

Mortality

ANNUAL REPORT

FY 2021

This is the twentieth 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 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 270 deaths reported during the 2021 fiscal year (July 1, 2020 – June 30, 2021) including death rates and life expectancy, for individuals in the DDS database who were ever served by DDS.

SECTION THREE OF THIS REPORT:

CT DDS MORTALITY REVIEW PROCESS DATA OVERVIEW

This section includes information and analysis of data generated for the 214 deaths reviewed by the DDS nurse investigators, regional mortality review committees and Independent Mortality Review Board (IMRB) for the period of July 1, 2020 – June 30, 2021.

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, 2020 to June 30, 2021.
Data in this report was obtained from the CT DDS Database system.

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Executive Summary 2021 Report

- There were 270 deaths resulting in a crude **mortality rate of 15.4/1000**
- The strongest precipitating factors 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 61 years
- There was a progressive increase in mortality starting at 50 years of age in individuals receiving services from DDS.
- People receiving services from DDS have a shortened 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
- Due to COVID-19 Infectious Disease was the most common cause of death in the CT DDS population (17.4%)
- Aspiration pneumonia/pneumonia accounted for 5.9% of all deaths
- The percentage of deaths related to cancer in the DDS population (5.9%) was lower than the national (17.5%) and state (18.8%)^{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 56.5 years. Cardiac Arrest was the leading cause of death for people with Down syndrome
- Hospice supports were provided in 32% 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 business 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, 2020 – JUNE 30, 2021)

NUMBER OF DEATHS REPORTED = 270 *

Overall Mortality Rate

During the 12 month time period between July 1, 2020 and June 30, 2021 a total of **270** deaths of individuals known to CT DDS were reported **resulting in a mortality rate of 15.4** (Figure 1 & 2 below).

Figure 1

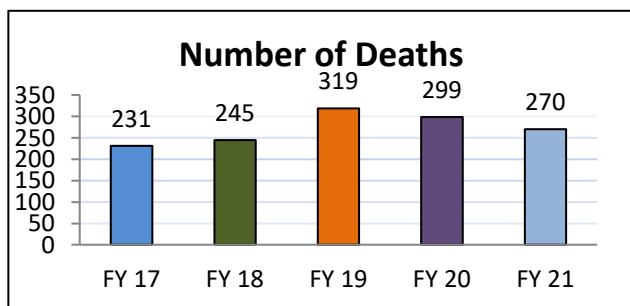


Figure 2

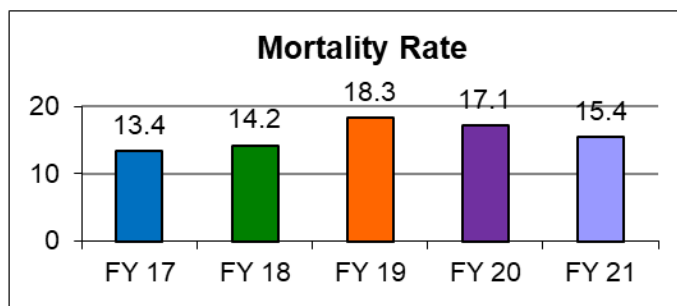


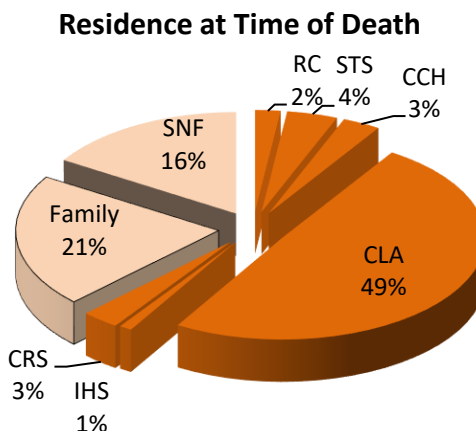
Table 1

Mortality and Residence

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

	% Deaths	% DDS population
CLA	49	21
Family	21	51
SNF	16	2
STS	4	1
CCH	3	2
CRS	3	4
RC	2	1
IHS	1	17

Figure 3



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.

* 10 individuals died in previous years, but their deaths were reported in FY2021.

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Section Two Continued

Figure 4



Figure 4 (above) depicts the actual number of deaths by where people reside. This year, the greatest number of deaths occurred in CLAs followed by family homes, skilled nursing facilities and STS. Of note: Sixty-eight percent (68%) of the people DDS supports reside in family homes or in their own home with or without in home supports, 21% in group homes (CLA's) and only 2% in skilled nursing facilities. Figure 3 shows 49% of reported deaths were people living in CLAs and 16% were living in a SNF at time of death. This variance is expected due to the higher level of care needs for individuals living in these settings.

Figure 5

Mortality Rate by Where People Reside No. Deaths per 1000 people FY 2021

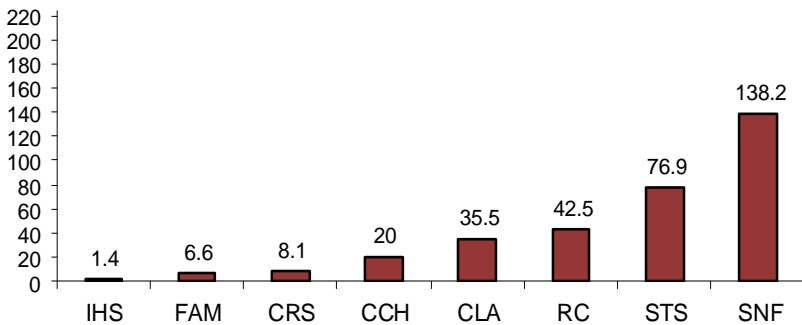


Figure 5 (left) depicts the number of people who died for every 1,000 people served by type of support.

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 comorbidities.

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Section Two Continued

Mortality and Residence Definitions

Family Home: People who live with their family without residential DDS supports or independently represent 51% of the DDS population. However, in FY 2021 58 deaths (21.5% of all deaths) occurred in a family home with an associated mortality rate of 6.6/1000 deaths. All DDS deaths of children were for those who lived with their families. Thirty-two of the 58 people died in a hospital or hospital emergency department, hospice or SNF.

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. These settings serve people with varying levels of intellectual disability. In FY 2021, 133 or 49.3% of all deaths occurred in CLA's compared to 45.5% in FY 2020. Ninety-four of the 133 people died in a hospital, hospital emergency department, hospice or SNF.

Community Companion Home (CCH): A family setting that is not the individual's own family. CCH provider has received training and is licensed by DDS to provide services. (Formerly known as CTH, Community Training Home.) There were 8 reported deaths in the community companion homes compared with 9 reported deaths in FY 2020. The CCH mortality rate of 20 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% of the reported deaths. Five of the 8 people died in a hospital, hospital emergency department, hospice or SNF.

Continuous Residential Supports (CRS): 24 hours of support for individuals to live in their own home. People receiving continuous residential supports in their own homes, in most cases, are less medically involved than people living in other settings. Six or 2.2% of reported deaths occurred in this environment. Four of the 6 people died in a hospital or hospital emergency department.

Individualized Home Supports (IHS): Less than 24 hours of support for individuals 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. 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 4 or 1.5% of reported deaths occurred in this environment compared with 3.7% last year. All 4 of the people died in the hospital or hospital emergency department.

Southbury Training School (STS): 24-hour support is provided in a large campus setting serving a population of older adults. The higher mortality rate of 76.9 is not surprising as this larger campus setting serves a population of older adults (average age of 75.6 years). Twelve deaths were reported at STS this past fiscal year representing 4.4% of all DDS deaths. Last year the Training School accounted for 4.7% of all deaths. Eight of the 12 people died in a hospital, hospital emergency department or hospice.

Regional Centers (RC): Are facilities for over 16 people that provide 24-hour staffing. Less than one percent of DDS individuals reside at DDS regional centers. Six RC residents died in FY 2021 accounting for 2.2% of all DDS deaths. Three of the individuals died in a hospital or hospital emergency department.

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. Only 1.5% of people served by CT DDS reside in a skilled nursing facility. This older (average age 67.5 years) and medically fragile population accounted for 42 or 15.6% of all reported deaths. People living in licensed nursing facilities had the highest mortality rate 138.2 per thousand. Seven percent of all DDS consumers over 60 years of age live in a skilled nursing facility. It is important to note that 15 of the 42 people died in a hospital, hospital emergency or hospice.

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Section Two Continued

Mortality and Sex

Table 2

Mortality Rate by Sex- 2021

Gender at Birth	Total Number of Individuals Served by DDS	% of Individuals Served by DDS	Number of Deaths	% of Deaths	Rate (Deaths Per 1000 people)
Men	10,256	60%	156	58%	15
Women	6,967	40%	114	42%	16.1
Total	17,223	100%	270	100%	15.4

In FY 2021 both the number of males and females who died within the DDS was similar to the sex distribution of those people served by the department (Table 2).

