOTAL	296

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SECTION SIX: BENCHMARKS

Mortality Rate Comparison

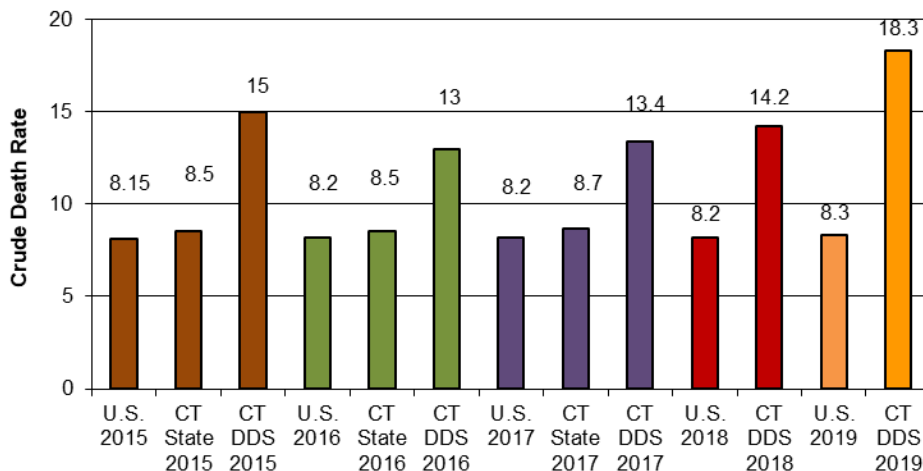
Benchmarks are standards by which similar items can be compared and allow the reader to place findings in context. Thus, the use of benchmarks including comparative data from other populations is an important mechanism for helping to understand analytical findings and trend data such as those presented in this report.

There are few relative data sets from other state agencies available for use in comparing mortality of persons with ID/DD. 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 18.3/1000 is higher than the rate of 8.7 in Connecticut general population (2017) and the rate of 8.3 in the general United States population (2019).^{1,14} This would be expected due to the many health and functional complications associated with intellectual disabilities.

Figure 24

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, the comparison should be made with caution recognizing there are differences in population characteristics, adjusted age and statistical methods etc.^{1,14}

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.

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Table 19

Comparison Leading Causes of Death National, State of CT and CT DDS (based on calendar year)

Rank	US 2015	State CT 2015	CT DDS 2015	US 2016	State CT 2016	CT DDS 2016	US 2017	State CT 2017	CT DDS 2017	CT DDS 2018	CT DDS 2019
1	Heart Disease 23.4%	Heart Disease 23.6%	Heart Disease 27.4%	Heart Disease 23.1%	Heart Disease 23.1%	Heart Disease 31.4%	Heart Disease 23%	Heart Disease 22.8%	Heart Disease 30.2%	Heart Disease 27.8%	Heart Disease 28%
2	Cancer 22%	Cancer 21.8%	Respiratory Disease 24.9%	Cancer 21.8%	Cancer 21.9%	Respiratory Disease 25.5%	Cancer 21.3%	Cancer 21.1%	Respiratory Disease 22.3%	Respiratory Disease 19.1%	Respiratory Disease 21.1
3	Respiratory Disease 5.7%	Accidents 5.9%	Cancer 7.9%	Accidents 5.9%	Accidents 6.5%	Cancer 6.8%	Accidents 6.0%	Accidents 6.6%	Cancer 7.4%	Cancer 4.3%	Cancer 8%
4	Accidents 5.4%	Stroke 4.5%	Sepsis 6.6%	Respiratory Disease 5.6%	Respiratory Disease 4.7%	Pneumonia 5.9%	Respiratory Disease 5.7%	Respiratory Disease 4.7%	Alzheimer's Disease 4.5%	Aspiration Pneumonia 4.3%	Aspiration Pneumonia 5.1%
5	Stroke 5.2%	Respiratory Disease 4.5%	Aspiration Pneumonia 6.2%	Stroke 5.2%	Stroke 4.2%	Sepsis 5%	Stroke 5.2%	Stroke 4.5%	Pneumonia 3.3%	Sepsis 4%	Pneumonia 4.7%
6	Alzheimer's Disease 4.1%	Alzheimer's Disease 3.2%	Pneumonia 4.1%	Alzheimer's Disease 4.2%	Alzheimer's Disease 3.4%	Aspiration Pneumonia 4.5%	Alzheimer's Disease 4.3%	Alzheimer's Disease 3.4%	Sepsis 3.3%	Brain 3.6%	Alzheimer's Disease 3.6%
7	Diabetes Mellitus 2.9%	Influenza/ Pneumonia 2.2%	Alzheimer's Disease 6.2%	Diabetes Mellitus 2.9%	Diabetes Mellitus 2.3%	Alzheimer's Disease 3.2%	Diabetes Mellitus 3%	Diabetes Mellitus 2.2%	Brain 3%	Alzheimer's Disease 2.2%	Sepsis 2.9%
8	Influenza/ Pneumonia 2.1%	Diabetes Mellitus 2.1%	Stroke 2.5%	Influenza/ Pneumonia 1.9%	Sepsis 1.9%	Brain 3.2%	Influenza/ Pneumonia 2%	Influenza/ Pneumonia 2.1%	Aspiration Pneumonia 2.1%	Pneumonia 2.2%	Kidney/ Renal 1.8%
9	Kidney/ Renal 1.8%	Sepsis 2.1%	Seizure Disorder 2.1%	Kidney/ Renal 1.8%	Influenza/ Pneumonia 1.9%	Kidney/ Renal 1.8%	Kidney/ Renal 1.8%	Sepsis 2%	Digestive System 2.1%	Digestive System 1.8%	Asphyxia 1.1%
10	Intentional Self-Harm 1.6%	Kidney/ Renal 1.9%	Kidney/ Renal 1.7%	Intentional Self-Harm 1.6%	Kidney/ Renal 1.9%	Stroke 1.8%	Intentional Self-Harm 1.7%	Kidney/ Renal 1.8%	Kidney/ Renal 2.1%	Blunt Injury 1.4%	Seizure Disorder 1.1%

