NEBRASKA

DEPT. OF HEALTH AND HUMAN SERVICES

DIVISION OF DEVELOPMENTAL DISABILITIES

Mortality Annual Report

FY 2023

Issue Date: July 2023

Liberty Healthcare Corporation

THE FREEDOM TO SUCCEED™

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Executive Summary

This annual report provides an overview of the mortalities of participants supported by DHHS-DDD services that occurred between July 1, 2022, and June 30, 2023. Data for this report was collected from mortality notification reports and case reviews and was analyzed to reveal characteristics and relationships that might lead to improvements in services and initiatives to improve the quality of life and longevity of supported participants.

- There were **565** deaths reported resulting in a crude mortality rate of **44.86** per 1000 population.
- There were **76** deaths of participants receiving CDD waiver services (individuals designated with I/DD), for a crude mortality rate of **15.58** per 1000 population.
- The strongest predictors of mortality remain advanced age, history of or actual Fatal Five Plus conditions, and chronic comorbidities such as cardiovascular disease and respiratory disease.
- The average age at death for individuals receiving services from CDD/DDAD waiver programs was **53.63** years.
- The average age at death for individuals receiving services from the AD/TBI waiver programs was **75.12** years.
- Among CDD/DDAD waiver participants, **38.16%** of mortalities were classified as unexpected or unexplained, while among the AD/TBI waiver participants, **11.73%** were classified as unexpected or unexplained deaths.
- **Cardiovascular disease** continues to be the leading cause of death **(29.09%)** in both the participants in AD and CDD populations, followed by **Respiratory System diseases (20.21%)**.
- Hospice supports were provided in **44.6%** of deaths investigated, which allowed individuals to receive additional supports and comfort in their place of residence in the final stages of a terminal illness.

Nebraska DHHS/DDD Mortality Review Process

The review and analysis of deaths of participants receiving services is an important component of the quality and risk management systems within DHHS-DDD. The mortality review process collects and analyzes data from mortality reports and case reviews to identify important patterns and trends that may help increase knowledge about risk factors and provide information to guide system enhancements and improvements.

In July 2021, DHHS-DDD partnered with Liberty Healthcare Corporation to assist with the development and implementation of a redesigned and more robust mortality review process. Between July 1, 2022, and June 30, 2023, the mortality review process has evolved, resulting in the following improvements:

- Refinement and enhancement of the triage and mortality review processes
- Improvement of the validity and reliability of data collected from mortality reviews, as well as expansion

of the data collected about mortalities of supported individuals;

- More robust data analysis and reporting of mortality data, leading to both individual provider and systemic recommendations and interventions;
- Improved tools and guides to support mortality reviews and data collection;
- A more comprehensive and formalized training curriculum and supporting materials that are used to train new mortality review nurses;
- Operational weekly data dashboard that supports closer monitoring and tracking of cases during the entire mortality review process;
- Redesign of the technical platform (QIDS) used to document mortality reviews to align with updated processes and support enhanced data collection and analysis.

Additional improvements and enhancements are planned in the coming year that include building and implementing QIDS enhancements, combining mortality data with data from other functional domains (Critical Incident Management System and Quality Onsite Provider Reviews) to guide technical assistance and training to enhance provider capacity, and mortality nurses providing additional technical assistance in the form of educational programs for providers related to findings in mortality data.

Critical Components of the Mortality Review Process

- Notification of Death reporting system
- Triage (initial review) of individual cases
- Nurse Mortality Review and Investigation
- 2nd Level Physician Review
- 2nd Level Mortality Review Team Review
- Mortality Review Committee
- Follow-up and Closure Process
- Collection, analysis, interpretation, and reporting of mortality data

Notification of Death Reporting System

Until March 1, 2023, the Notification of Death process varied among the waiver groups and the Beatrice State Developmental Center (BSDC). DHHS-DDD, as part of an initiative to standardize and streamline waiver program processes, transitioned the AD/TBI waiver case management system to the Therap platform. As part of that transition, the AD/TBI service coordinators are now submitting General Event Records (GERs) in the Therap system, including GERs reporting participant deaths. This means that all mortalities of waiver participants are reported within 24 hours of discovery. When an Individual is residing at BSDC, notifications are still made according to Beatrice State Developmental Center Operational Guidelines, and a GER is completed.

Triage Process

Liberty's Mortality Review Nurses conduct an initial review (triage) of each death using a triage tool that yields a score to determine if the mortality falls into one or more of the following categories:

- Deaths associated with alleged or suspected abuse, neglect, exploitation, or criminal acts;

- Sudden and unexpected deaths: Deaths that occur without warning or are unanticipated.
- Deaths that could be due to a lack of standard medical care, or omitted or inappropriate clinical care.

If the death meets one of the above criteria, the mortality review is expedited. An expedited review requires a more in-depth investigation by a mortality review nurse, as well as a secondary physician review and review of the investigation findings by the Mortality Review Team. Expedited deaths are always prioritized to be completed within 45 calendar days following receipt of necessary documents.

If the initial triage review tool reveals potential signs of abuse/neglect or exploitation, the mortality nurse investigator follows the "Others at Risk" protocol to alert the DD Division Quality Administrator to the immediate concerns that may need to be addressed to protect the health and welfare of others.

If the initial review of a death determines the death was expected given the nature of the participant's health conditions and chronic illnesses, and there were no concerns as to the quality of care provided to the participant, the relevant mortality data is collected and the mortality case is closed.

Nurse Mortality Review

To start the in-depth review process, the Mortality Review Assistant begins collecting applicable documents within the state's technical platforms that house these documents. A list of additional documents needed to conduct a nurse mortality review is sent to the Provider, Service Coordinator, or BSDC staff. Receipt of those documents is tracked, and the documents are organized in preparation for the review.

The nurse mortality in-depth review is designed to answer the following questions:

1. *Could this death have been prevented?*
2. *Are there systems issues identified in the course of the review?*
3. *Are there case-specific issues identified in the course of the review?*
4. *What actions should DDD take to improve the health and safety of the individual and prevent avoidable deaths?*

The nurse mortality investigator completes the in-depth review using the documents received and completes the mortality review brief electronically, entering all appropriate data about the mortality. The mortality investigator completes a summary of the events and timeline leading up to the death, noting any concerns or issues identified during the investigation.

2nd Level Physician Review

The Liberty Mortality Review Physician completes a 2nd level review on all mortality cases that have been expedited and any non-expedited reviews that would benefit from further medical evaluation. The Nurse Mortality Investigator may flag certain aspects of the case for physician review and may have specific questions about the cause of death, the meaning or impact of medical conditions or illnesses related to the mortality, or the appropriateness of the medical care provided in days and weeks preceding the death. Findings from the 2nd Level Review may help to answer some of the questions listed above.

Mortality Review Team Review

Weekly Mortality Review Team (MRT) meetings are designed to provide a second-level review for expedited cases, unexpected or unexplained deaths, or cases that nurse investigators identify as having possible concerns that might warrant a multi-disciplinary discussion regarding recommendations. The Mortality Review Team might refer cases for further consideration and discussion to the Mortality Review Committee (MRC) or might make recommendations for improvements to providers or agencies for cases that do not rise to the level of

referral to the MRC. MRT meetings are attended by the Mortality Review Physician, Mortality Review Nurses, Mortality Review Manager, and other subject matter experts (SMEs) in the fields of IDD support networks, mortality review methodology, and healthcare.

Mortality Review Committee

The role of the Mortality Review Committee (MRC) is to review and evaluate individual mortality cases referred to the committee as well as aggregate data from mortality reviews, make recommendations for quality improvements for both individual providers and systems issues, and communicate those recommendations to the DDD Quality Improvement Committee to support systemic quality improvement initiatives. The goal of the MRC's recommendations is to improve the quality of supports and services and to prevent avoidable deaths.

The MRC reviews all unexplained deaths (deaths for which there is no known reason or cause) and unexpected deaths (deaths that are sudden and unanticipated based on pre-existing health concerns) that mortality reviews indicate a possible issue or concern. The MRC will identify factors that may have influenced the health of the participant and which may have contributed to the death, as well as any aspects of a mortality case that indicate the death was potentially preventable.

Before each bimonthly meeting, committee members receive access to the mortality briefs and documents related to referred cases that will be discussed at the meeting. In addition to discussing individual cases during the meetings, members review and discuss analyzed aggregate data from mortality reviews and develop systemic recommendations to send to the DDD Quality Improvement Committee for consideration.

Membership of the MRC includes a variety of stakeholders, including some members who have mortality review experience based on their training and expertise in the field of intellectual and developmental disabilities and/or aging. This includes members with expertise in nursing care, medical care, psychiatric care, behavioral analysis, pharmacy services, quality improvement, incident management review, and data analysis. Some stakeholders are internal resources within DDD or Liberty, and others are external to the Department, including community advocates for the populations served. The committee is chaired by the Liberty Mortality Review Manager.