Figure 6

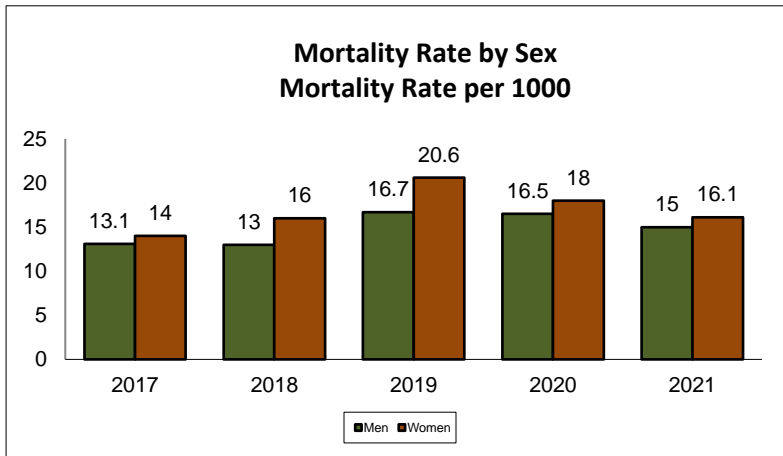
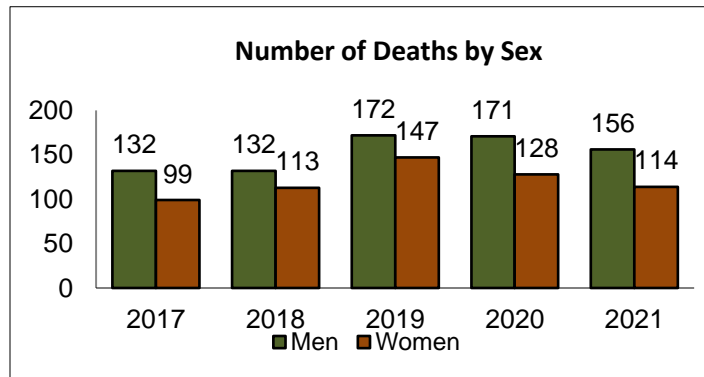


Figure 7

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 sex in the U.S.²¹

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Section Two Continued

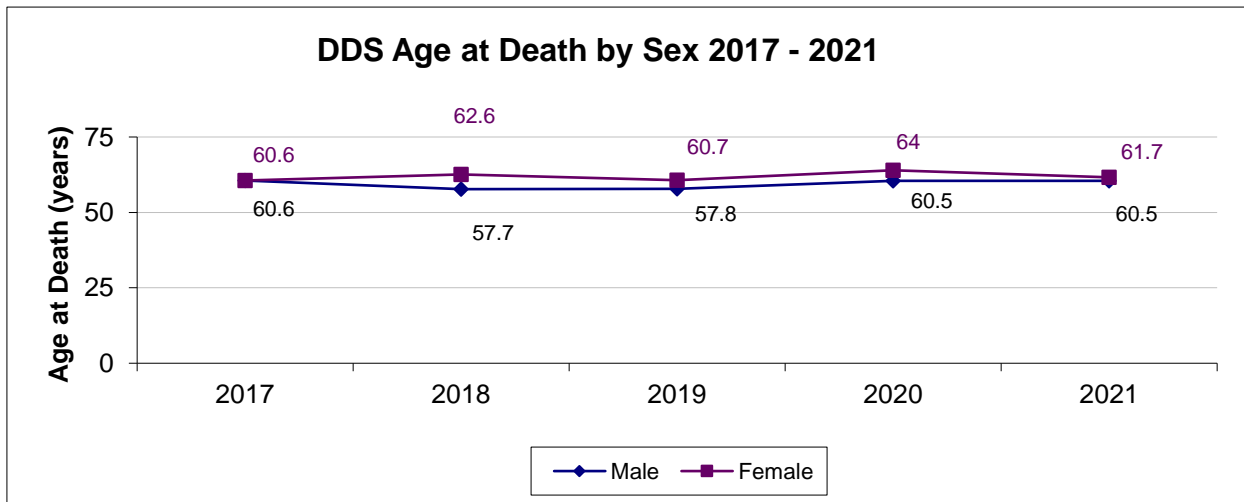
Mortality and Age

Table 3

Age of Death by Fiscal Year

Year	Men	Women	Average Age
FY2021	60.5	61.7	61
FY2020	60.5	64	62
FY2019	57.8	60.7	59.1
FY2018	57.7	62.6	60
FY2017	60.6	60.6	60.6

Figure 8



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Section Two Continued

Figure 9

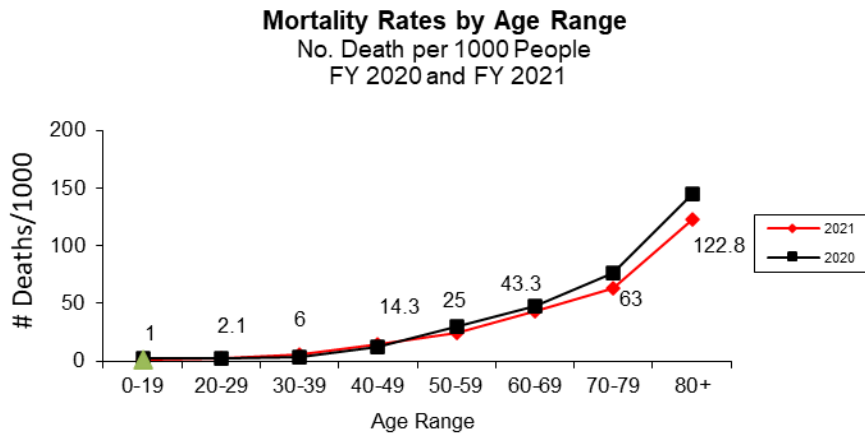


Figure 9 shows the relationship between age and mortality. As expected, when age increases mortality rates also increase. There is an increase in the mortality rate that begins early in the individual's fifties that continues to increase with advancing age. This finding is consistent with previous CT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

Table 4

Mortality Age Range Distribution Data
FY 2021

AGE RANGE	# OF DEATHS	MORTALITY RATE
Age 0-19	-*	1
Age 20-29	-*	2.1
Age 30-39	19	6
Age 40-49	28	14.3
Age 50-59	54	25
Age 60-69	77	43.3
Age 70-79	52	63
Age 80+	28	122.8
TOTAL	270	

Mortality statistics for the DDS population in Table 4 reveal a progressive increase in the mortality rate as the age range increases.

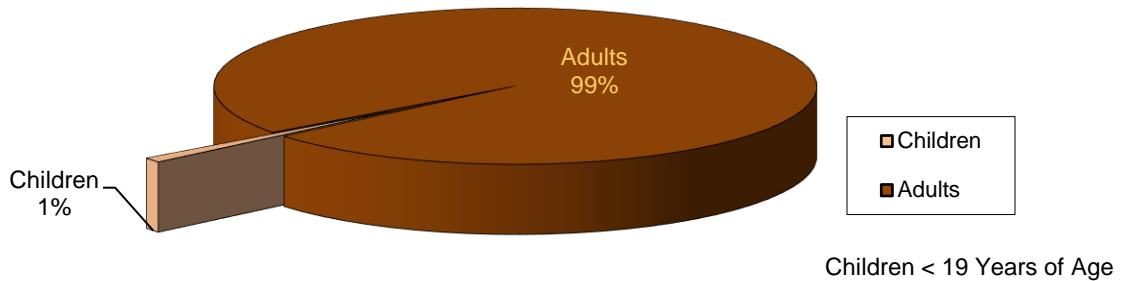
*Information suppressed per CMS guidelines, for counts being lower than 10.

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Section Two Continued

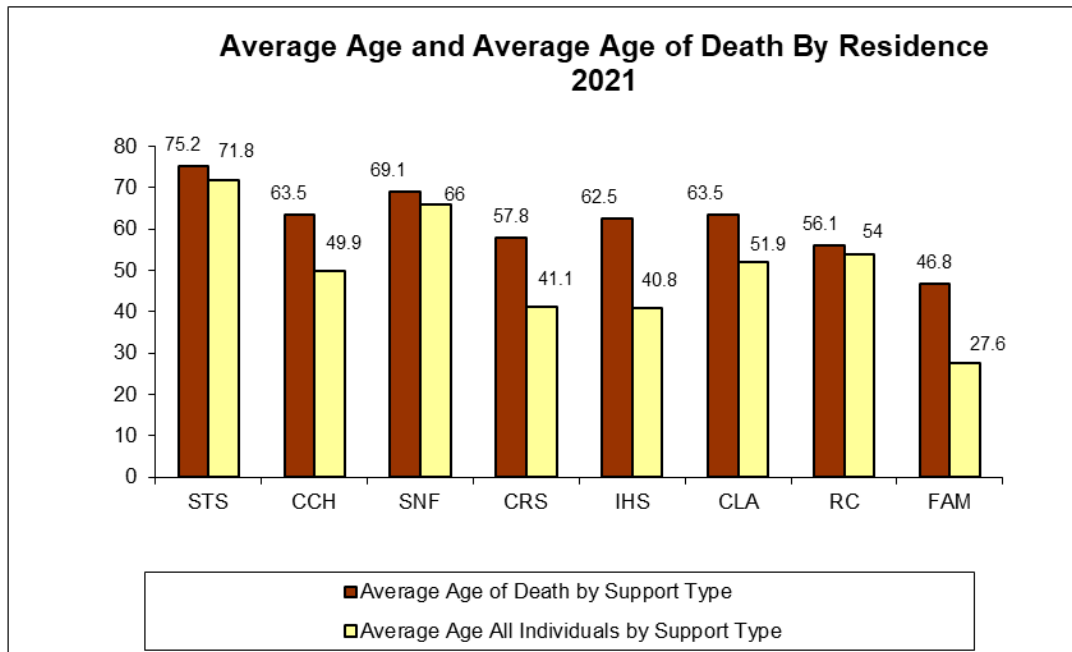
Figure 10

Deaths of Children and Adults



In FY 21 all children reported lived at home with their family.

