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Developmental Services

Mortality Report FY24
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01 GREETINGS

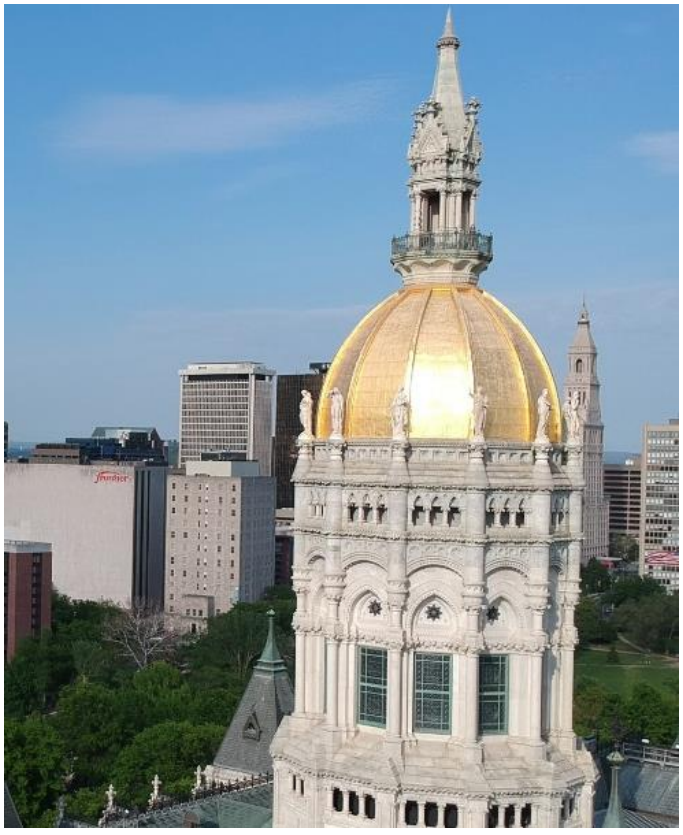
Remarks from DDS Commissioner Jordan A. Scheff.

GREETINGS

Remarks from Commissioner Jordan A. Scheff

As the Commissioner of the Department of Developmental Services (DDS), it is with a deep sense of responsibility and commitment that I present the 2024 Annual Report of the Intellectual Disability Independent Mortality Review Board (IMRB) and the Fatality Review Board (FRB).

Our department is dedicated to protecting the well-being of every individual under our care and support. The IMRB and FRB play a crucial role in this mission. These boards, comprised of diverse subject matter experts, thoroughly review medical care and the circumstances surrounding the deaths of individuals believe to have died from abuse or neglect. This task is fundamental to our commitment to transparency and improvement. This annual report not only presents the findings of our investigations but also our commitment to enhance the quality of care and protect some of our most vulnerable state residents.



It is our hope that this report serves as a valuable resource for community activists, public servants, and all stakeholders committed to improving outcomes for individuals with intellectual disability. Through our shared knowledge and collaborative efforts, we can continue to make meaningful advances in safeguarding the rights and well-being of individuals with intellectual disability.
Thank you for your dedication to this important cause.

Sincerely,
Jordan A. Scheff
Commissioner
Department of Developmental Services

02 Introduction

Policy requirements, timeframe definition and layout of data overview.

INTRODUCTION

This report will show trends, analyses, findings, and recommendations.

Updates

The DDS Mortality Report has remained largely unchanged for more than a decade. Updates to these annual reports began with the FY23 report. Updates are efforts to produce actionable information in a timely manner. Policy review helped identify requirements for the report. The layout of this report will be maintained in future years.

Policy

Requirements for the DDS Mortality Report stem from Governor Dannel P. Malloy's Executive Order No. 57 which states

> *"The IMRB shall report to the Governor and the Co-Chair of the Public Health Committee annually. Such reports shall reflect data, trends, analysis, and recommendations…"*

Timeframe

Report timeframe focused on deaths reported between July 1, 2023 and June 30, 2024 (i.e., Fiscal Year 2024). For information about mortality reviews, data focused on reviews completed within the same timeframe. This means not all reported deaths were reviewed in the same timeframe as they were originally reported.