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Section Six Continued

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 data for the State of Connecticut (2017), and United States (2017). Year over year data comparisons continue to demonstrate consistency in the leading causes of death data.^{13,17}

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 greater in the DDS population at 28% versus 22.8% in the CT general population and 23% nationally.

Respiratory Diseases Is the second leading cause of death in the CT DDS population (21.1%). This category which includes influenza causes death in the CT DDS population at a rate over 3 times the rates reported in the CT and national vital statistics data base (4.7%) and (5.7%) respectively .

Cancer Is the third leading cause of death in the CT DDS population responsible for 8% of deaths. Unlike the other mentioned leading causes of death, cancer occurs less frequently in the CT DDS population than in the CT (21.1%) and national (21.3) general populations.

Aspiration Pneumonia is the fourth leading cause of death in the DDS population (5.1%) 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 fifth leading cause of death accounting for 4.7% of CT DDS deaths compared to 2% in the national and CT general 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 2019 the percent of deaths resulting from Alzheimer's disease in the CT DDS system (3.6%) was the sixth leading cause of death and was slightly higher than the percentage of Alzheimer's disease deaths in the 2017 CT general population (3.4%) and lower than in the 2017 US population (4.3%).

Septicemia Originating from various sites and usually acute in onset is the seventh leading cause of death in the CT DDS population resulting in 2.9% of deaths . Septicemia is the ninth leading cause of death in the CT general population (2%) and not reflected in the national vital statistics as one of the top ten leading causes of death.

Renal/Kidney Disease is the eighth leading cause of death in the DDS population. Renal/Kidney Disease accounts for 1.8% of deaths in the DDS population and also accounts for 1.8% of deaths in both the State of CT population and the national population.

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 2019. 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.

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SECTION SEVEN: SUMMARY MORTALITY CASE REVIEW FINDINGS

The CT DDS mortality review process has evolved into a powerful quality assurance system for ensuring the delivery of optimal health care oversight and services in the CT DDS. The regional and state recommendations regarding health care oversight and standardization of health care practices for professional and non-professional staff have improved basic health care services and mitigated health related risk. The impact of mortality findings and recommendations has been observed within DDS and has extended to community based health care providers including practitioners in private practice licensed nursing facilities, acute care hospitals, hospice providers, health and dental clinics and other state agencies.

Table 20

Mortality Case Review Summary (FY 2019)

<i>Death Reviewed by Regional Committees *</i>	<i>Cases Closed at Regional Level *</i>	<i>Cases Closed at Regional Level **</i>	<i>Cases Referred and Reviewed by IMRB **</i>	<i>QA Cases Closed by Region **</i>	<i>Total Cases Reviewed by IMRB **</i>
169	137 (81%)	54 (62%)	32 (38%)	4 (7%)	36 (42%)

The table above, provides a summary of all deaths reviewed by the CT DDS Mortality Review Committees. Eighty-one percent of the 169 cases reviewed were closed by the local regional mortality committees. The regional committees referred 32 mortality cases to the state IMRB 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 7% of cases closed by regional mortality committees.

* Includes Abridged Reviews.

** Does not include Abridged Reviews

Table 21

Cases Referred to IMRB (32)	
Pending Abuse/Neglect Investigation	10
Medical/Health Care	7
postmortem Examination	6
Pending DPH Investigation	4
Nursing Concerns	4
Sudden Death	1

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Section Seven Continued

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.	<ul style="list-style-type: none"> • 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.	<ul style="list-style-type: none"> • 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.	<ul style="list-style-type: none"> • 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.	<ul style="list-style-type: none"> • Reinforced commitment to ensuring individuals remain in their homes and communities regardless of their ability or age represented in Health Services collaboration in the Agging 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.	<ul style="list-style-type: none"> • DDS continues to foster partnerships with Department of Public Health, DPH, 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	<ul style="list-style-type: none"> • The department's Fall Prevention Protocol, is currently under consideration for modification based on this year's fall data.

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Section Seven Continued

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. postmortem 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.