Figure 11



The average age of death in the CT DDS population is 61. 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 61.3 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 2021 THEREFORE, THE MORTALITY DATA WILL DIFFER FROM THE INFORMATION PRESENTED AND DISCUSSED IN SECTION TWO OF THIS REPORT

NUMBER OF IMRB ENTERED REVIEWS = 214 cases*
~ 113 of the 214 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-two individuals received hospice services: 38% lived in a training school, 31% lived in a community living arrangement or received individual home support, 22% lived in a nursing home, 6% lived in a regional center and 3% lived in a community companion home. The average age of death for people receiving hospice services was 69.

Thirty-two people (32% of all reviewed deaths, excluding Abridged Reviews) 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:	9 (4.2% of reviewed deaths)
Number of postmortem examination performed by CT OCME:	7

*IMRB entered reviews are all reviews sent to IMRB. However, some cases have completed reviews at the regional level and do not receive an IRMB review in addition to the completed region review. Additionally, some deaths occurred outside of the FY reported on in this report.

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Section Three Continued

Precipitating Factors

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. 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.

Table 5

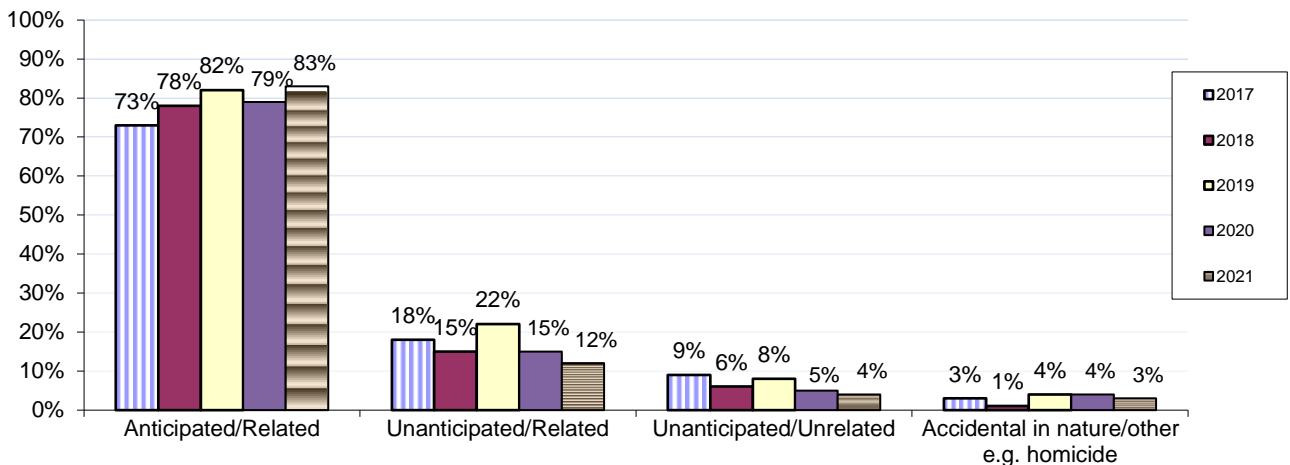
	Anticipated	Unanticipated
Related to a Pre-Existing Condition	83%	12%
Unrelated to Pre-Existing Condition	1%	4%

Death was accidental/homicidal/undetermined in nature 3%

Of the 6 deaths that were accidental/homicidal/undetermined in nature, 2 were included in the “unanticipated and unrelated to a preexisting diagnosis” percentage, 3 were included in the “unanticipated but related to a preexisting diagnosis” percentage and 1 was included in the “anticipated and related to a preexisting diagnosis” percentage.

Figure 12

Precipitating Factors of Death 2017 - 2021



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 96% 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 214 cases reviewed during FY 21, 208 (97%) were classified as **due to natural causes**. Six cases were determined to be the result of an accident.

Table 6

FY 21 Manner of Death

<i>Manner of Death</i>	<i>No.</i>	<i>Percent</i>
<i>Natural</i>	<i>208</i>	<i>97%</i>
<i>Accident</i>	<i>6</i>	<i>3%</i>
<i>Total</i>	<i>214</i>	<i>100%</i>

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

Choked	(4)
Fell	(2)

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Section Three Continued

UNANTICIPATED/UNRELATED DEATHS:

Of the 8 deaths that were unanticipated and not related to a known condition reasons include: Cardiac arrest; sudden cardiopulmonary arrest; blunt impact injury of neck; asphyxia due to airway obstruction; bowel ischemia complicating small intestine volvulus; unknown natural causes; pneumonia and Covid 19 and brain herniation.

ACCIDENTAL DEATHS

Choking was the reason for 4 of the 6 accidental deaths. Falls were the reason for the other 2 accidental deaths. Implementation of Health Standard 16-2: Safe Eating and Drinking Guidelines, along with related attachments, seeks to help keep choking related incidents low. Additionally, the implementation of the Fall Risk Assessment in 2011 aims to help reduce all fall risks. The Fall Risk Assessment has also been revised to continue to improve the impact on individuals supported by DDS.

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 214 mortality cases reviewed in FY 2021

Table 7

174 cases had a DNR order in place
97% of the DNR orders were formally reviewed by DDS
99% of the DNR orders met the established DDS medical criteria

In 3% 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 3 cases the medical criteria to support the decision to initiate the DNR was met. DDS continues to educate community healthcare professionals at hospitals, skilled nursing facilities and private practices, through written documentation and verbal as well as in-person meetings specific to the DDS DNR review process and Connecticut General Statute (CGS) 17a-236(g). Additional education and support services are provided to those agencies that fail to notify of a DNR implementation.

OF NOTE: eighty-six percent (86%) of DDS individuals residing in *skilled nursing facilities* had a DNR order in place at the time of their death.

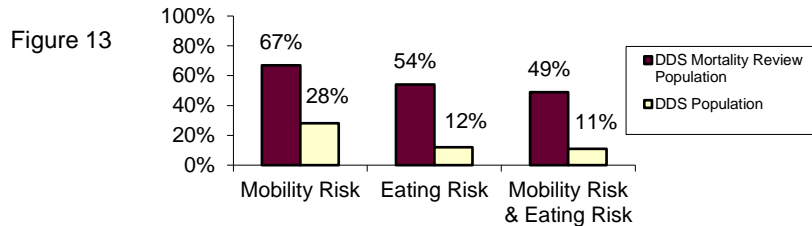
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Section Three Continued

Risk Factors

In this section of the report, information relates to people who had an IMRB review within the FY (101). 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 2021 data illustrates the relationship between these risk factors and mortality (see Figure 13 below).

Risk Factors 2021



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 2021, 67 (66%) of the individuals reviewed by IMRB did not ambulate independently.

Table 8

* MORTALITY REVIEW POPULATION ONLY	* TOTAL DDS POPULATION
66% did not ambulate independently 53% did not eat independently	28% do not ambulate independently 12% do not eat independently
* Does not include Abridged Reviews	

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

	2017	2018	2019	2020	2021	Percent of Population
Mild	1.9	3.1	3	2.6	2.1	51
Moderate	3.3	3.7	4.2	3	4.5	22
Severe	4.3	4.3	5.3	5.4	7.5	12
Profound	31.2	17.5	24.5	28.2	41.7	5

Table 9

Traditionally intellectual disabilities have been divided into four levels of severity based largely on IQ scores. Information about level of ID is provided at eligibility determination by a health care provider. Table 9 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. It is important to note that severe or profound intellectual disabilities are associated with multiple medical complications, chronic diseases, and immobility, which are factors contributing to increased mortality rates.

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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 214 mortality cases reviewed by DDS, 18 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.

Table 10

<u>Disposition of DDS/AID Cases</u>	
<i>Neglect substantiated</i>	7
<i>Neglect not substantiated</i>	9
<i>Cases still open</i>	2

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 2021 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.

Table 11

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 – 5
cases closed - 3
citations, violations found – 0

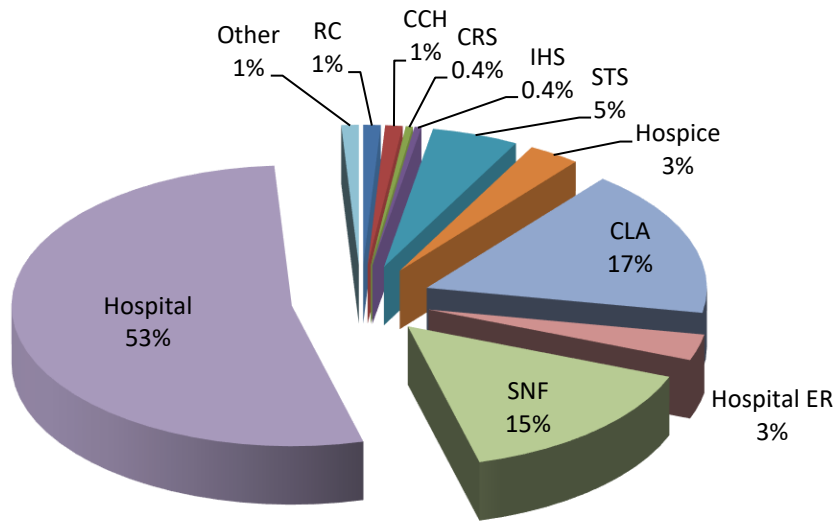
Mortality ANNUAL REPORT - 2021

Section Three Continued

Pronouncement of Death (Location at Time of Death)

Figure 14 below depicts the location where death was pronounced.