Layout of data

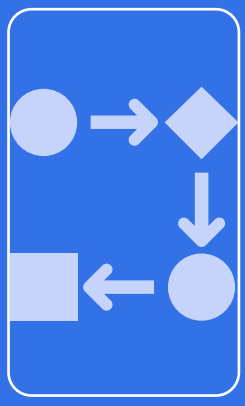
Data analysis reviewed trends for five fiscal years (FY). This helped identify any variations over time. Comparing DDS mortality data to the DDS active population data provided a point of reference and facilitated identification of any deviations from expected values.

03 Year in Review

Updates on accomplishments from reporting year.

YEAR IN REVIEW

DDS Health Services Division continues to implement trainings and initiatives to help individuals live happy, healthy, and fulfilling lives.



- Developed an improved workflow for referrals to FRB.
  - The FRB Team discussed several key factors needed for referral from IMRB circumstances surrounding untimely deaths that need further review and discussion.

- Data reformatting for waiver reports.
  - Staff turnover created a gap in knowledge about reporting. Documentation for the new process and a scripted extract creates comparable and quick information.

04 Data Analysis

Data review for deaths reported to DDS. Analysis on demographics, the manner, cause, and location of death, A/N, and Hospice

DATA ANALYSIS

Reported Deaths

Trends on reported deaths

Reporting timeframe and Date of Death

As mentioned in the introduction, the date that an individual's death was reported can be outside of the fiscal year (FY) in which the death occurred. Table 1 below shows the number of deaths reported compared to the number of deaths that occurred during each FY. Most deaths are reported within the current or prior fiscal year. In some situations, there are deaths reported years later. In FY24, seven deaths were reported that occurred in FY12. Overall, 263 deaths were reported in FY24. Of those 263 deaths, 256 occurred during FY24.