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The next Annual Mortality Report UPDATE will be issued in March of 2021

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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**

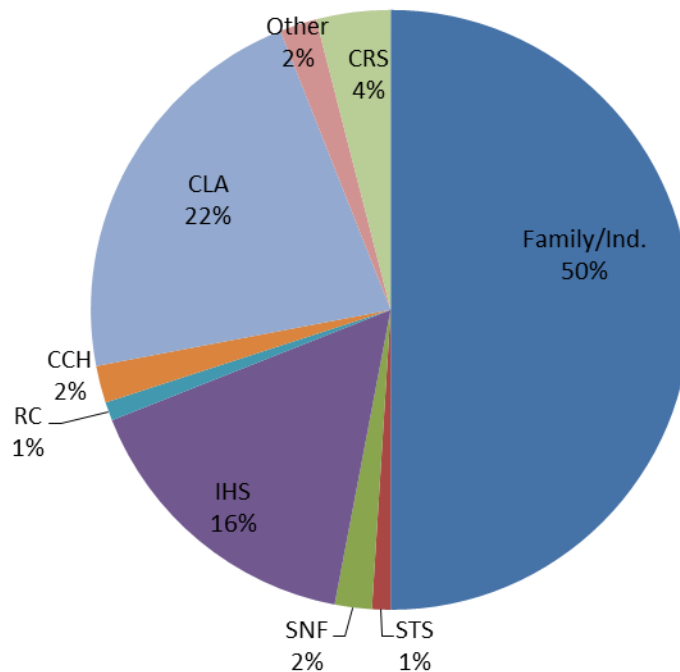
**Appendix D: Age Category and Residence
Consumers by Program Type**

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, 2019 **17,127** individuals with intellectual disability were being supported by the department.

Overview of DDS Population Percentage by Setting



Half of the people served by CT DDS live at home with their family with no ongoing in home supports. One quarter 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 20% 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

Type of Support	2018		2019		2017-2018
	# of Consumers	Percent	# of Consumers	Percent	% Change
Family	8,519	50%	8,510	50%	-1%
CLA (Group Home)	3,728	22%	3,746	22%	1%
IHS, CRS	3,446	20%	3,565	21%	3%
Training School	197	1%	173	1%	-12%
Other	305	2%	288	2%	-6%
Community Companion Home (CCH)	380	2%	390	2%	3%
SNF	311	2%	304	2%	-2%
Regional Center (RC)	152	1%	151	1%	-1%
TOTAL	17,038	100%	17,127	100%	

DDS Resident Population by Age 2015 - 2019

	2015	2016	2017	2018	2019
Children (0-19)	3,249	3,430	3,463	3,343	3,255
Adults (20 - over)	13,079	13,294	13,488	13,695	13,872
TOTAL ALL AGES	16,328	16,724	16,951	17,038	17,127

Adults (55 - over)	3,121	3,214	3,420	3,523	3,755
Adults (65 - over)	1,243	1,307	1,401	1,456	1,602

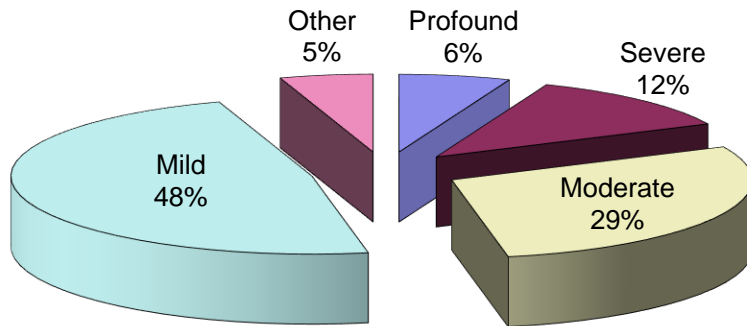
APPENDIX C

Percent Population by Age Ranges

FY 2019

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,255	19%
Age 20-29	4,191	25%
Age 30-39	2,872	17%
Age 40-49	1,946	11%
Age 50-59	2,302	13%
Age 60-69	1,655	10%
Age 70-79	725	4%
Age 80+	181	1%
TOTAL	17,127	100%

CT DDS Population - Level of Intellectual Disability



APPENDIX D

AGE CATEGORY AND RESIDENCE FY 2019

Residential Type	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
CLA (Group Home)	32	2935	779	3,746
CRS (Continuous Residential Supports)	7	666	45	718
CCH (Community Companion Home)	2	319	69	390
Family Home/Independent Living	2868	5486	156	8,510
IHS (Individualized Home Supports)	249	2368	230	2,847
RC (Regional Center)	0	134	17	151
SNF (Skilled Nursing Facility)	0	140	164	304
STS (Southbury Training School)	0	51	122	173
Other	97	171	20	288
TOTAL	3,255	12,270	1,602	17,127
PERCENT	19%	72%	9%	100%

Individuals Age 19 - 64 Years By Program Type

CLA	78%
CRS	93%
CCH	82%
Family/Independent	64%
IHS	83%
RC	89%
SNF	46%
STS	29%

Individuals over the Age of 65 By Program Type

CLA	21%
CRS	6%
CCH	18%
Family/Independent	2%
IHS	8%
RC	11%
SNF	54%
STS	71%