Follow-up and Closure Process

Based on the mortality review findings, Liberty and the MRC may make recommendations regarding actions to be taken by the Provider, Service Coordinator (SC), or Beatrice State Developmental Center (BSDC). Recommendation letters are generated by Liberty, amended or approved by the DDD Quality Administrator (or designee), and then sent to the applicable provider, SC or BSDC. Liberty, in collaboration with the Quality Unit of DDD, may provide technical assistance to providers of services based on recommendations from the mortality reviews or MRC. Mortality review cases are considered closed when either a recommendation letter or a closure letter is sent to the applicable party (provider, SC or BSDC).

Collection, Analysis, Interpreting, and Reporting of Mortality Data

Multiple sets of data are collected and stored during initial and in-depth mortality reviews. These data elements are case factors, characteristics, and attributes that assist in identifying trends, correlations, and themes associated with mortalities when used in data analysis. Some of these data elements include:

- Age at death
- Location of death
- Provider of services
- Cause of death
- Pre-existing illnesses and conditions
- Residential setting
- Waiver program funding services
- Fatal Five Plus pre-existing & contributing conditions

Additional data elements are added to the data collection system as new questions emerge from data analysis. Data collected and analyzed from mortality reviews are grouped into four focus areas: Abuse, neglect, and exploitation issues related to deaths; gaps in the level of services; the quality of care and support; and delays in

summoning or providing emergent care for health crises.

Data is aggregated and analyzed on a monthly, quarterly, and annual basis, and before each bimonthly MRC meeting. Data analysis is geared toward identifying trends and correlations that reveal opportunities for improvement in the quality of services. Results of data analysis are included in monthly, quarterly, and annual reports and presented to the MRC to facilitate the development of recommendations for improvement.

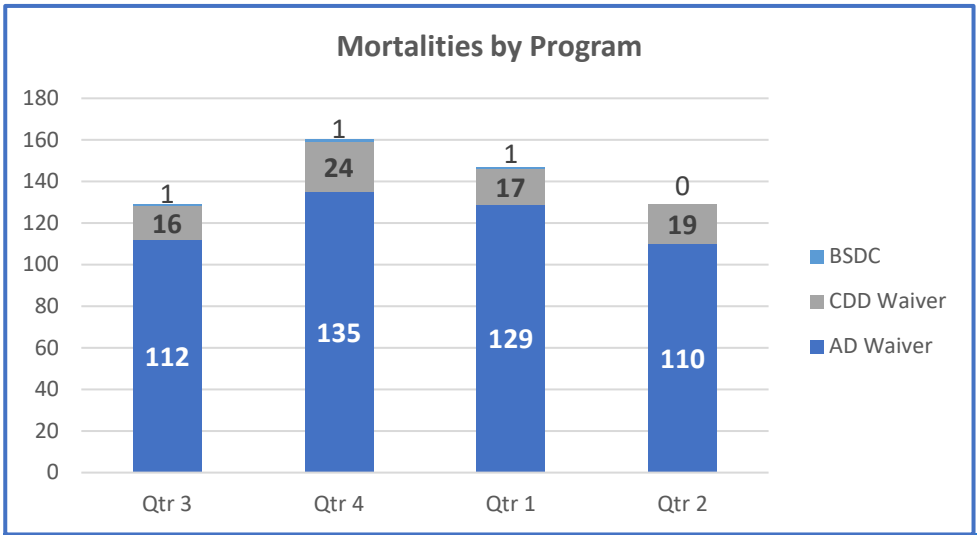
Analysis of All DHHS DDD Mortalities

Overall Mortality Rate

Between July 1, 2022, and June 30, 2023, a total of **565** deaths occurred across all waiver programs and the Beatrice State Developmental Center, resulting in an overall crude mortality rate of **44.86** per 1,000.

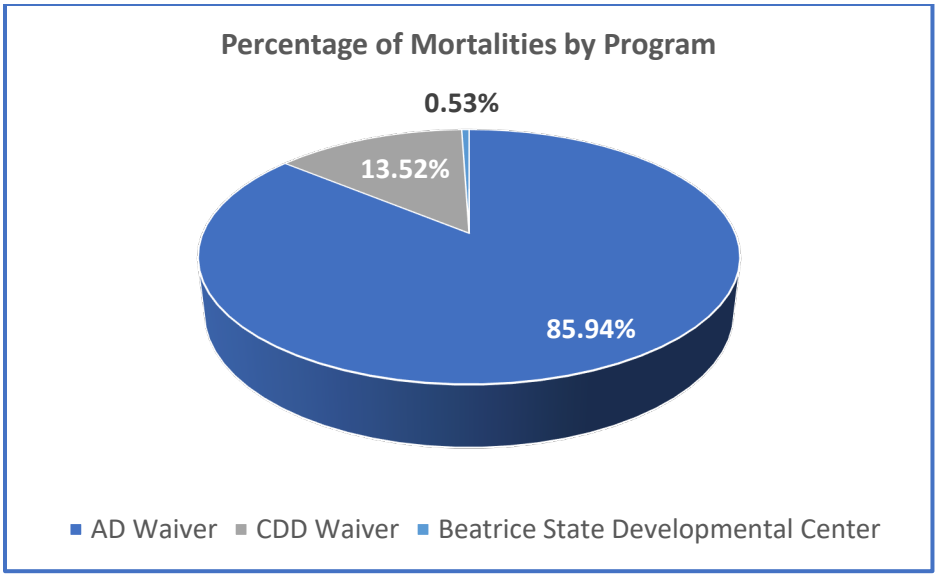
The overall mortality rate is not very useful for evaluating the mortality rate for the population of individuals with intellectual and developmental disabilities (IDD) because it includes a large percentage of the aging population receiving services from the Aging and Disabled (AD) waiver program. The AD waiver program serves 7,302 individuals, 4,528 (62%) of whom are 60 years and older, 95% of whom are not designated as IDD.

To arrive at a more accurate mortality rate as well as other statistical data for an IDD population within the service network, the data analysis separated the waiver programs into primarily two groups, the AD/TBI waiver participants and the CDD/DDAD waiver participants. While there are 354 individuals with a designation of Intellectual and Developmental Disabilities receiving AD waiver services, we were unable to distinguish the data for any of those individuals who may have died.



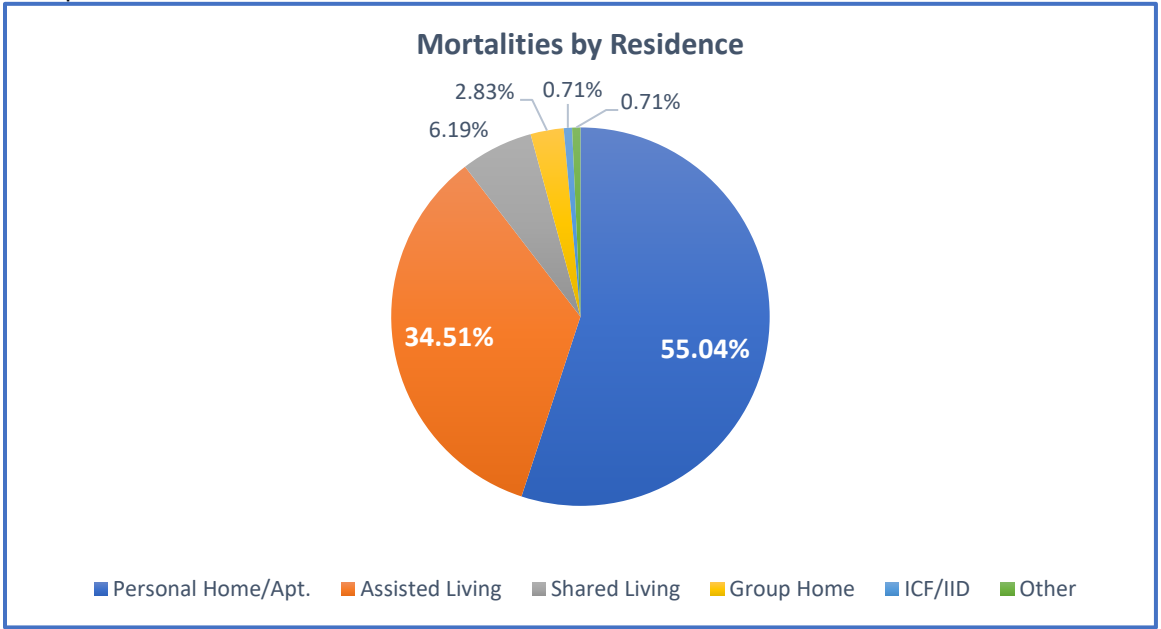
Year	2022		2023	
Waiver	**Qtr 3**	**Qtr 4**	**Qtr 1**	**Qtr 2**
AD Waiver	112	135	129	110
CDD Waiver	16	24	17	19
BSDC	1	1	1	0
Total	**129**	**160**	**147**	**129**

The chart above illustrates the mortalities by quarter for the past year, as well as by the waiver program. The chart below shows the mortalities by percentage for the past year per waiver program.