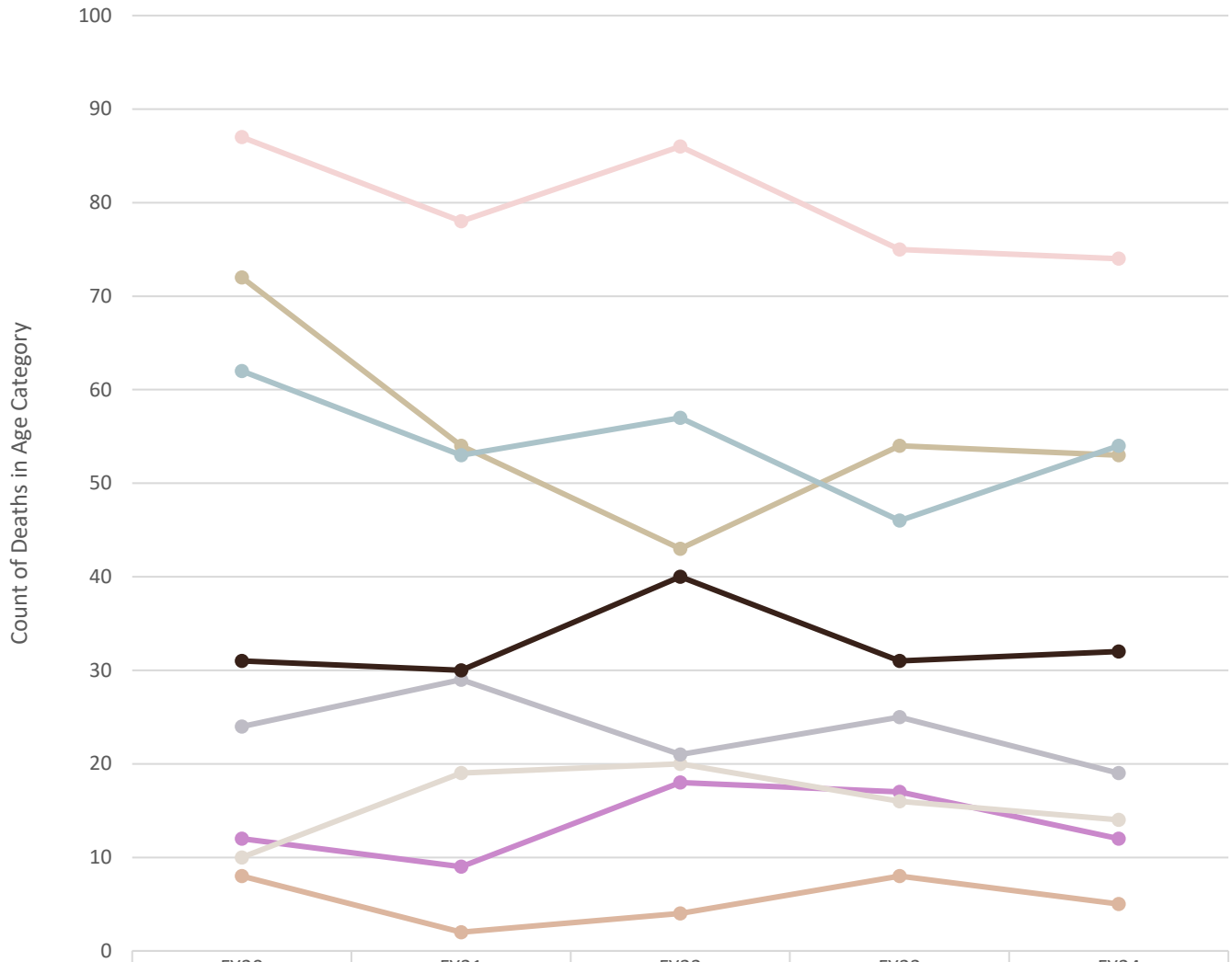
Table 1 Fiscal Year Reported

	FY20	FY21	FY22	FY23	FY24
Total Deaths Reported	306	274	289	272	263
Deaths Occurring in FY Reported	292	271	280	261	256
Deaths Occurring prior to FY Reported	14	3	9	11	7
FY of oldest death reported	FY12	FY18	FY19	FY01	FY12