Figure 14



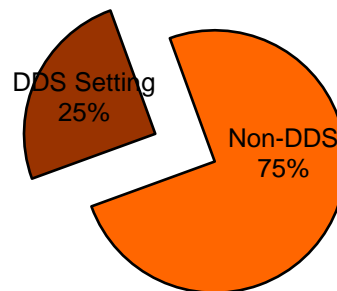
KEY: Location of Death

- 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 2021 Mortality Reviews

As can be seen in Figure 15 to the right, 75% of all deaths reviewed by the mortality review committee during FY 21 occurred outside of a DDS operated, licensed or funded residential setting, this represents a decrease in the number of people dying outside of a DDS setting compared to FY 20 (80%).



Mortality ANNUAL REPORT - 2021

Section Three Continued

SUMMARY OF MORTALITY DATA ***for the 214 deaths that were reviewed in FY21***

- **100%** of required cases were reviewed **Regionally**.
- **39%** of all cases were reviewed by the **IMRB**. *
- **32%** of the individuals received **Hospice** supports prior to their deaths. *
- **4%** 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.
- **49%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance). *
- **97%** of the deaths reviewed were due to **Natural** causes.
- **6** deaths that were classified as **Accidental**.
- **8** referrals to **Department of Public Health**.
- **18** referrals to **Abuse Investigation Division**.
- **7** **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 twenty 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 sex 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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Section Four Continued

Figure 16

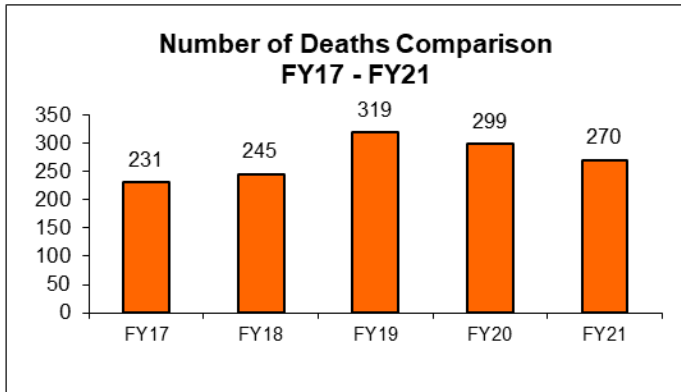
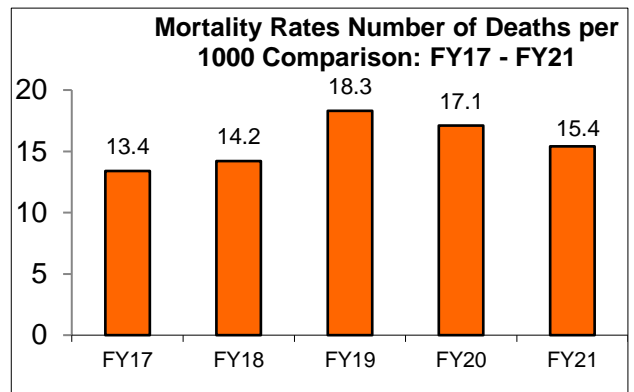


Figure 17



For Figures 16 and 17 total number of reported deaths are depicted on an annual basis the number of deaths and the death rate for FY 2017 – 2021 within the population served by DDS. The death rate average over the five year period of time is 15.7/1000 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, RC, STS) 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.

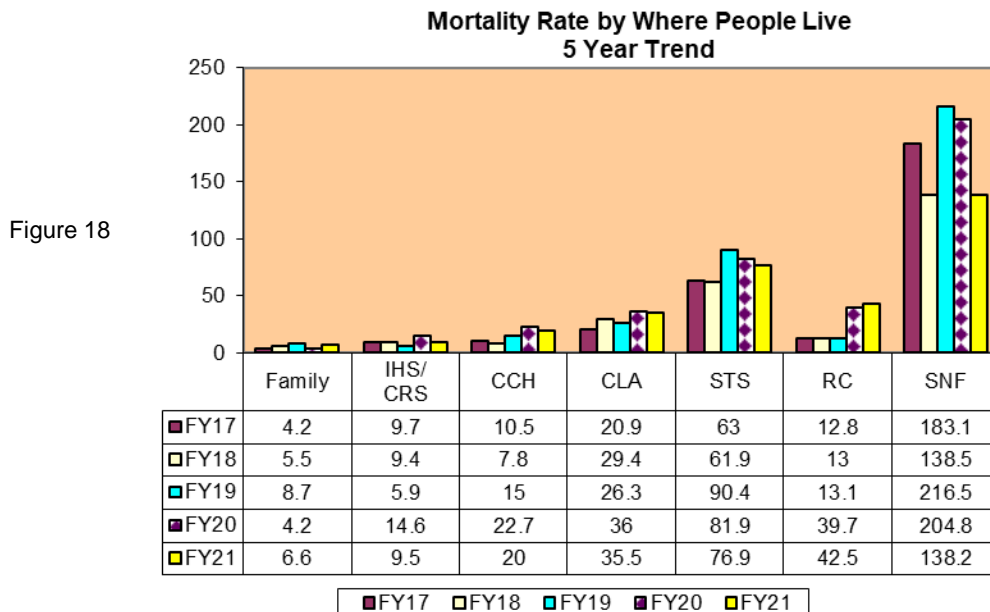


Figure 18

Mortality ANNUAL REPORT - 2021

Section Four Continued

Table 12

**Mortality and Gender at Birth
(FY2017 - 2021)**

Year	# Deaths Men	# Deaths Women	Mortality Rate Men	Mortality Rate Women
FY17	132	99	13.1	14
FY18	132	113	13	16
FY19	172	147	16.7	20.6
FY20	171	128	16.5	18
FY21	156	114	15	16.1

Over the past five years more men died annually than women. However, the mortality rate for women exceeded the mortality rate for men.

Figure 19

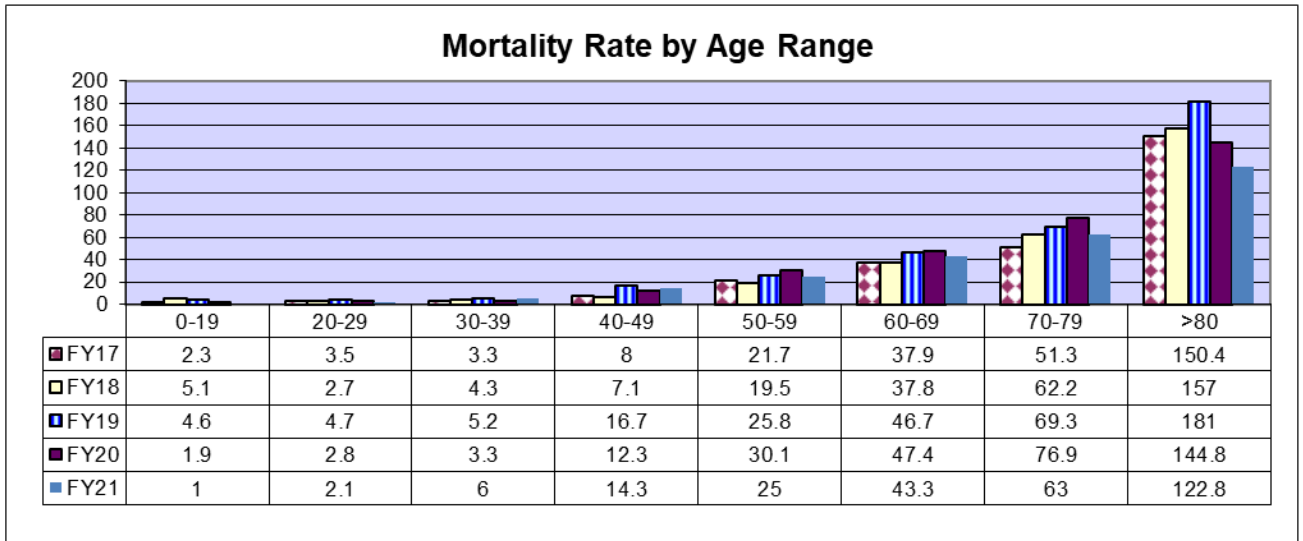


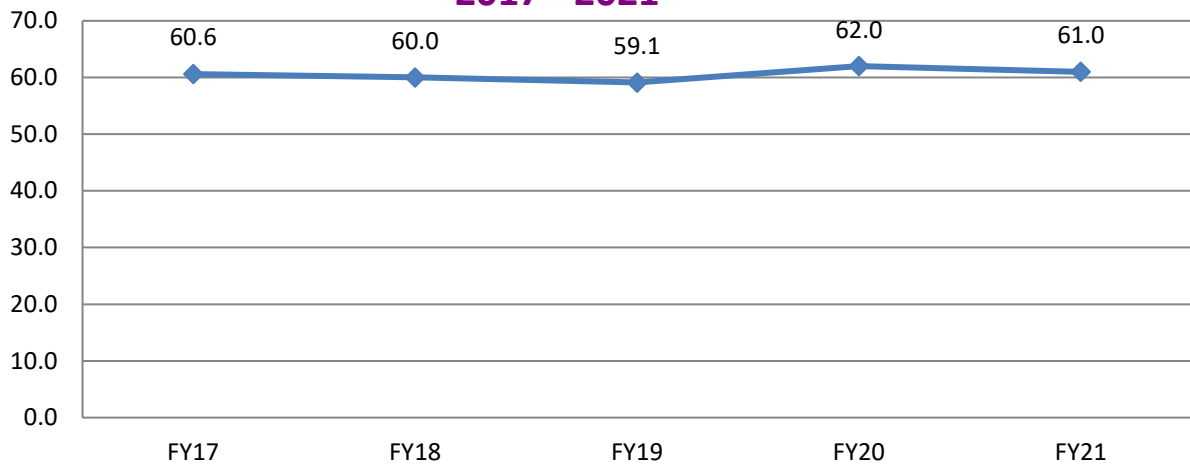
Figure 19 (above) illustrates mortality rate by age range. The data over the past five fiscal years reveals a consistent pattern of increasing mortality rates with each age range. The mortality rates increase markedly for adults who are in their 50s. The data also demonstrates that within each age range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