Mortality and Residential Setting

Over half (55.04%) of participants who died were residing in their own homes immediately prior to death and 93.24% of those individuals were receiving AD waiver services. Assisted Living settings accounted for 34.51% of residential settings at the time of death, and all but one of those participants were receiving AD waiver services. The remaining individual was receiving CDD Services. All mortalities who were residing in Shared Living received services from the CDD Waiver program, as did all of the Group Home mortalities.



Residence Type	# of Mortalities	% by Residence
Personal Home/Apt.	311	55.04%
Assisted Living	195	34.51%
Shared Living	35	6.19%
Group Home	16	2.83%
ICF/IID	4	0.71%
Other	4	0.71%

Residential Settings Definitions

Assisted Living Facility - a facility where shelter, food, and care are provided for remuneration for a period of more than 24 consecutive hours to four or more persons residing at the facility who require or request such services due to age, illness, or physical disability.

Shared Living - a residential service delivered in a private home owned or leased by an individual, couple, or a family known to the participant and who is an independent contractor of the agency provider. The Shared Living contractor and the participant live together in the same home and the participant shares daily life with the Shared Living family in their home and community. The home is both the Shared Living contractor and the participant's sole residence.

Group home - a Continuous Home Care setting in which care is delivered in a provider-owned or leased, operated, or controlled residential setting and is provided by agency staff not living in the setting.

Personal Home or apartment - a non-HCBS waiver-funded residential setting that is not service provider owned or operated.

Intermediate Care Facility (ICF) - The Beatrice State Developmental Center (BSDC) is a 24-hour state and federally-funded residential treatment facility dedicated to the provision of specialized psychological, medical, and developmental supports to people with intellectual and developmental disabilities. BSDC is a campus-like setting with 188 acres.

Mortality and Gender

Mortality Percentages and Rates by Gender for AD/TBI Waivers

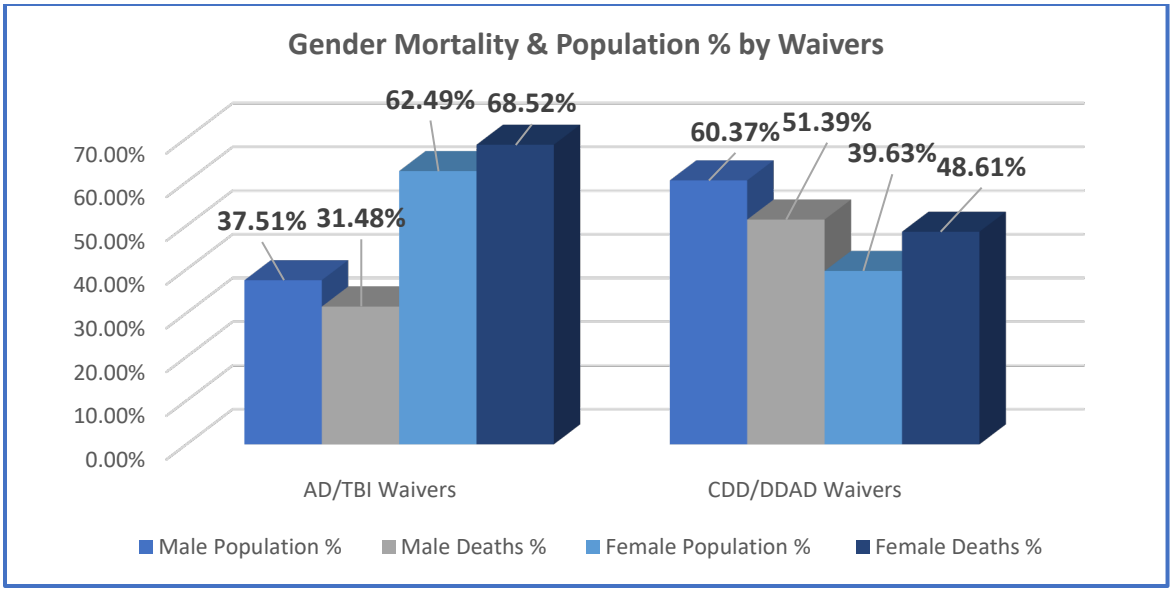
Gender	% Waiver Population	Waiver Population Totals	% of Waiver Deaths	Total Waiver Deaths	Waiver Mortality Rate* by Gender
Male	37.51%	2746	31.48%	153	55.78
Female	62.49%	4574	68.52%	333	72.80

**Rate is the number of deaths per 1000 AD/TBI Waiver of same-gender participants.*

Mortality Percentages and Rates by Gender for CDD/DDAD Waivers

Gender	% Waiver Population	Waiver Population Totals	% of Waiver Deaths	Total Waiver Deaths	Waiver Mortality Rate* by Gender
Male	60.37%	3185	51.39%	45	13.56
Female	39.63%	2091	48.61%	31	18.94

**Rate is the number of deaths per 1000 CDD/DDAD Waiver same-gender participants*

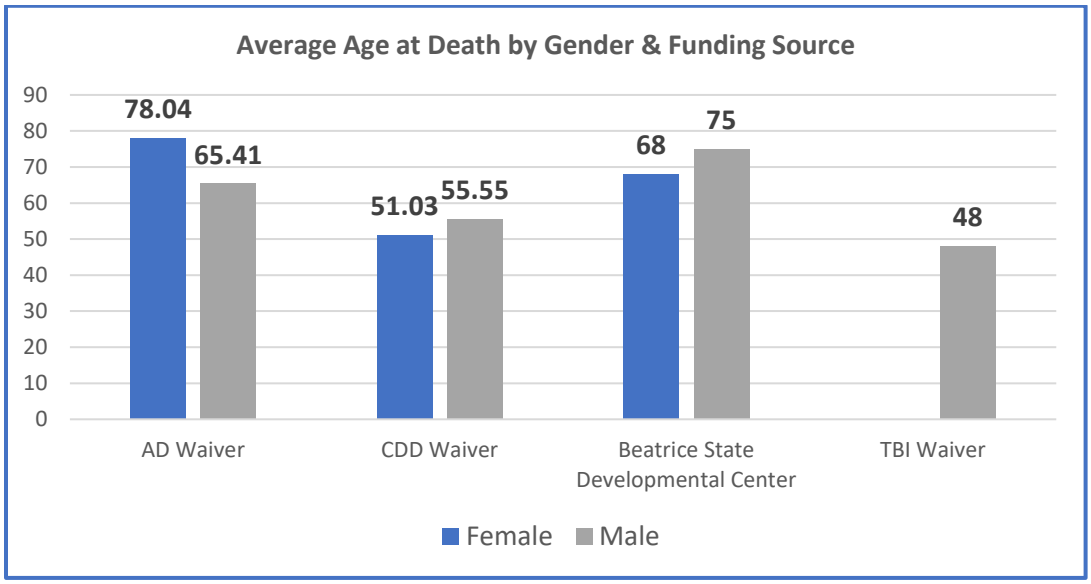


The higher mortality rate for the AD/TBI waivers is a result of the predominance of older individuals in that population. In both waiver populations, the female death rate was higher than the male death rate. The percentage of mortalities by gender was similar to the gender percentages in the population for both the Waiver groups with only a 5-10% disparity, as shown in the chart above.

Mortality and Age

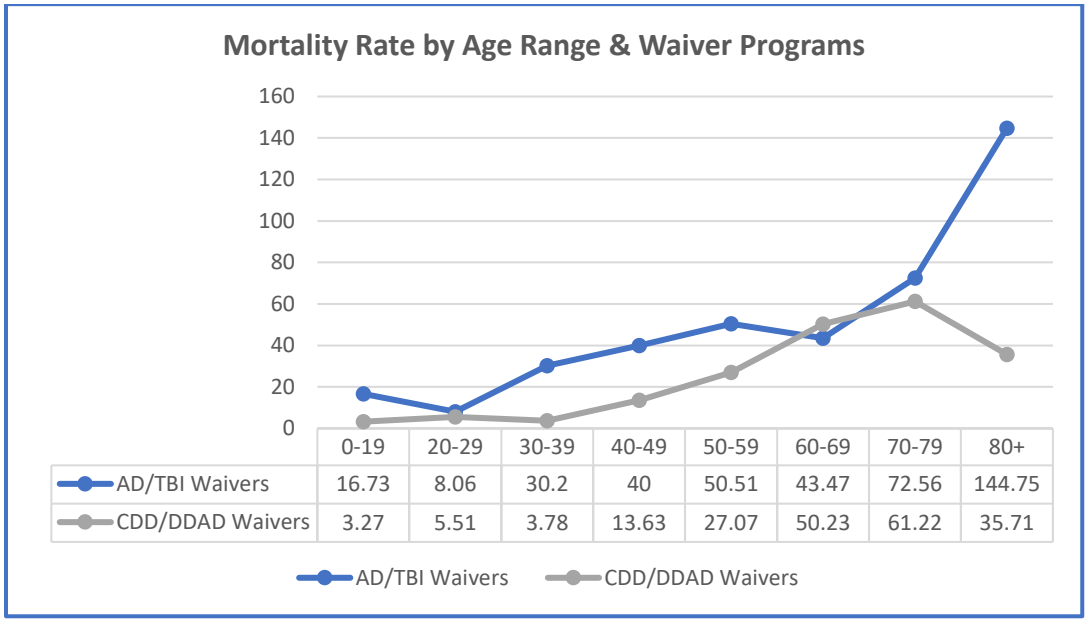
The average age at death across all waivers was **72.22** years. The average age at death for CDD/DDAD waiver mortalities was **53.63** years. The average age at death for AD/TBI waiver mortalities was **75.12**.