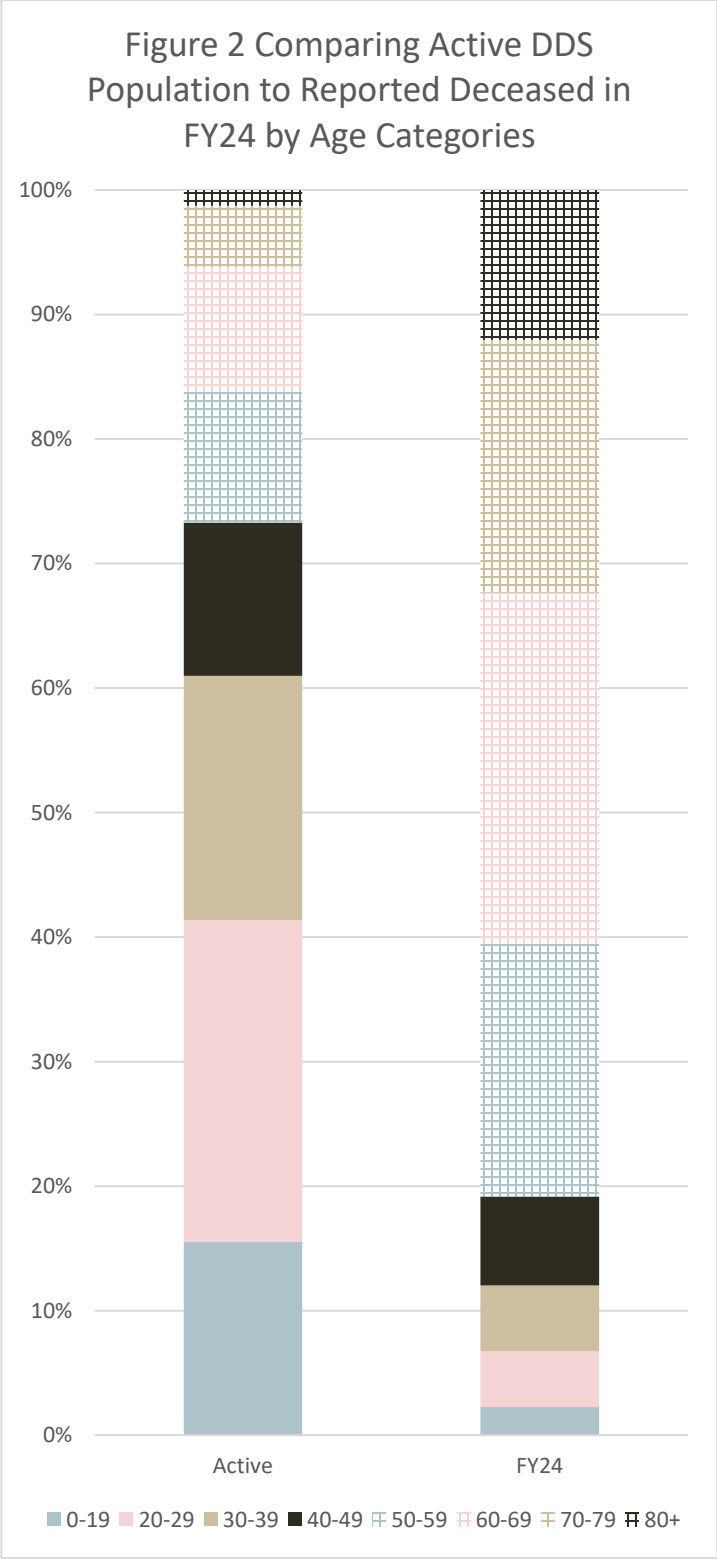
Age

When considering age of individuals at time of death, variation is expected. However, the age category 60-69 has consistently been the most common age category at which individuals died. This can be seen in Figure 1, which displays the number of deaths in each age category by FY.

Figure 1 Number of Deceased by Age Category and Reported Fiscal Year



	FY20	FY21	FY22	FY23	FY24
0-19	8	2	4	8	5
20-29	12	9	18	17	12
30-39	10	19	20	16	14
40-49	24	29	21	25	19
50-59	72	54	43	54	53
60-69	87	78	86	75	74
70-79	62	53	57	46	54
80+	31	30	40	31	32

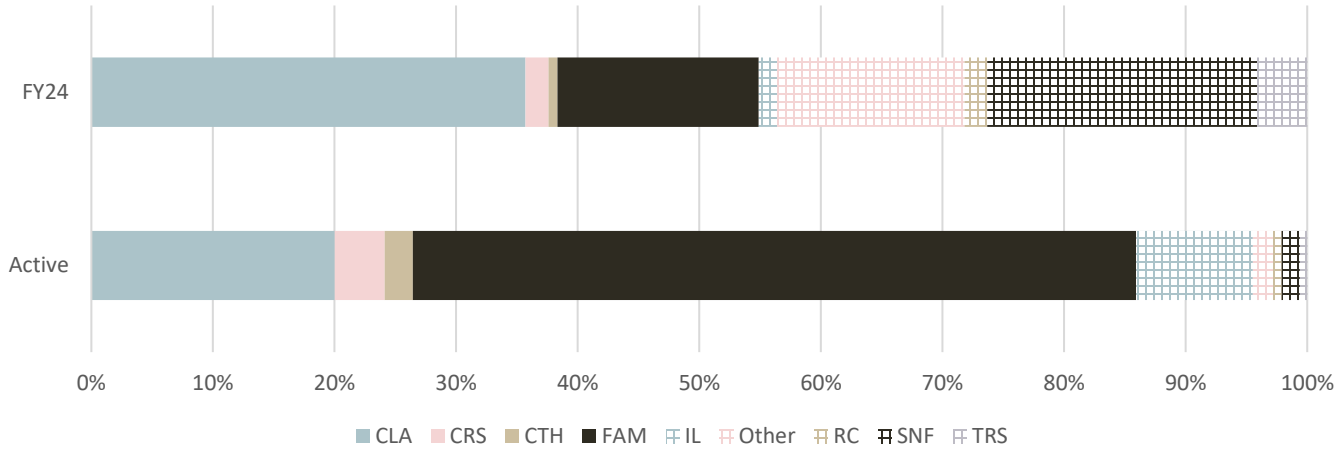


In Figure 2 (shown left), the age category at death is compared to the active population as of June 30th, 2024, the last day of the fiscal year. The difference in distribution is notable, where proportionally more individuals in the older categories died compared to the proportion in the active population. This is expected as individuals are more likely to die as they age. Conversely, while the age category 20-29 was the largest for the DDS active population, it was one of the smallest for deaths in FY24.