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Section Four Continued

Figure 20

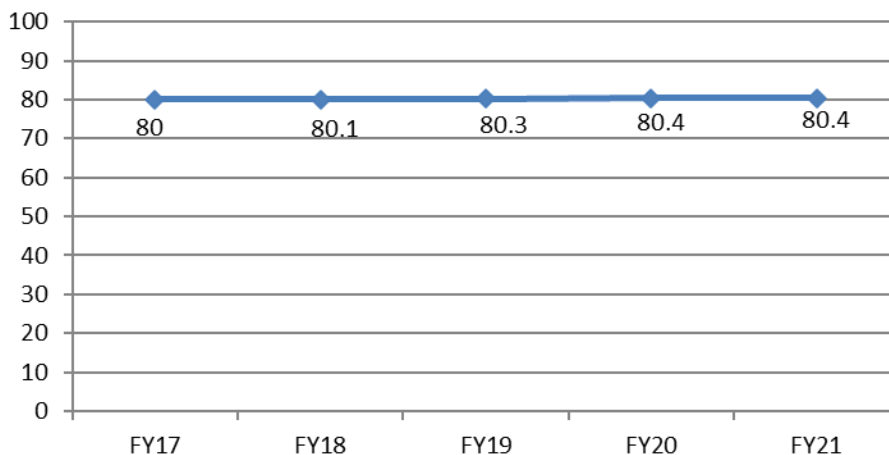
CT DDS Average Age of Death 2017 - 2021



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 (80.4) ¹ and the Connecticut life expectancy (80.8). ¹⁵

Figure 21

National Life Expectancy 2017 - 2021



Mortality ANNUAL REPORT - 2021

Section Four Continued

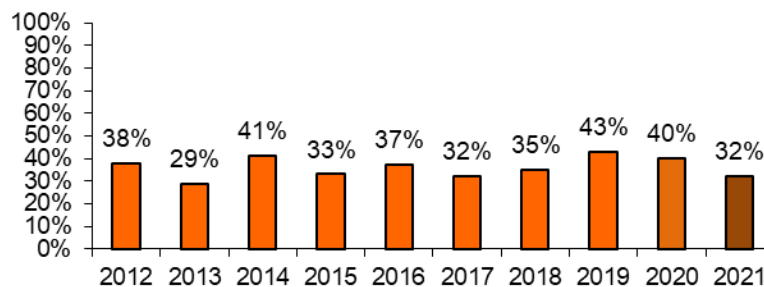
Table 13
RESIDENCE AT TIME OF DEATH TRENDS
 (2017 - 2021)

	2017	2018	2019	2020	2021
CCH	2%	1%	3%	3%	3%
CLA	35%	46%	32%	45%	49%
Family	18%	19%	23%	12%	22%
IHS/CRS	4%	5%	7%	7%	5%
RC	1%	1%	1%	2%	2%
SNF	33%	20%	26%	26%	16%
STS	6%	5%	5%	5%	4%
Other	1%	3%	3%	0%	0%

Table 13 depicts the percentage of deaths within various support types over a five 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
 (2012 - 2021)



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 14

Leading Cause of Death Data CT DDS (based on the 2021 fiscal year)

17.4%	<i>of deaths were due to</i>	Infectious Disease	<i>including</i>	Complications from COVID-19
16.3%	<i>of deaths were due to</i>	Heart Disease	<i>including</i>	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
12.6%	<i>of deaths were due to</i>	Respiratory Disease	<i>including</i>	Respiratory Failure, Pulmonary Embolism, Influenza, Multi-System Failure, COPD, ARDS, Asthma
5.9%	<i>of deaths were due to</i>	Cancer	<i>including</i>	Wide variety of primary origin sites
3.7%	<i>of deaths were due to</i>	Alzheimer's Disease	<i>including</i>	Dementia
3.7%	<i>of deaths were due to</i>	Aspiration Pneumonia	<i>including</i>	Aspiration Pneumonia
3.3%	<i>of deaths were due to</i>	Brain Disorders	<i>including</i>	TBI, Subdural Hematoma
3.3%	<i>of deaths were due to</i>	Sepsis	<i>including</i>	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
2.6%	<i>of deaths were due to</i>	Renal/Kidney	<i>including</i>	Renal Failure chronic and acute
2.2%	<i>of deaths were due to</i>	Pneumonia	<i>including</i>	Pneumonia

The 10 leading causes of death in 2021 (Table 14) are noted above. Unlike past years, due to COVID-19, Infectious Disease is the leading cause of death for the DDS population, Heart Disease is the second leading cause of death followed by Respiratory failure. Cancer, Alzheimer's Disease and Aspiration Pneumonia rounds out the top five causes of death.

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.

Mortality ANNUAL REPORT - 2021

Section Five Continued

Table 15

Location Where Death Pronounced (FY 2017 - 2021)

Location	2017	2018	2019	2020	2021
Hospital	61	49	72	58	113
SNF	31	31	35	28	32
CLA	24	32	32	17	36
Hospital ER	11	10	10	17	7
STS	4	2	6	3	11
RC	3	0	0	1	2
IHS	3	3	2	3	1
Hospice	8	7	4	6	7
Other	1	4	8	3	5

Table 16

Number of Autopsies (FY 2017 – FY 2021)

	2017	2018	2019	2020	2021
Autopsies	17	5	8	9	9

As noted in Table 16 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 2021 show no substantial change for the past 3 years.

Mortality ANNUAL REPORT - 2021

Section Five Continued

Table 17 provides detail of the cardiac deaths that were reviewed as part of the DDS mortality review process.* In FY 21 more men died as a result of heart disease than women. When considering cardiac/heart deaths, women died later in life.

Table 17

Deaths Due to Heart Disease

Year	Number of Male Deaths	Number of Female Deaths	Average Age Male	Average Age Female	Average Age
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
FY 20	21	8	66.6	76.1	69.2
FY 21	24	20	62.9	67.8	65.1

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.

Respiratory Disease

The 2021 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 18

Deaths Due to Respiratory Disease, Pneumonia and Aspiration Pneumonia

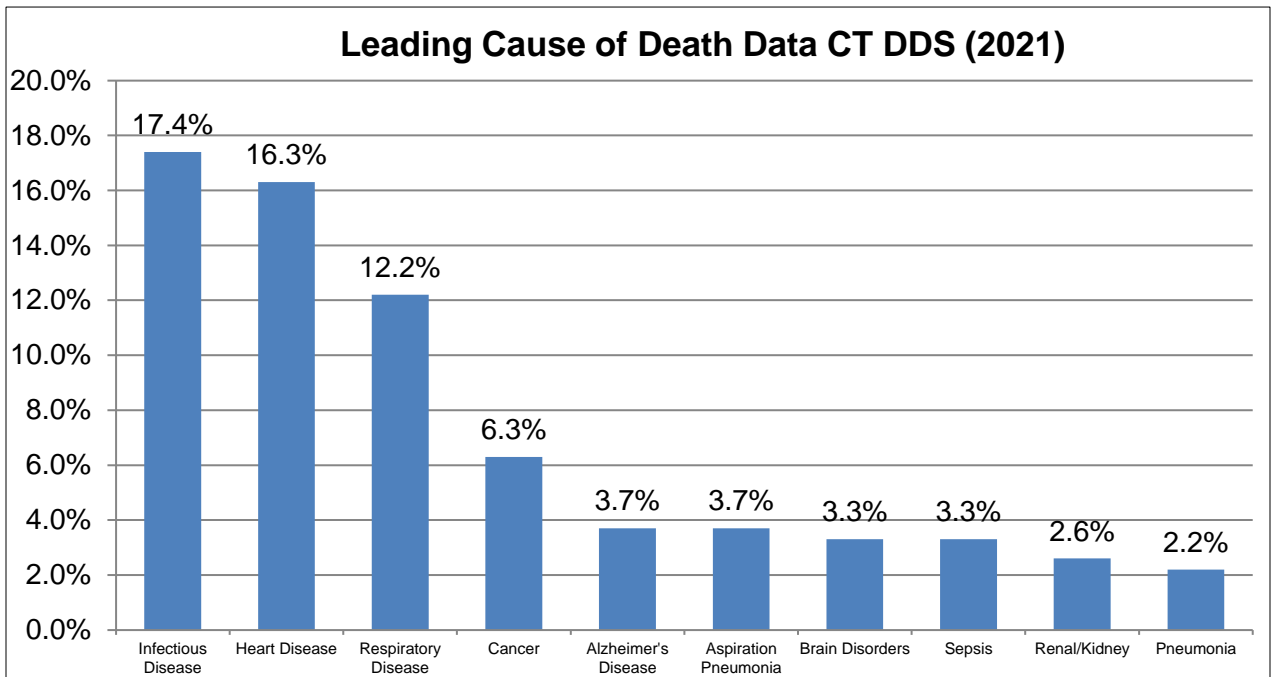
Year	Number of Males	Number of Females	Avg. Age of Males	Avg. Age of Females	Ave. Age
FY 17	21	10	61.4	62.3	61.4
FY 18	19	6	61.3	77.8	65.3
FY 19	16	13	66.5	69.2	67.7
FY 20	10	18	64	63.8	63.9
FY 21	33	17	61.6	65.4	62.9

* Abridged Reviews Excluded

Mortality ANNUAL REPORT - 2021

Section Five Continued

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 18.5% of all deaths in 2021 which was higher than the deaths caused by cardiac disease (16.3%).