The following chart illustrates the average age at death by gender for each of the waiver groups or funding sources:



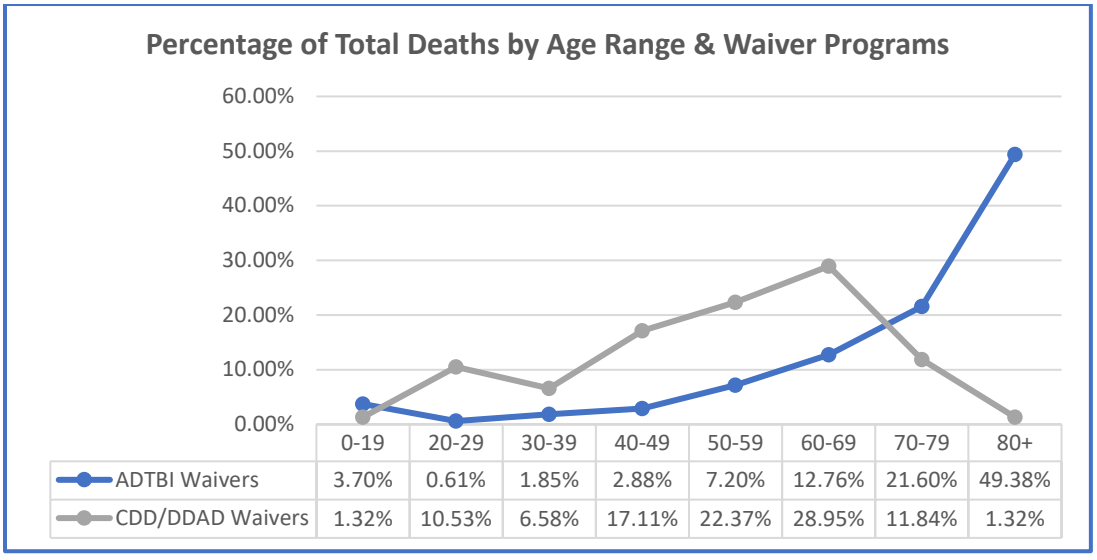
The relationship between age and mortality is illustrated in the chart below for the AD/TBI and CDD/DDAD waiver programs. The trends demonstrated follow the expected upward trend in mortality rates as participants age. There is a marked increase in the mortality rates of the CDD/DDAD waiver program population by the 5th decade of life, while the significant increase in the mortality rate for the AD/TBI waiver program population does

not occur until the 7th decade of life.



	0-19	20-29	30-39	40-49	50-59	60-69	70-79	80+
AD/TBI Waivers	16.73	8.06	30.2	40	50.51	43.47	72.56	144.75
CDD/DDAD Waivers	3.27	5.51	3.78	13.63	27.07	50.23	61.22	35.71

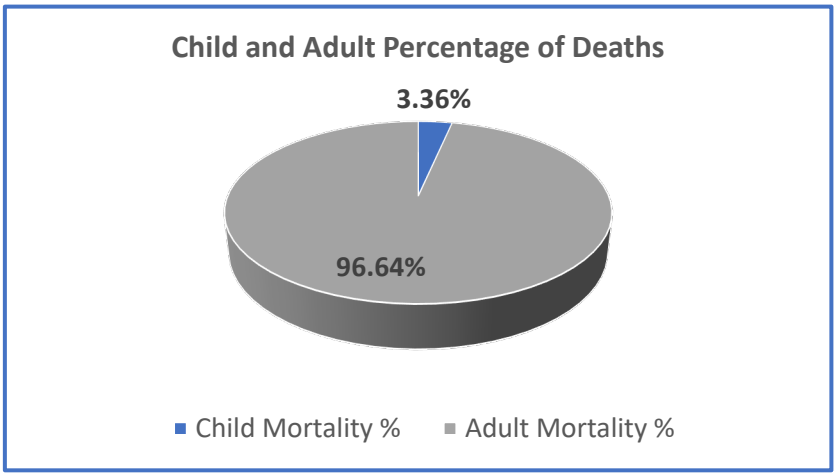
The chart below shows the percentage of deaths for each age range for the AD/TBI and CDD/DDAD waiver programs. For the CDD/DDAD waiver participants, the percentage of deaths peaks during the 6th decade, reflecting the lower life expectancy of the IDD population. In the AD/TBI waiver programs, the percentage of deaths continues to dramatically increase into the 8th decade.



	0-19	20-29	30-39	40-49	50-59	60-69	70-79	80+
ADTBI Waivers	3.70%	0.61%	1.85%	2.88%	7.20%	12.76%	21.60%	49.38%
CDD/DDAD Waivers	1.32%	10.53%	6.58%	17.11%	22.37%	28.95%	11.84%	1.32%

The chart to the right illustrates the percentage of child deaths as compared to adults. A child is defined as 19 years of age or younger.

Eighteen (18) children died between 7/1/2022 and 6/30/2023. All child participants who died were living in personal homes; seventeen (17) were receiving AD waiver services and one (1) was receiving CDD waiver services.



Data Generated from the Mortality Review Process

The information presented in this section of the report summarizes only those mortalities that were reviewed by the nurse investigators. Therefore, the mortality data will differ from the information presented in the previous section.

The mortality nurse investigators completed **574** investigations in this reporting period. Investigations yield a much richer set of mortality data than initial reviews (triage), increasing the ability to complete more in-depth analysis and to determine trends and significant correlations that will lead to individual and systemic improvements.

Expected, Unexpected, and Unexplained Deaths

Expected deaths are deaths that occur due to advanced age and/or progression of a diagnosed life-threatening illness.

An unexpected mortality is a death that was not anticipated because

- The cause of death is from external causes (unnatural) or is unrelated to pre-existing illnesses or conditions, *OR*
- Any pre-existing illnesses or conditions were not life-threatening and were being managed effectively and the individual was less than 75 years old.

The possible causes of death for an unexpected mortality might include accidental death, sudden acute illness unrelated to pre-existing medical illnesses or conditions, neglect or abuse, or homicide/suicide.

An unexplained mortality is a death with an unknown cause and an autopsy is not performed or the results of the autopsy are either inconclusive or unknown.

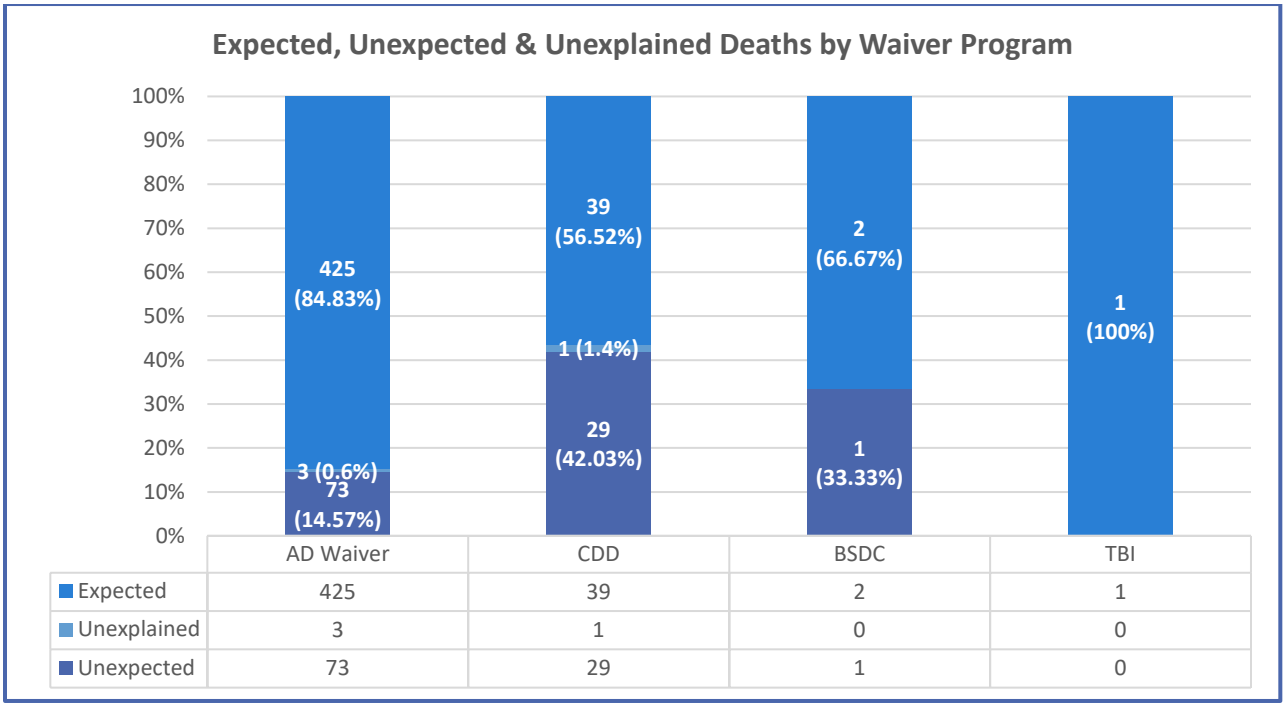
A focus on unexpected deaths provides the opportunity to:

- identify areas of concern;
- identify opportunities for improvement;
- develop intervention strategies;
- develop systemic improvement strategies;
- develop risk mitigation strategies, promote safety, support well-being, and avoid preventable adverse outcomes.