Residence

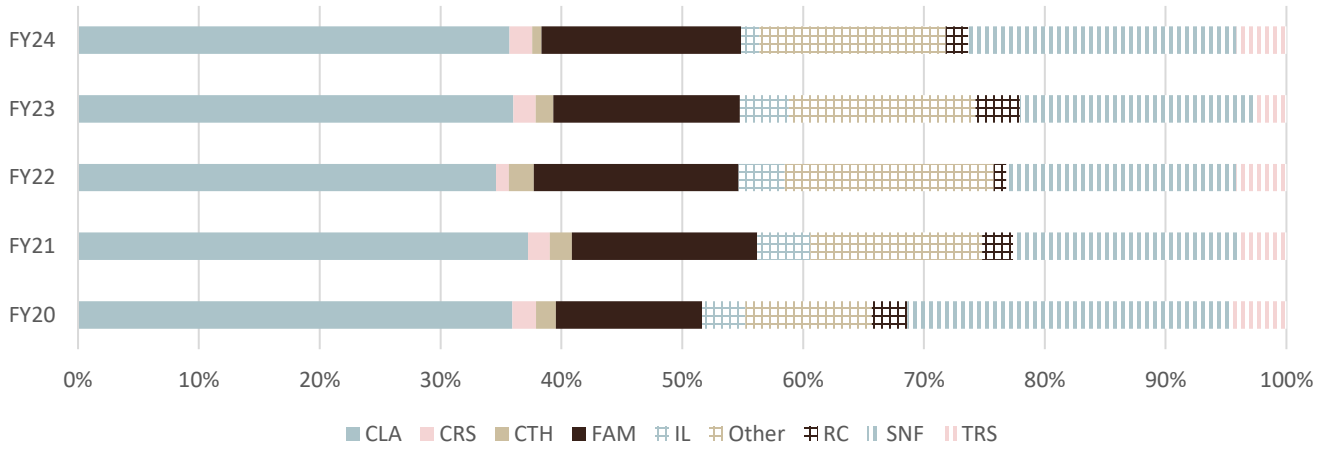
When considering where people lived, comparing active and deceased individuals in FY24, Figure 3 shows several disparities. The proportion of deceased individuals who resided in Community Living Arrangements (CLA) and Skilled Nursing Facilities (SNF) at time of death was greater than the proportion of active individuals residing in those settings during the same timeframe. Given that CLA and SNF are 24-hour residential settings with nursing care, this is not surprising. Conversely, a smaller proportion of deceased individuals had been residing in Family Homes (FAM) and Independent Living (IL) at time of death, compared to the proportion of active individuals living in those settings at that time.

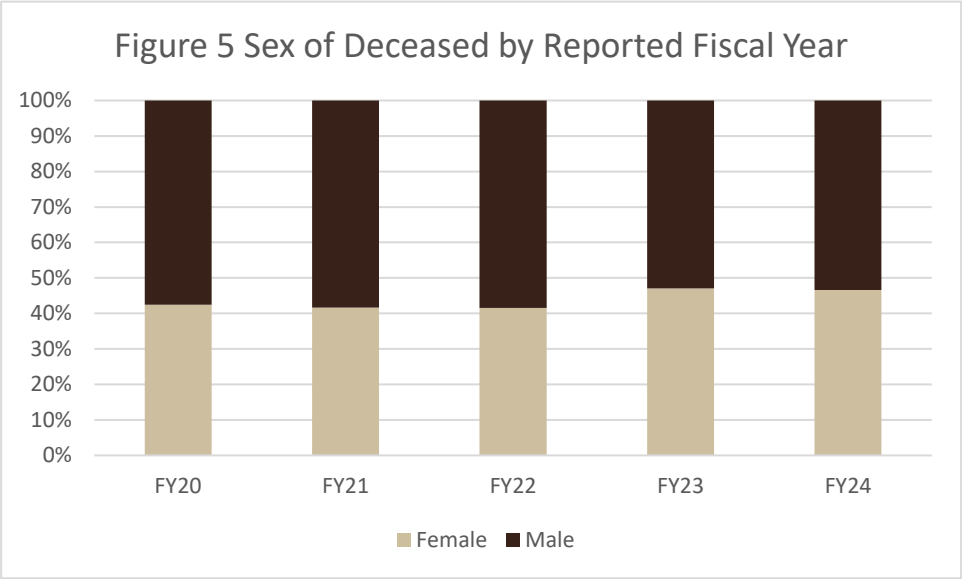
Figure 3 Comparing Active DDS Population to Reported Deceased in FY24 by Residence Type