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 fifth leading cause of death (3.7%) in the CT DDS population. During the mortality review process, it was determined that in 19% of the 101 deaths*, the person had a diagnosis of Alzheimer's disease at the time of their death.

* Abridged Reviews excluded

Mortality ANNUAL REPORT - 2021

Section Five Continued

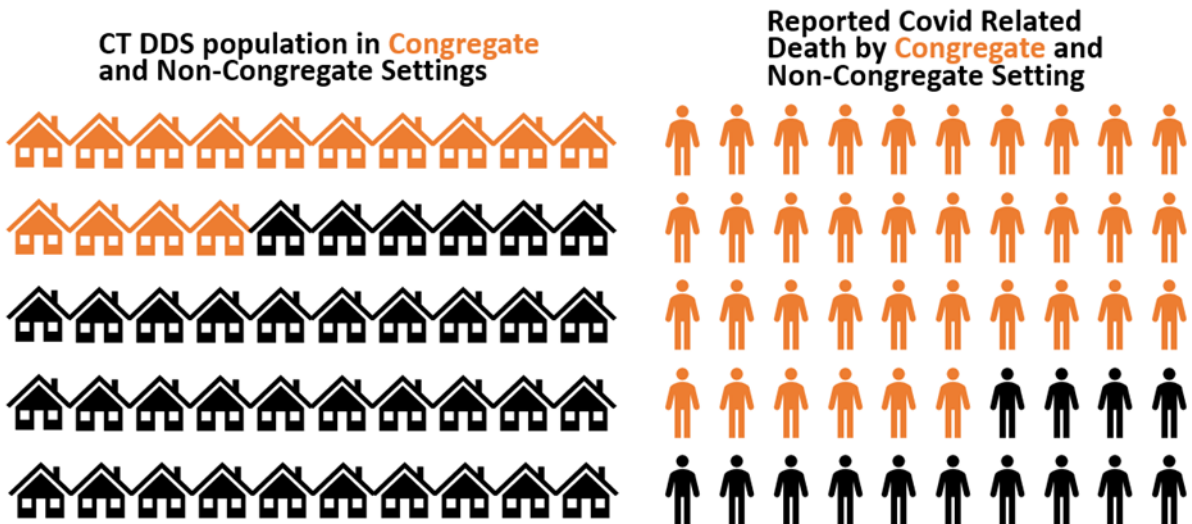
COVID-19

In fiscal year 2021 (FY21), there were 47 reported deaths attributed to COVID-19 related sequelae. Of those deaths, in relation to gender at birth there were twice as many males (33; 70%) to females (14; 30%). In the general CT DDS population 60% were reported as male and of individuals that were deceased in FY21 58% were male.

The average age for all COVID-19 deaths was 66 years, with the youngest death being a 20 year-old man and the oldest person was a 97 year-old woman. It is important to note that the majority of the individuals who had a COVID related death, resided in residential homes classified as congregate settings, such as group homes identified as community living arrangements (CLA) and continuous residential supports (CRS), and intermediate care facilities for individuals with intellectual disability (ICF/IID). In FY21, 51% of the population served by DDS resided in family homes or independently in the community. However, only 22% of total deaths occurred among that population and only 15% of COVID-related deaths occurred in those settings. In comparison, 82% of COVID-related deaths occurred among persons residing in congregate settings. This disparity in deaths per residence was anticipated due to known challenges with containing viral spread in congregate settings.¹¹

Figure 24

DDS Settings and Deaths in Relation to Settings



Mortality ANNUAL REPORT - 2021

Section Five Continued

Table 19

Leading Causes of Death CT DDS

Rank	CT DDS 2017	CT DDS 2018	CT DDS 2019	CT DDS 2020	CT DDS 2021
1	Heart Disease 25.9%	Heart Disease 32.2%	Heart Disease 27.9%	Heart Disease 20.1%	Infectious Disease 17.4%
2	Respiratory Disease 23.8%	Respiratory Disease 20.8%	Respiratory Disease 22.3%	Respiratory Disease 15.7%	Heart Disease 16.3%
3	Cancer 8.2%	Cancer 6.1%	Cancer 8.5%	Infectious Disease 12.4%	Respiratory Disease 12.6%
4	Alzheimer's Disease 5.2%	Aspiration Pneumonia 4.5%	Aspiration Pneumonia 4.4%	Aspiration Pneumonia 4.3%	Cancer 5.9%
5	Pneumonia 4.8%	Brain 3.7%	Sepsis 3.4%	Cancer 4.3%	Alzheimer's Disease 3.7%
6	Sepsis 4.8%	Sepsis 3.7%	Pneumonia 2.5%	Pneumonia 4.3%	Aspiration Pneumonia 3.7%
7	Brain 2.6%	Alzheimer's Disease 3.3%	Alzheimer's Disease 2.2%	Alzheimer's Disease 3%	Brain 3.3%
8	Kidney/ Renal 2.2%	Pneumonia 2%	Brain 2.2%	Brain 2.3%	Sepsis 3.3%
9	Aspiration Pneumonia 1.7%	Digestive System 1.6%	Asphyxia 2%	Sepsis 2%	Kidney/ Renal 2.6%
10	Digestive System 1.3%	Kidney/ Renal 1.6%	Digestive System 1.9%	Digestive System 1.7%	Pneumonia 2.2%

Based on 2021 Fiscal Year Data

Table 19 compares the top ten leading causes of death with CT DDS data from previous years. Unlike other years, due to COVID-19, this year Infectious Disease is the leading cause of death followed by Heart Disease.

Respiratory disease, aspiration pneumonia and pneumonia as a cause of death represented approximately 1/5 of all CT DDS deaths.

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Section Five Continued

Leading Causes of Death for People with Down Syndrome *

Table 20

FY21 Primary Cause of Death/Down Syndrome

Cardiac Disease	5
Respiratory Failure	4
Alzheimers	1
Aspiration Pneumonia	1
Cancer	1
Infectious Disease	1
Intracranial Hemorrhage	1
Total	14

This year Cardiac Disease was the leading cause of death for persons with Down syndrome (36%). (Table 20)

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 56.5.

Based on the DDS Down syndrome and death data (Table 21) 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, 43% of people with Down syndrome had a diagnosis of Alzheimer's disease at the time of their death. This data supports other research studies that found increased prevalence of Alzheimer's disease in people with Down syndrome.^{4,5}

Table 21

Average Age of Death Data

	2020	2021
Down syndrome:	55.9	56.5
Down syndrome & Alzheimer's disease:	58.4	59.7
Down syndrome without Alzheimer's disease:	52.5	54.1

* Does not include abridged reviews

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Section Five Continued

Analysis of Cancer Deaths

Table 22

FY 21 Analysis of Cancer Deaths		
Primary Site	Number of Deaths	Average Age at Death
Colon	3	62
Bladder	1	63.3
Blood	1	60
Brain	1	66.2
Esophagus	1	81
Leukemia	1	17.8
Liver	1	64
Lymphoma	1	58.1
Melanoma	1	39.6
Ovary	1	41
Pancreas	1	69.4
Peritoneal	1	65.8
Small Intestine	1	47
Uterus	1	57
TOTAL	16	57.3

In FY 2021 cancer was the fourth leading cause of death for people supported by the CT DDS

For FY 21 the distribution of cancers in men were Colon (2), Brain (1), Bladder (1), Leukemia (1), Liver (1), Lymphoma (1).

The FY 21 distribution of cancers in women were: Blood (1), Colon (1), Esophageal (1), Melanoma (1), Pancreas (1), Peritoneal (1), Ovarian (1), Small Intestine (1), Uterine (1).

The average age of death for all cancer victims (57.3 years) was below the average age of death for all CT DDS deaths (61 years).

The rate of death due to cancer in the CT DDS population (0.9/1000) is lower than the rate in the state of CT and nationally.^{13,17}

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SECTION SIX: BENCHMARKS

Mortality Rate Comparison

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 15.4/1000 is higher than the rate of 9.5 in Connecticut general population (2021) and the rate of 8.4 in the general United States population (2021).^{1,13 18} This would be expected due to the many health and functional complications associated with intellectual disabilities. 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}

Of note, DDS includes all deaths for all individuals the Department has record of. As a result, there are more deaths than would be included based on the population definition. At this time DDS does not collect data transactionally to identify which deaths should and should not be included. Therefore, the rates of death for DDS individuals is higher than reality.