A comparison of expected, unexpected, and unexplained mortalities of the AD waiver and the CDD waiver

programs reveals that the unexpected/unexplained deaths for the AD waiver mortalities comprised only 15% of all AD Waiver deaths, while unexpected/unexplained deaths in the CDD waiver mortalities were 43.43% of the total CD waiver deaths.

There were only three (3) deaths of participants residing at the BSDC, one (1) of which was an unexpected death.

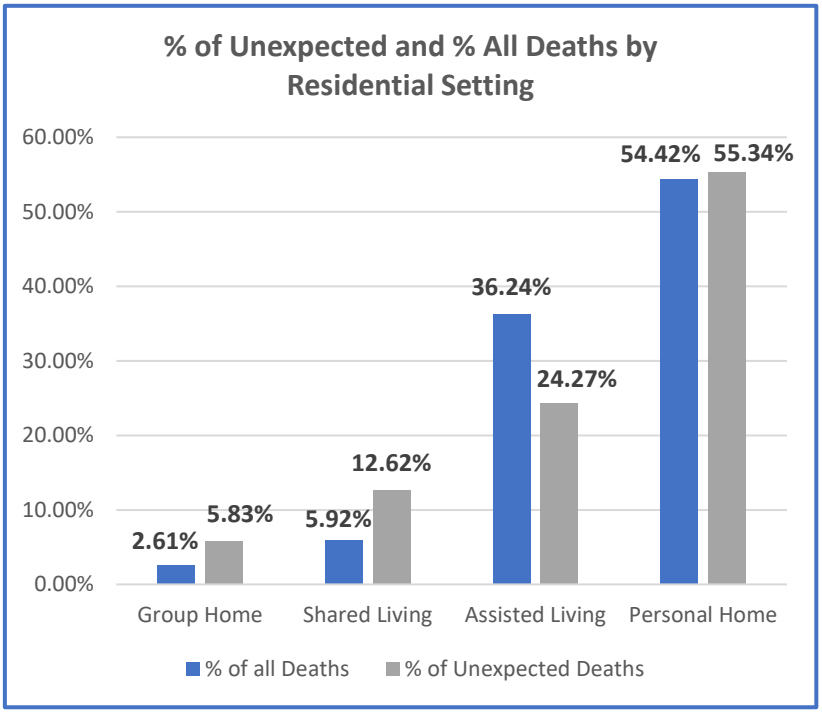


	AD Waiver	CDD	BSDC	TBI
Expected	425	39	2	1
Unexplained	3	1	0	0
Unexpected	73	29	1	0

81.36% of all mortalities were expected and the causes of death were related to the pre-existing medical conditions and illnesses experienced by participants. For example, people who died suddenly of a cardiac arrest and had a medical history that included coronary artery disease are considered expected deaths.

Unexpected Deaths and Residential Setting

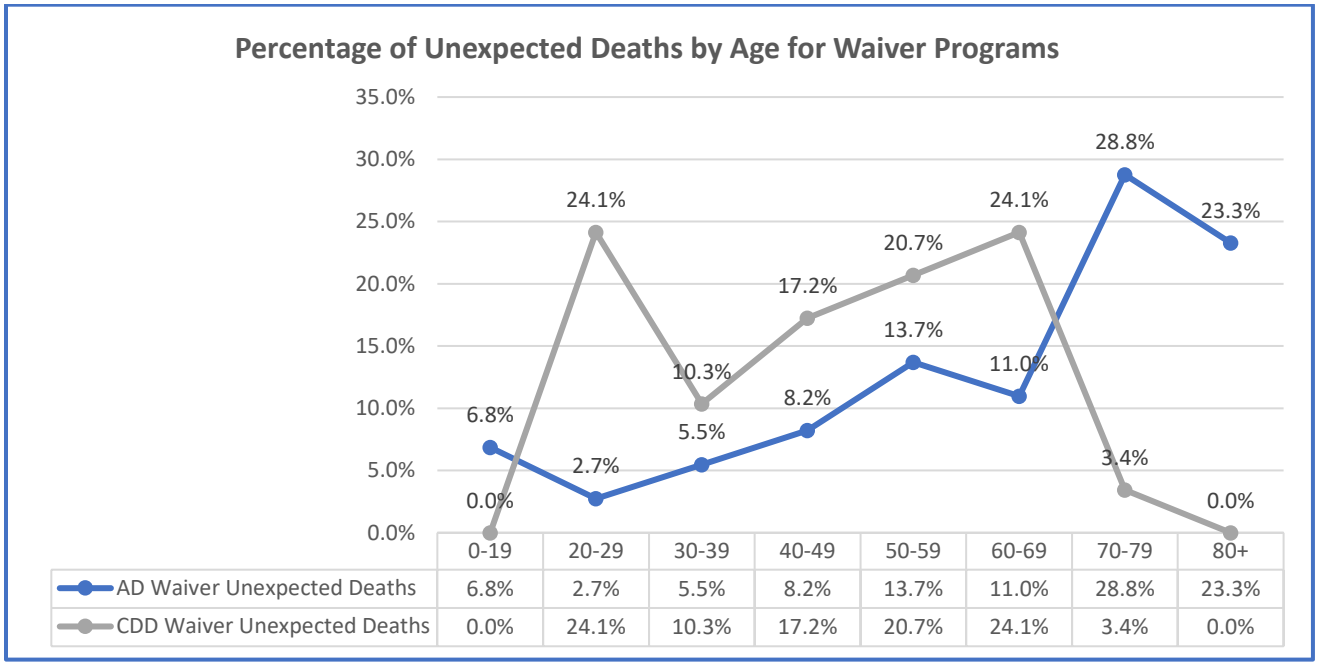
When the percentages of unexpected and total deaths were examined in residential settings, there were significant findings:



- **2.61%** of all deaths were participants living in a group home setting, but **5.83%** of unexpected deaths were group home residents. The average age at death for those unexpected deaths was 46.83 years.
- Deaths of participants residing in a Shared Living setting accounted for **5.92%** of all deaths, but unexpected deaths of Shared Living residents accounted for **12.62%**. The average age at death for Shared Living mortalities was 46.69 years.
- The average age at the time of death of participants living in assisted living settings was 85.25 years which contributes to a lower-than-expected percentage of unexpected deaths. By comparison, the average age at the time of death for individuals living in their own homes was 64.67 years.

Unexpected Deaths and Age

The graph below illustrates the percentages of unexpected deaths by age range for the AD waiver and the CDD waiver programs. 72.3% of all unexpected deaths for CDD waiver mortalities occurred before the age of 60, while only 36.9% of unexpected deaths for AD waiver mortalities occurred before the age of 60.



Risk Factors

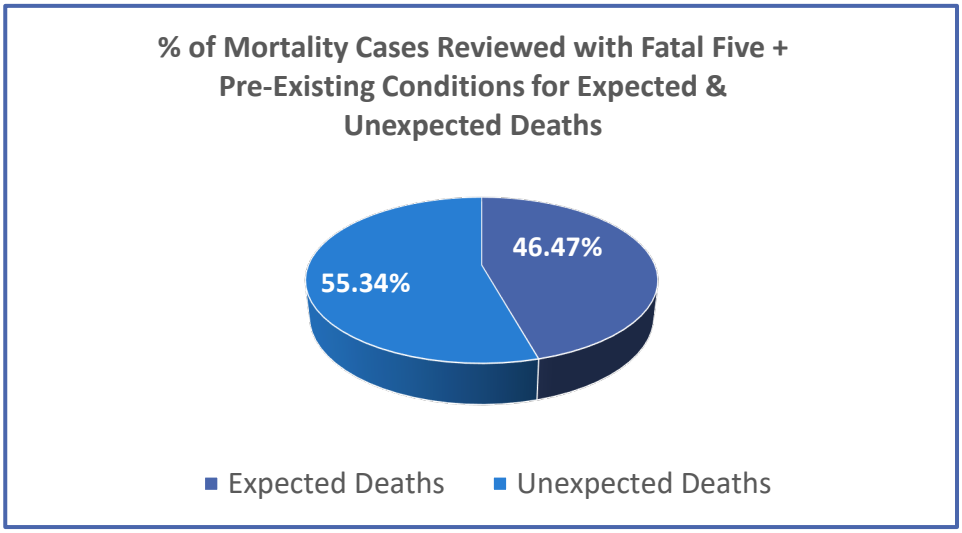
Fatal Five Plus

There is a strong body of literature that identifies illnesses and conditions that are risks for mortality in the intellectually and developmentally disabled population, known as the "Fatal Five." More recently, an additional condition has been added to the original "Fatal Five" which has been renamed "Fatal Five Plus." These conditions include:

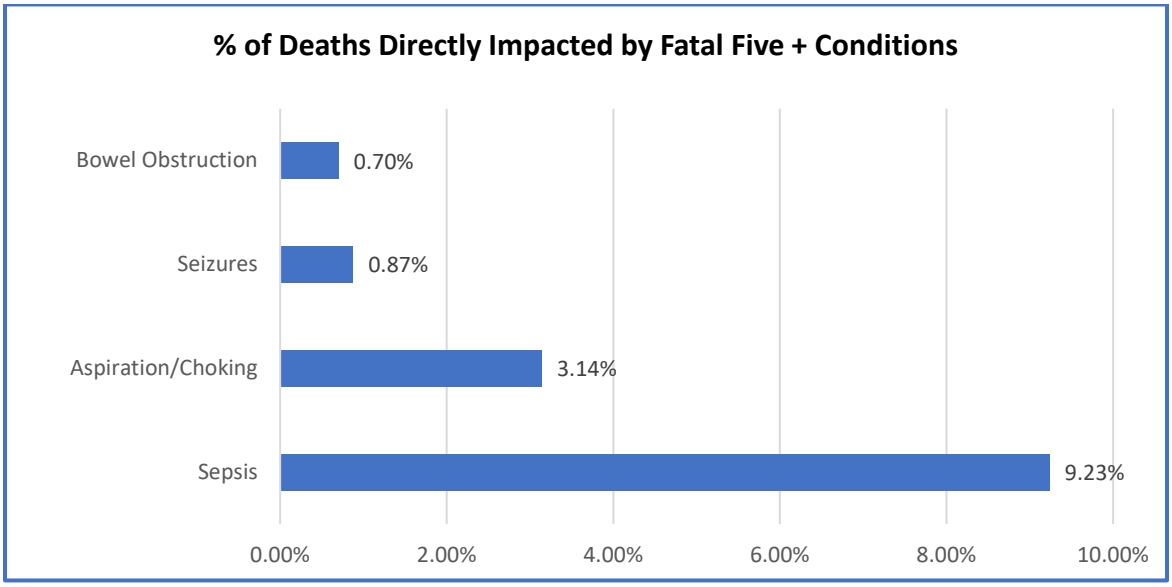
- Aspiration/Choking
- Bowel Obstruction/Constipation
- Dehydration
- Gastroesophageal Reflux Disease (GERD)
- Seizure Disorders
- Sepsis and Septicemia

The Fatal Five Plus conditions are all mortality risks that can be mitigated when identified early enough in the course of the illness or when steps are taken to prevent the development of the condition.

The chart on the right shows the percentage of mortalities who had Fatal Five Plus pre-existing conditions that were noted in mortality investigations completed in the past year for both expected and unexpected deaths. The percentage of Fatal Five Plus conditions is almost 10% higher in unexpected deaths than in expected deaths.



Below is a graphic that illustrates the percentages of deaths that were found to be directly impacted by each of the Fatal Five Plus conditions that were investigated in the past year.



There were no deaths found to be directly impacted by dehydration or gastroesophageal reflux disease.

Mortality and Falls

Literature supports the experience of falls as a predictive factor for mortality, especially in the elderly. The data obtained from DDD mortality reviews support that premise. During the reporting period, half **(50.61%)** of all mortalities that were investigated had evidence of 1 or more falls during 6 months preceding the time of death. A similar percentage **(49.51%)** was found in unexpected mortalities. This data analysis finding could lead to several possible conclusions:

- An increase in incidents of falls should trigger concern about overall health decline and frailty concerns that might warrant healthcare and level of service evaluation, AND/OR
- Falls themselves may increase the risk for premature death, so routine frailty/mobility assessments and implementation of individualized fall prevention strategies might be warranted to decrease fall risk.

39.13% of CDD waiver mortalities experienced falls in the 6 months prior to death, while **50.9%** of the AD waiver mortalities experience a fall in the 6 months prior to death.

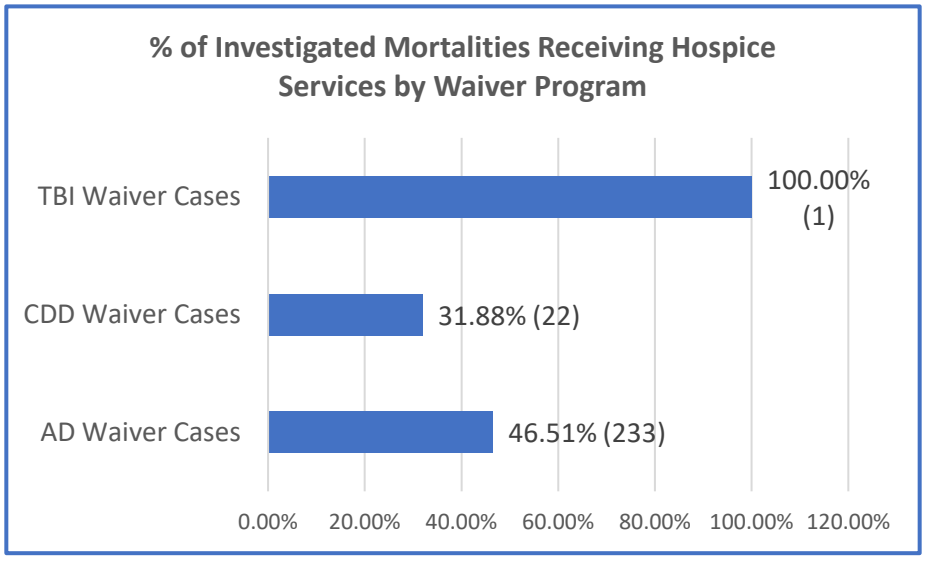
Abuse, Neglect, and Exploitation

Of the 574 mortalities investigated this year, **23** cases were found to have suspected abuse or neglect and were referred to Adult Protection Services for investigation. These referrals were either made by DDD, Mortality Nurse Investigators, or by outside entities, such as the hospital in which the participant passed. The referrals were primarily reflected by the concerns about the lack of provision of appropriate healthcare and the lack of attending to the basic needs of a vulnerable adult. All of these situations likely led to a chain of events that may have contributed to the timing of the individual's death or the quality of the end-of-life experience. Additional data about the attributes of suspected abuse or neglect cases are contained in the table below:

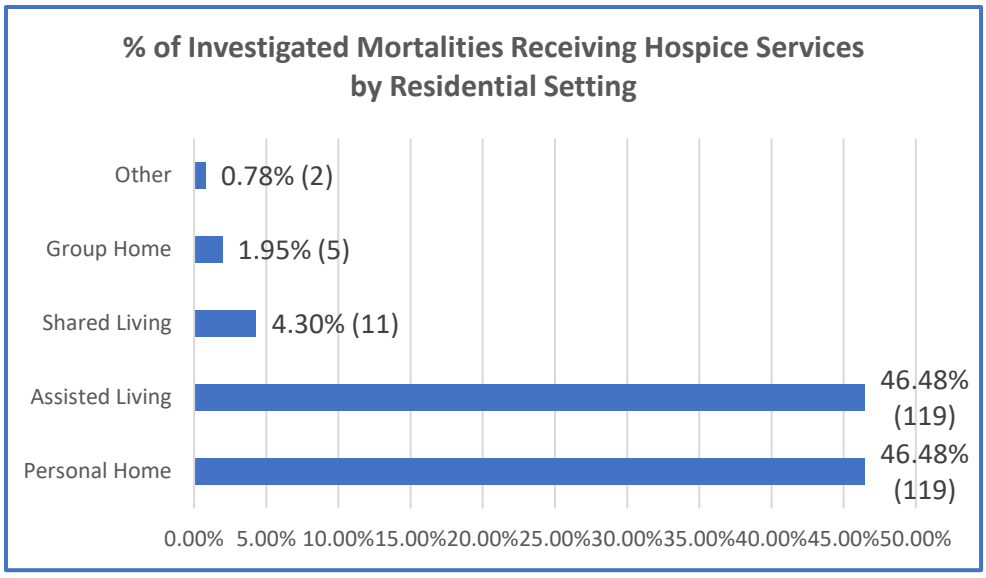
Age Range	Residential Setting	Type of Death	Waiver Program
29-40 (2)	Personal Home (15)	Expected (15)	AD waiver (21)
41-60 (5)	Assisted Living (6)	Unexpected (8)	CDD waiver (2)
61-80 (8)	Shared Living (1)		
80+ (8)	Group Home (1)		

Mortality and Hospice Care

The inclusion of end-of-life planning, including hospice care, for individuals receiving services, has been supported by NE DHHS DDD. The use of hospice services supports people through the final stages of terminal and/or chronic irreversible progressive illness while assisting them to remain in their residence of choice. **256** (44.6%) of all mortality cases investigated were receiving hospice care at the time of their deaths.