When looking at the residence type for all individuals reported deceased in the last 5 fiscal years (Figure 4 below), you can see the over representation of CLA and SNF is consistent across years. Similarly, the under representation of deceased individuals residing in FAM and IL was consistent across years. The number of deaths in CLA and SNF consistently decreased from FY20 to FY24. Simultaneously, deaths in FAM increased over the last five fiscal years.

Figure 4 Residence Type of Deceased by Reproted Fiscal Year





Sex

Currently, DDS only records biological sex of individuals. Data systems at DDS do not include gender information. Consequently, this report only focuses on biological sex. Figure 5 to the left shows the percentage of reported deaths from FY20 to FY24 by biological sex. From FY20 to FY22 the percentage of female deaths was 42% and the percentage of male deaths was 58%. The percentage of female deaths increased to 47% in FY23, and this percentage remained the same in FY24. Conversely, the percentage of male deaths decreased to 53% in FY23, and this percentage remained the same in FY24.

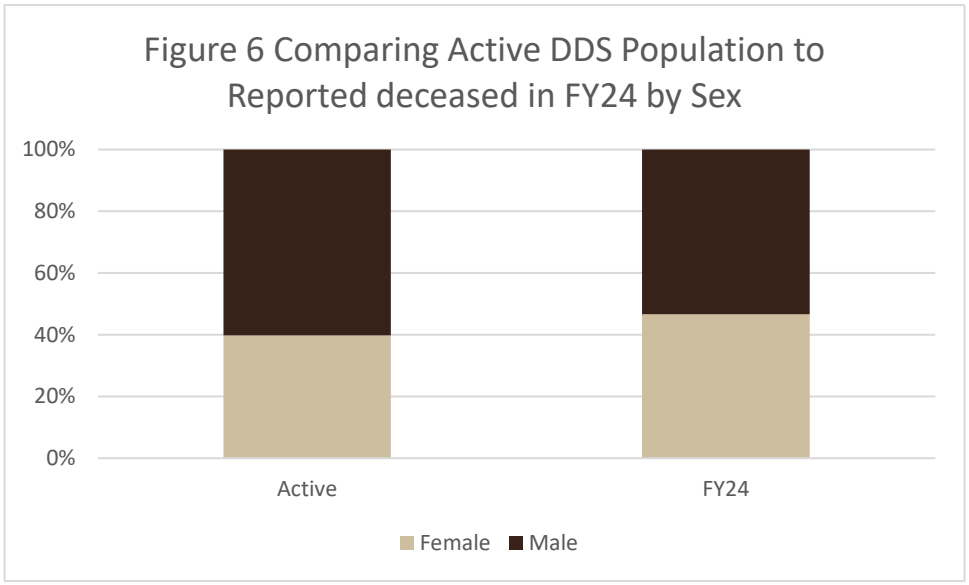


Figure 6 to right compares reported deaths in FY24 to the active DDS population by biological sex. The population at DDS is not evenly split between males and females. In Connecticut, males account for approximately 60% of the DDS population while females account for 40%. The disproportionate distribution of sex has been consistent for many years, in both the active DDS