Figure 25

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

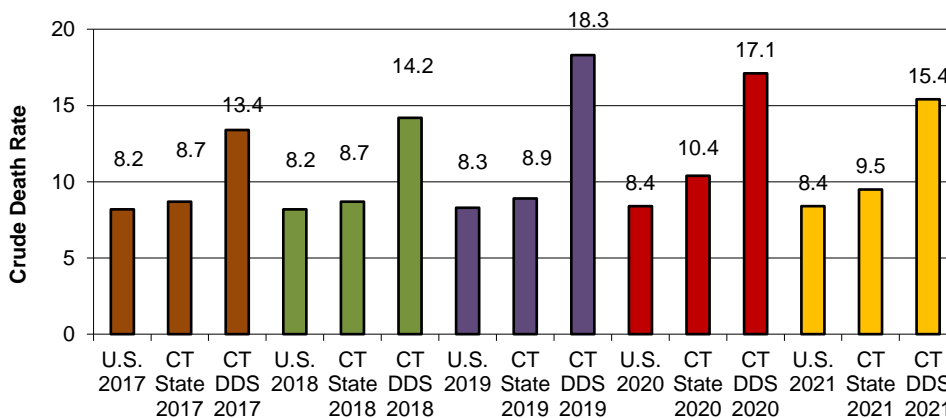


Table 23

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.

$$\text{Crude Death Rate} = \frac{\text{\# of deaths}}{\text{total population}} \times 1000$$

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Section Six Continued

Table 24

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

US 2017	State CT 2017	CT DDS 2017	US 2018	State CT 2018	CT DDS 2018	US 2019	State CT 2019	CT DDS 2019	US 2020	State CT 2020	CT DDS 2020	US 2021	State CT 2021	CT DDS 2021
Heart Disease 23%	Heart Disease 22.8%	Heart Disease 30.2%	Heart Disease 23.1%	Heart Disease 22.9%	Heart Disease 27.8%	Heart Disease 23.1%	Heart Disease 23.1%	Heart Disease 28%	Heart Disease 20.5%	Heart Disease 18.6%	COVID 19 16.5%	Heart Disease 20%	Heart Disease 19.5%	Heart Disease 13.5%
Cancer 21.3%	Cancer 21.1%	Respiratory Disease 22.3%	Cancer 21.1%	Cancer 20.6%	Respiratory Disease 19.1%	Cancer 21%	Cancer 20.4%	Respiratory Disease 18.5	Cancer 17.8%	Cancer 17.4%	Heart Disease 16.2%	Cancer 17.5%	Cancer 18.8%	Respiratory Disease 13.5%
Accidents 6.0%	Accidents 6.6%	Cancer 7.4%	Accidents 5.9%	Accidents 6.4%	Cancer 4.3%	Accidents 6.1%	Accidents 6.9%	Cancer 8%	COVID 19 10.3%	COVID 19 15.3%	Respiratory Disease 12.7%	COVID 19 12%	COVID 19 7.9%	COVID 19 11.4%
Respiratory Disease 5.7%	Respiratory Disease 4.7%	Alzheimer's Disease 4.5%	Respiratory Disease 5.6%	Respiratory Disease 4.5%	Aspiration Pneumonia 4.3%	Respiratory Disease 5.5%	Respiratory Disease 4.4%	Aspiration Pneumonia 5.1%	Accidents 5.7%	Accidents 6.4%	Cancer 5.4%	Accidents 6.5%	Accidents 7.7%	Cancer 3.8%
Stroke 5.2%	Stroke 4.5%	Pneumonia 3.3%	Stroke 5.2%	Stroke 4.4%	Sepsis 4%	Stroke 5.3%	Stroke 4.3%	Pneumonia 4.7%	Stroke 4.7%	Stroke 3.9%	Alzheimer's Disease 3.8%	Stroke 4.7%	Stroke 4.2%	Aspiration Pneumonia 3.5%
Alzheimer's Disease 4.3%	Alzheimer's Disease 3.4%	Sepsis 3.3%	Alzheimer's Disease 4.3%		Brain 3.6%	Alzheimer's Disease 4.3%		Alzheimer's Disease 3.6%	Respiratory Disease 4.5%		Aspiration Pneumonia 2.9%	Respiratory Disease 4.5%		Brain 2.8%
Diabetes Mellitus 3%	Diabetes Mellitus 2.2%	Brain 3%	Diabetes Mellitus 3%		Alzheimer's Disease 2.2%	Diabetes Mellitus 3.1%		Sepsis 2.9%	Alzheimer's Disease 4%		Brain 2.9%	Alzheimer's Disease 3.4%		Pneumonia 2.8%
Influenza/Pneumonia 2%	Influenza/Pneumonia 2.1%	Aspiration Pneumonia 2.1%	Influenza/Pneumonia 2.1%		Pneumonia 2.2%	Kidney/Renal 1.8%		Multi-Organ Failure 2.5%	Diabetes Mellitus 3%		Pneumonia 2.2%	Diabetes Mellitus 3%		Alzheimer's Disease 2.1%
Kidney/Renal 1.8%	Sepsis 2%	Digestive System 2.1%	Kidney/Renal 1.8%		Digestive System 1.8%	Influenza/Pneumonia 1.7%		Kidney/Renal 1.8%	Influenza/Pneumonia 1.6%		Sepsis 1.9%	Liver Disease 1.6%		Kidney/Renal 2.1%
Intentional Self-Harm 1.7%	Kidney/Renal 1.8%	Kidney/Renal 2.1%	Intentional Self-Harm 1.7%		Blunt Injury 1.4%	Intentional Self-Harm 1.7%		Syndromes 1.5%	Kidney/Renal 1.6%		Digestive System 1.3%	Kidney/Renal 1.6%		Sepsis 2.1%

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Section Six Continued

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

Table 23 compares the top ten leading causes of death for people served by CT DDS with data for the State of Connecticut (2021), and United States (2021). 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) tied with Respiratory Diseases as the number one and number two cause of death for the CT DDS population. Like last year the prevalence of cardiac disease is lower in the DDS population at 13.5% versus 19.5% in the CT general population and 20% nationally.

Respiratory Diseases tied with Heart Disease as the number one and number two cause of death in the CT DDS population (13.5%). This category which includes influenza causes death in the CT DDS population at a rate over 3 times the rates reported in the national vital statistics data base (4.1%). Respiratory Diseases was not one of the top 5 causes of death for the 2021 CT general population.

Infectious Disease (COVID-19) is the third leading cause of death for the CT DDS population at 11.4% in 2021. COVID-19 was also the third leading cause of death nationally (12%) and statewide (7.9%).

Cancer Is the fourth leading cause of death in the CT DDS population responsible for 3.8% of deaths. Unlike the other mentioned leading causes of death, cancer occurs less frequently in the CT DDS population than in the CT (18.8%) and national (17.5%) general populations.

Aspiration Pneumonia is the fifth leading cause of death in the DDS population (3/5%) 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 leading causes of death.

Brain Disorders Is the sixth leading cause of death in the CT DDS population (2.8%). This category includes traumatic brain injury and subdural hematoma. Brain Disorders is not reflected in the state of CT or national vital statistics as one of the top leading causes of death.

Pneumonia Is the seventh leading cause of death accounting for 2.8% of CT DDS deaths. Many of the multiple comorbidities 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 2021 the percent of deaths resulting from Alzheimer's disease in the CT DDS system (2.1%) was the eighth leading cause of death and is slightly lower than the 2021 US population (3.4%). Alzheimer's Disease was not one of the top five causes of death for the 2021 CT general population.

Renal/Kidney Disease is the ninth leading cause of death in the DDS population. Renal/Kidney Disease accounts for 2.1% of deaths in the DDS population and accounts for 1.6% of deaths in the national population.

Septicemia Originating from various sites and usually acute in onset is the tenth leading cause of death in the CT DDS population resulting in 2.1% of deaths. Septicemia is not reflected in the national vital statistics as one of the top ten leading causes of death or the CT general population as one of the top five leading causes of death.

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 2021. 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. Health standards, nursing practices, additional trainings, health screenings, updating and creating policies help to health and safety of the individuals supported by CT DDS.

Table 25

Mortality Case Review Summary (FY 2021)

<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>
214	175 (82%)	62 (61%)	39 (39%)	3 (3%)	42 (42%)
* Included Abridged Reviews					
** Does Not Include Abridged Reviews					

The table above, provides a summary of all deaths reviewed by the CT DDS Mortality Review Committees. Closed cases are cases reviewed by the Regional Mortality Review Committee with no concerns arising during the review. Cases with concerns are referred to the Independent Mortality Review Board (IMRB) for additional review. Eighty-two percent of the 101 cases reviewed by IMRB were closed by the local regional mortality committees. The regional committees referred 39 mortality cases to the state IMRB for further review. The reasons for the case referrals are noted in Table 26 (below).

The CT DDS Mortality Review Process requires that at least 10% of all cases that are closed at the regional level are reviewed by the Independent Mortality Review Board (IMRB) for quality assurance purposes. This year the IMRB reviewed 5% of cases closed by regional mortality committees.

Cases Referred to IMRB (39)	
Medical/Health Care	11
Pending Abuse/Neglect Investigation	10
Postmortem Examination	9
Pending DPH Investigation	7
DNR Concerns	1
Unexpected Death	1

Table 26

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Section Seven Continued

CT DDS Mortality Review: General Findings

Precipitating Factors of Mortality in the ID Population

- age
- mobility status
- level of intellectual disability
- the need for special assistance when eating