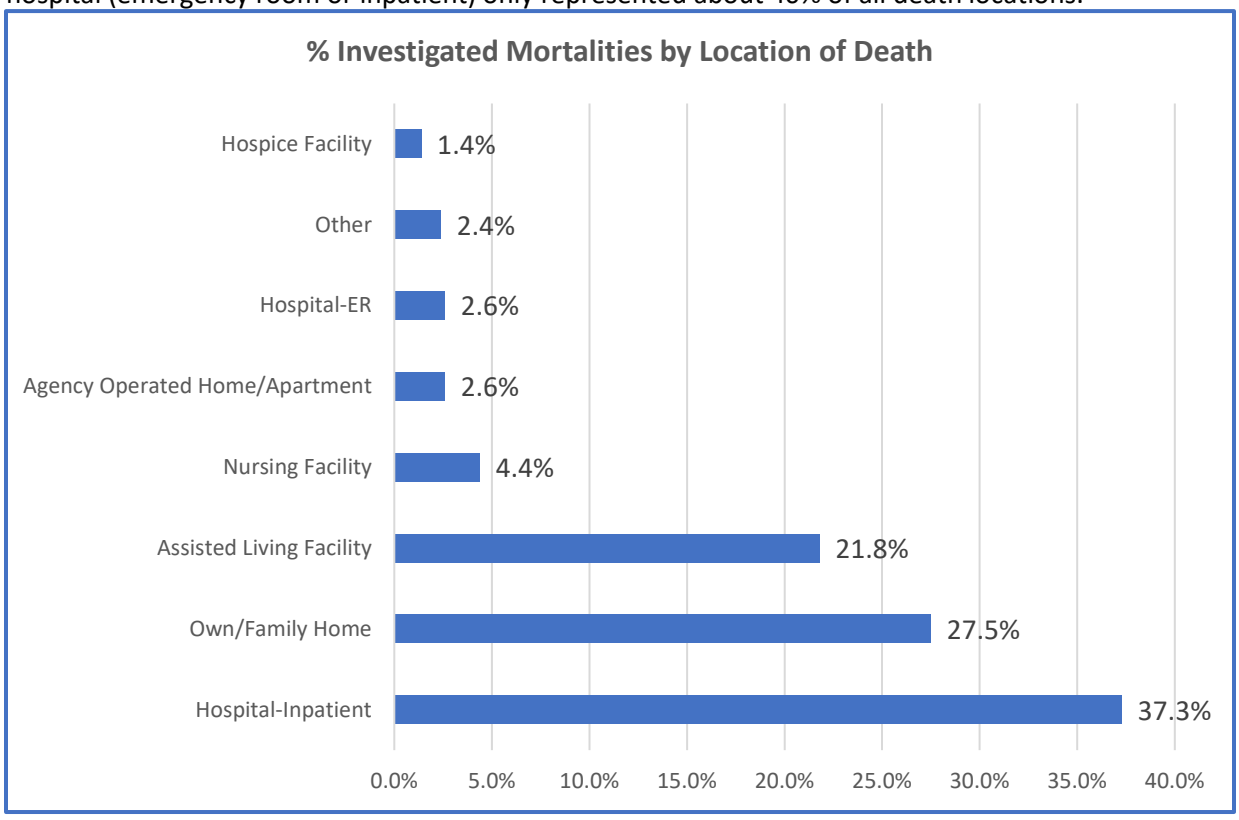
46.51% of AD Waiver mortalities received hospice services, compared to **31.88%** of CDD Waiver mortalities.



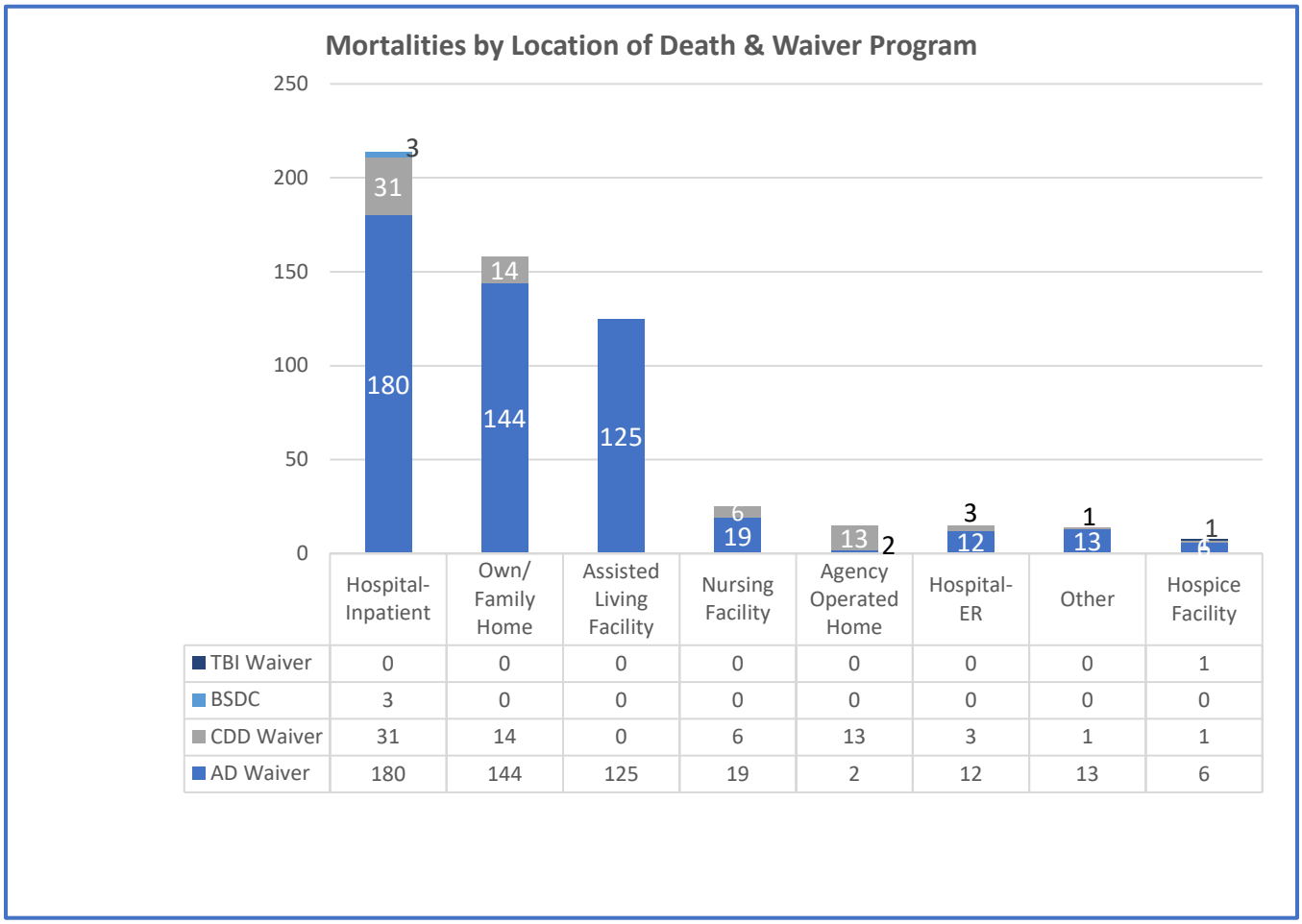
Most (93.36%) of the recipients of hospice care were living in their personal homes and assisted living and 97.9% of those were receiving AD waiver services.

Mortalities and Location of Death

The graph below illustrates the percentages of investigated mortalities by the location of death. Deaths in a hospital (emergency room or inpatient) only represented about 40% of all death locations.



The graph below shows the location of death by funding program. The "Agency Operated Home" refers to the combination of Shared Living settings and Group Homes.



Leading Causes of Death

545 causes of death were received from vital records for the deaths investigated during the reporting period. The table below illustrates the cause of death categories in rank order, their prevalence, and sub-categories:

Cause of Death Category	Percentage of Deaths	Sub-Categories Included
Cardiovascular System Disease	29.09%	Sudden cardiac death, Myocardial Infarction, Congestive Heart Failure, Cardiac Arrest, Atherosclerosis, Arrhythmia
Respiratory System Disorder	20.21%	Respiratory disease, Respiratory Failure, Respiratory Condition
Nervous System Disorders	14.98%	Alzheimer's and Dementia, Encephalopathy, Parkinson's, Seizures/Epilepsy, Stroke
Infections	12.20%	Aspiration Pneumonia, Influenza, Pneumonia, Sepsis, UTI, Respiratory Infection, COVID-19
Cancers	6.97%	Breast, Colon, Leukemia, Lung, Lymphoma, Pancreatic
Renal System Disorders	0.87%	(No sub-categories identified)
Gastrointestinal/Digestive	0.87%	Bowel Obstruction, GI Bleed, Other GI

System Disorders		Disease
External Causes	0.87%	Choking/Aspiration, Falls, Motor Vehicle Accident
Endocrine System Disorder	0.35%	Diabetes, Other
Musculoskeletal Disorders	0.35%	(No sub-categories identified)

Heart disease remains the leading cause of death, and is followed by Respiratory System Disease. 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 a heart attack (myocardial infarction), heart failure, and arrhythmias. Respiratory System Disorders can include COPD/Emphysema, respiratory failure, and other chronic lung diseases. Respiratory infections and Aspiration pneumonia were not included in this category but were included in the "Infections" category. Multiple co-morbidities, particularly cardiovascular disease, and respiratory illness, are associated with increased mortality risk.