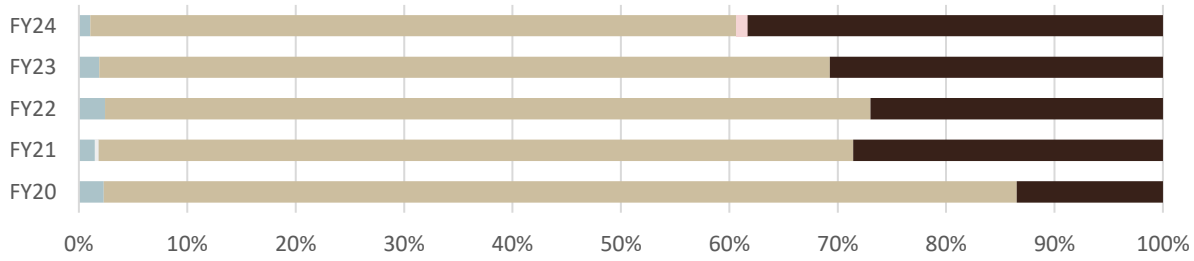
population and in reported deaths. This deviation from a 50/50 split in sex is common in IDD populations and seen across the United States. (https://legacy.nationalcoreindicators.org/charts/2017-18/?i=97&st=undefined)

Manner and Cause of Death

Manner of Death

Across years, most individuals died of natural causes. Accidental deaths remain under 10 per FY and homicide remains at 1 or less with none in FY24. In FY24 one death was the result of suicide. The number of deaths with undetermined cause increased from 41 to 78 between FY20 and FY21. This number remained the same from FY21 to FY22 then increased again to 82 in FY23. The number of deaths with undetermined cause decreased from 82 to 36 between FY23 and FY24.

Figure 7 Manner of Death by Fiscal Year



	FY20	FY21	FY22	FY23	FY24
Accidental	7	4	7	5	1
Homicide	0	1	0	0	0
Natural	256	190	204	180	56
Suicide	0	0	0	0	1
Undetermined	41	78	78	82	36

Cause of Death

Cause of death is determined by medical professionals and reported to DDS via the death certificate. Cause of death is coded into the groups shown in Table 2 below. Of

the deaths with known cause, heart/cardiovascular system and the respiratory system are the most common causes of death.

Table 2 Cause of Death					
	FY20	**FY21**	**FY22**	**FY23**	**FY24**
MALIGNANT NEOPLASM (CANCER)	14	14	19	16	19
CENTRAL NERVOUS SYSTEM	2	6	4	4	4
CHROMOSOMAL ABNORMALITY	0	0	0	0	4
HEART/CARDIOVASCULAR SYSTEM	59	45	57	55	24
GASTROINTESTINAL TRACT	5	1	3	4	2
INFECTIOUS DISEASE	37	45	26	4	8
KIDNEY, LIVER, OR PANCREAS	4	11	4	8	1
METABOLIC DISEASE	0	0	1	4	0
RESPIRATORY SYSTEM	40	34	44	46	48
OTHER	84	57	74	59	39
UNKNOWN	61	61	57	72	121

Reviews and Investigations

Regional Mortality Reviews

Regional mortality reviews (RMRs) are completed when a medical desk review (MDR) indicates additional review is needed. This could be due to location of death, residence type at death, suspicion of abuse and neglect (A/N), or other factors. The number of RMRs was higher in FY21 and FY22 compared to FY20, as seen in Table 3 below. These reviews conduct an in-depth look and provide opportunities for improvements to help reduce adverse effects from DDS. The number of reviews decreased from 78 in FY23 to 11 in FY24.

Table 3 Number of Regional Reviews by FY					
Fiscal Year	FY20	FY21	FY22	FY23	FY24
Number of Reviews	77	96	93	78	11