I. Findings and Quality Enhancement Action

Mortality Review Finding	DDS Quality Enhancement Action
<p>Health care coordination by registered nurses remains an essential support for the ID/DD population who are at risk for chronic and acute health conditions.</p>	<ul style="list-style-type: none"> • A Health Coordination of Care Factsheet was previously developed through a collaborative workgroup consisting of nurses and other representatives from DDS and private provider. This document continues to be utilized.
<p>Acute and chronic health issues continue to contribute to morbidity and mortality in people with IID/DD, which presents a unique challenge to caregivers in all settings.</p>	<ul style="list-style-type: none"> • DDS continues to focus on acute and chronic medical conditions which may be exacerbated by physical and cognitive challenges unique to persons with ID/DD. • In 2021, DDS released Health Standard 21-1: Osteoporosis Guidelines with Attachment A - Osteoporosis Information Sheet. Health Standard 21-1 focuses on best nursing practice for the care of individuals diagnosed with osteoporosis and preventive measures to minimize the risk for falls and impaired mobility. • The impact of the COVID-19 pandemic continued to be the primary health concern during FY21. DDS continued to provide updated memos pertaining to SARS-CoV-2 (COVID-19 virus) related guidance for residential caregivers, individuals, families, day programs, respite centers, medical and allied health professionals, and other persons and programs involved in the care and providing services to persons with ID/DD. • From January 2021 through December 2021, DDS released multiple memos and documents providing information and guidance on COVID-19 outbreak response, visitation in residential homes and intermediate care facilities for individuals with intellectual disability (ICF/IDD), vaccine fact sheets and consent forms, vaccine mandates, updated post-exposure measures, prevention of COVID-19 infection and transmission, and updated recommendations for COVID-19 testing, isolation, quarantine, and travel. <p>The specific documents may be accessed via the DDS portal website link below: https://portal.ct.gov/DDS/General/COVID19/COVID-19-Updates-for-DDS-Providers https://portal.ct.gov/DDS/General/COVID19/COVID-19-Updates-for-DDS-Individuals-and-Families</p> <ul style="list-style-type: none"> • The DDS Director of Health and Clinical Services and other members of Executive Management continue to engage in collaborative efforts with the Department of Public Health to minimize COVID-19 infections and subsequent deaths.
<p>The mortality review process differed among the three DDS regions and Southbury Training School.</p>	<ul style="list-style-type: none"> • DDS has continued to utilize mortality review processes which were implemented following a collaborative process with the National Association of State Directors of Developmental Disabilities Services (NASDDDS), utilizing Culture of Quality. The mortality review processes among the three DDS regions, including Southbury Training School (STS) have continued to operate with consistency in the Regional Mortality Review procedures.

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Section Seven Continued

II. General Community Awareness Recommendations

These are general findings that we believe the community at large should be aware of. The findings and recommendations are applicable to persons in residential homes/facilities; however, use for persons residing independently in the community or with family is encouraged.

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. The DDS Minimum Preventive Care Guidelines for Persons with Intellectual/Developmental Disabilities (I/DD) provides an outline of the United States Preventive Services Task Force (USPSTF) recommendations for routine screenings for all adults, including persons with I/DD. Nurses supporting individuals with I/DD are responsible for advocating for community healthcare providers to routinely screen persons, obtain the family history, and recommend age-appropriate vaccinations, in accordance with USPSTF recommendations, or to discuss with the individual or legal representative and document when routine screening is not recommended, deferred, or to advise an alternative screening. DDS Health Standards (HS) are developed to address specific medical/nursing related concerns for supported individuals. In FY2020, DDS released Health Standard 19-1: Consent Required for Medical or Dental Procedures including Emergency Surgery. HS 19-1 clarifies that non-adjudicated individuals or the legal representatives of adjudicated persons are authorized to consent to medical treatment and procedures including emergency medical care. HS 19-1 outlines the steps to take when the legal representative cannot be reached.
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. The results of postmortem examinations have contributed to statewide recommendations for nursing care and the development and revisions of DDS policies and procedures which focus on the health and safety of persons with I/DD. Specific recommendations have included nursing reviews of medical conditions and physical anomalies in which personal care, cardiopulmonary resuscitation, or physical restraint may require individual-specific additional education and training, modifications, or medical follow-up.
3. As individuals age, the “aging in place phenomenon” within the I/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. DDS Division of Health and Clinical Services routinely meets with statewide nurse managers and nurses representing qualified providers to identify and develop best practice policies and procedures which support and facilitate the ability for individuals to age in place in their residential homes whenever feasible. Some barriers to aging in place include various advanced medical conditions which require skilled level of nursing care or the need for additional medical supports which cannot be provided in a community-based residence. DDS advocates for measures to support and facilitate end-of-life care, such as hospice care, in the individual’s residential home. The health and safety of the individual is always a primary concern; however, DDS also advocates for quality of life and supports individuals to live and die with respect and dignity. In addition to supporting the individual, DDS provides supportive measures and resources for housemates, residential caregivers, and family members of individuals who are at the end of their lives.
4. The aging Down syndrome population requires specialized and comprehensive supports. Specific concerns and best practice nursing recommendations are shared via the statewide DDS public programs and quarterly private nurses’ meetings. The DDS Director of Health and Clinical Services, with input from statewide nurse managers, nurse consultants, and nurses representing qualified providers, develops uniform nurses’ meeting agenda items which are shared with DDS public programs and private provider nurses. The nurses’ meeting minutes capture best practice recommendations for nurses as well as new or revised Health Standards. Down syndrome is recognized and being associated with medical conditions and physical anomalies in which personal care, cardiopulmonary resuscitation, or physical restraint may require individual-specific education and training, modifications, and medical follow-up.

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The next Annual Mortality Report will be issued in FY 2023

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APPENDICES

Appendix A: Overview of DDS Population

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

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

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

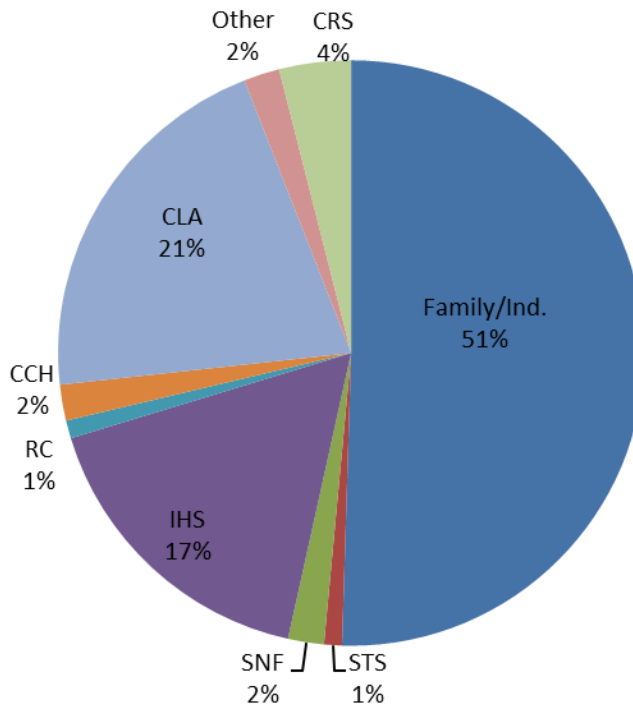
APPENDIX A

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 years. As of June 30, 2021 **17,223** 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 21% 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	2020		2021	
	# of Consumers	Percent	# of Consumers	Percent
Family	8,669	50%	8,795	51%
CLA (Group Home)	3,641	21%	3,612	21%
IHS, CRS	3,603	21%	3,590	21%
Training School	157	1%	144	1%
Other	305	2%	292	2%
Community Companion Home (CCH)	387	2%	392	2%
SNF	272	2%	262	2%
Regional Center (RC)	145	1%	136	1%
TOTAL	17,179	100%	17,223	100%

DDS Resident Population by Age 2017 - 2021

	2017	2018	2019	2020	2021
Children (0-19)	3,463	3,343	3,255	3,150	3,027
Adults (20 - over)	13,488	13,695	13,872	14,029	14,196
TOTAL ALL AGES	16,951	17,038	17,127	17,179	17,223

Adults (55 - 64)	3,420	3,523	3,755	2,159	2,102
Adults (65 - over)	1,401	1,456	1,602	1,625	1,691

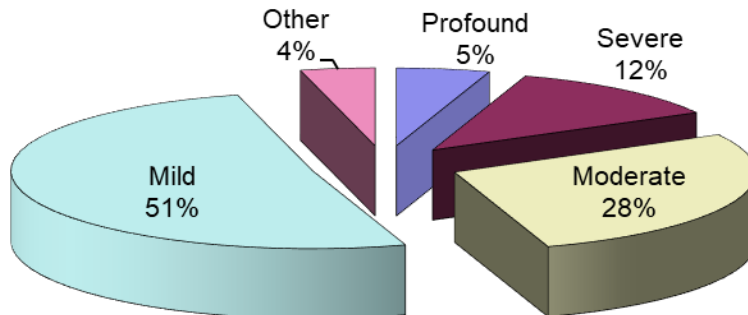
APPENDIX C

Percent Population by Age Ranges

FY 2021

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,027	18%
Age 20-29	4,320	25%
Age 30-39	3,126	18%
Age 40-49	1,932	11%
Age 50-59	2,144	12%
Age 60-69	1,701	10%
Age 70-79	773	4%
Age 80+	200	1%
TOTAL	17,223	100%

CT DDS Population - Level of Intellectual Disability



APPENDIX D

AGE CATEGORY AND RESIDENCE FY 2021

Residential Type	(0-19)	(20-64)	(65+)	TOTALS
CLA (Group Home)	17	2781	814	3,612
CRS (Continuous Residential Supports)	4	683	50	737
CCH (Community Companion Home)	0	323	69	392
Family Home/Independent Living	2680	5924	191	8,795
IHS (Individualized Home Supports)	225	2366	262	2,853
RC (Regional Center)	0	117	19	136
SNF (Skilled Nursing Facility)	0	110	152	262
STS (Southbury Training School)	0	30	114	144
Other	101	171	20	292
TOTAL	3,027	12,505	1,691	17,223
PERCENT	17%	73%	10%	100%

Individuals Age 19 - 64 Years By Program Type

CLA	76%
CRS	93%
CCH	82%
Family/Independent	67%
IHS	83%
RC	86%
SNF	42%
STS	21%

Individuals over the Age of 65 By Program Type

CLA	18%
CRS	7%
CCH	18%
Family/Independent	2%
IHS	9%
RC	14%
SNF	58%
STS	79%