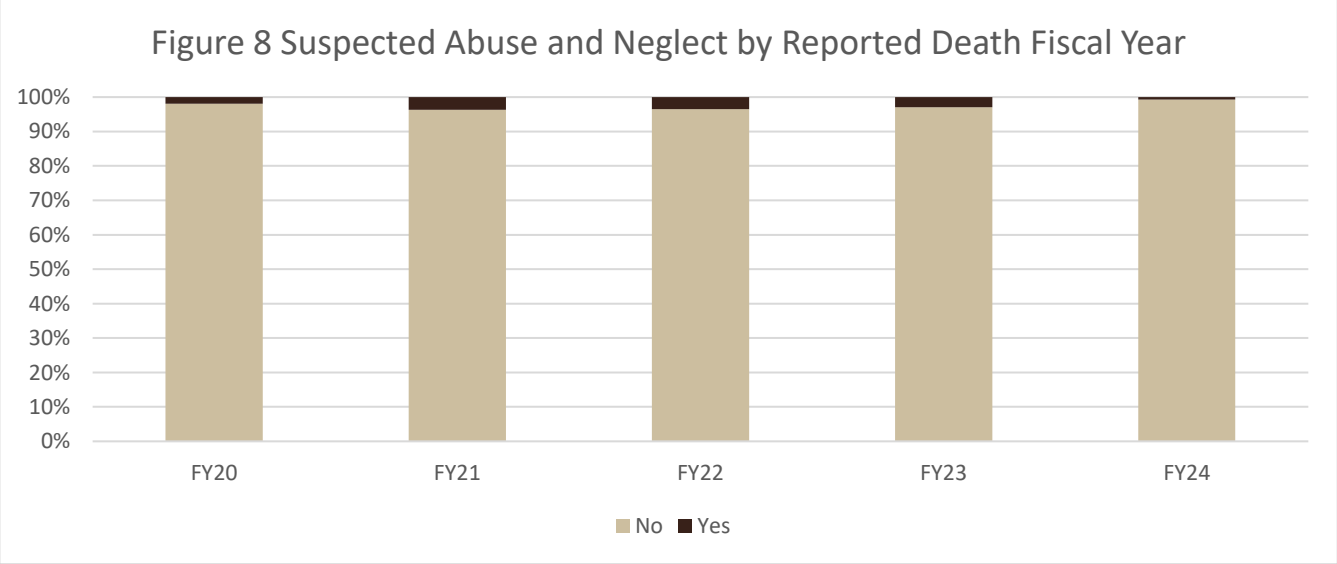
IMRB

If the RMR committee determines additional oversight is needed, the case is referred to the IMRB. There has been a consistent decline in the number of IMRB reviews since FY21 with the sharpest decline observed between FY23 and FY24. This can be seen in Table 4 below.

Table 4 Number of IMRB Reviews					
Fiscal Year	FY20	FY21	FY22	FY23	FY24
Number of Reviews	31	34	27	24	4

Investigations

DDS is committed to helping individuals live safe and fulfilling lives. Through Connecticut General Statute 46a 11c, DDS has the responsibility to investigate suspected abuse and neglect allegations. Abuse and neglect allegations associated with a death are reviewed here. Across years, 1-4% of deaths were suspected of abuse and neglect. In Figure 10 below the outcome of the investigations are detailed. Overall, very few deaths had suspicion of abuse and neglect. In FY24, only 1% of deaths had suspicion of abuse and neglect compared to 4% of deaths in FY21. In FY20, 2% of deaths were suspected of abuse and neglect and in FY22 & FY23, 3% were suspected of abuse and neglect.



05 Findings

Key Findings and recommendations as appropriate are provided.

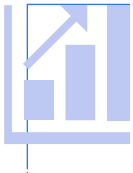
FINDINGS

Key Findings and Recommendations

Individuals who died age 60-69 created the largest age group.

Leading cause of death in FY24 was Respiratory System.

All deaths are reviewed for suspicion of abuse and neglect. Less than 1% of deaths were suspected to be the result of abuse and neglect in FY24.



There was a sharp increase in the number of deaths with unknown cause in FY24.

Recommendations

Future reports should look at level of ID, Race, Ethnicity, and Language.

Additional analysis on the findings from the IMRB and RMRs would help add context to the report.

Identify potential gaps in process used to identify and document causes of death.

06 Recognition

Acknowledgements for author and contributors to the report.

RECOGNITION

A special thank you to those who contributed to this report.

Author:

Julia Walsh
Data Scientist

Ricardo Salas Murillo
Durational Program Manager

Jennifer Richardson
Associate Research Analyst

Contributors:

Gloria Jones
Director of Health and Clinical Services

Elliann Sylvester
Nurse Consultant

IMRB committee members

FRB committee members