The table below illustrates the incidents of the top five (5) causes of death for each waiver group, with Alzheimer's and Dementia incidents shown separately from the Nervous System Disorders. The average age at death for each waiver group is also shown. On average, the participants in the CDD/DDAD waivers and the BSDC participants died **22.32** years earlier than the participants in the AD/TBI waivers with similar causes of death.

Cause of Death	Incidents AD/TBI Waivers	Incidents CDD/DDAD/ BSDC Waivers	Average Age At Death AD/TBI Waivers	Average Age At Death CDD/DDAD Waivers & BSDC
Cardiovascular Disease	151	17	76.43	54.59
Respiratory Disease	100	11	70.42	48
Nervous System Disorders	81	8	80.49	42.5
Alzheimer's/Dementia	37	0	85.38	NA
Infections	50	19	71.8	62.21
Cancers	33	6	74.94	55.17

Analysis of Cancer Deaths

Lung cancer is the most prevalent, comprising 30% of all mortalities from cancers. 30% of all cancers were not specified on the death notices, limiting a more thorough analysis.

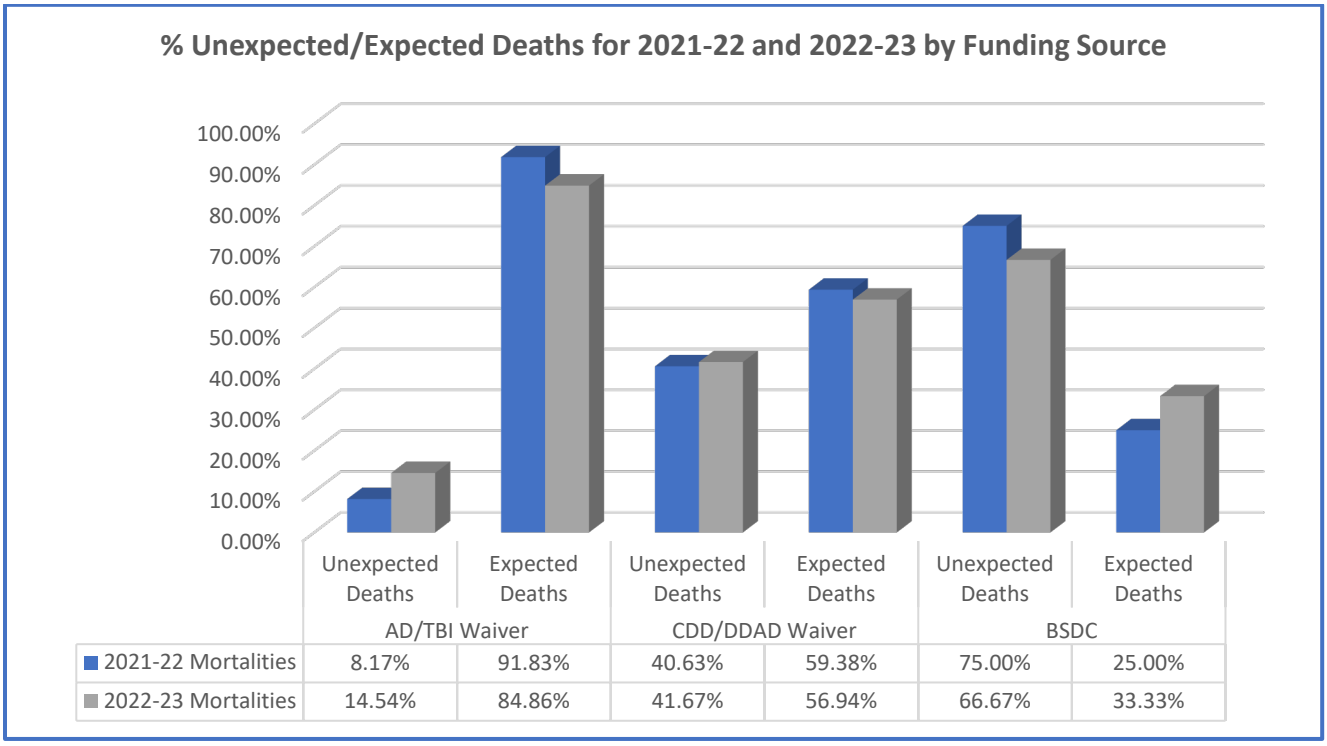
Type of Cancer	# of Cancer Deaths	% of Cancer Deaths
Lung	12	30.77%
Colon	5	12.82%
Breast	3	7.69%
Endometrial/Uterine	3	2.56%
Lymphoma	1	2.56%
Leukemia	1	2.56%
Prostate	1	2.56%
Waldenstrom Macroglobulinemia	1	2.56%
Not specified	12	30.77%

Mortality Trends

This is the second annual mortality report for Nebraska DHHS-DDD. While we have a limited number of years of mortality data, we can make a few comparisons between the current year's data and last year's data.

Expected and Unexpected Deaths

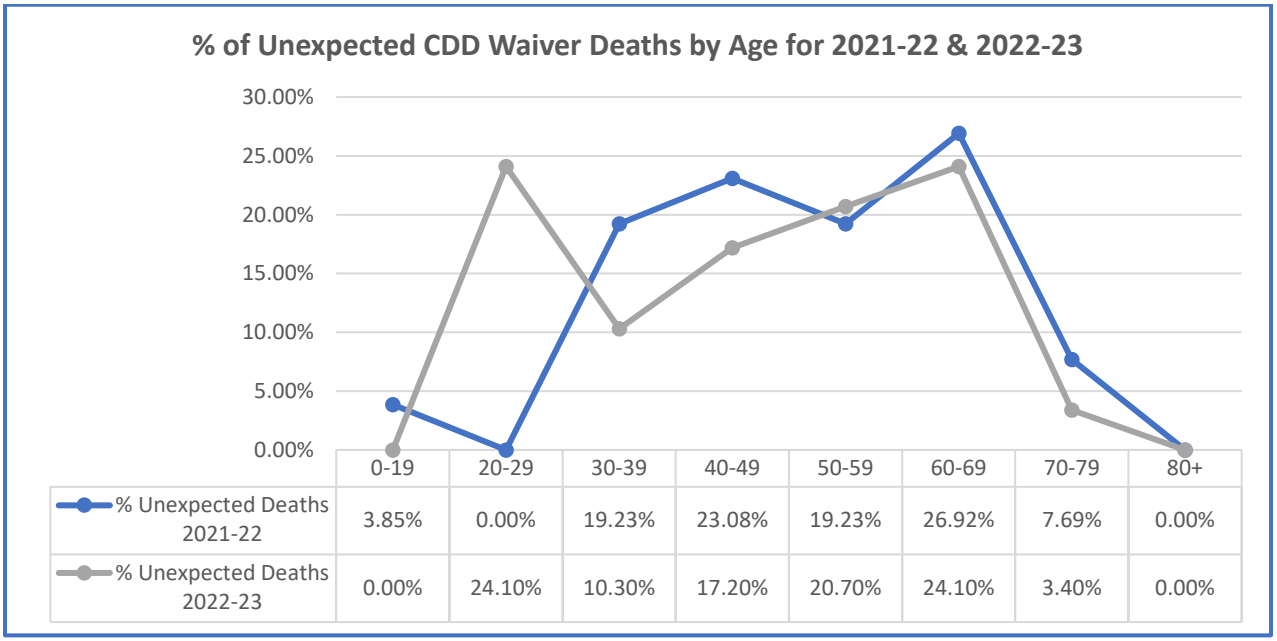
There were only slight differences identified in the comparison of the 2021-22 and 2022-23 data in expected and unexpected deaths, as shown in the chart below. There continues to be a much greater percentage of unexpected deaths occurring in the IDD population than in the AD population, likely a reflection of the increased age of the AD population and the lower life expectancy of the IDD population.



	AD/TBI Waiver		CDD/DDAD Waiver		BSDC	
	Unexpected Deaths	Expected Deaths	Unexpected Deaths	Expected Deaths	Unexpected Deaths	Expected Deaths
2021-22 Mortalities	8.17%	91.83%	40.63%	59.38%	75.00%	25.00%
2022-23 Mortalities	14.54%	84.86%	41.67%	56.94%	66.67%	33.33%

Deaths and Age

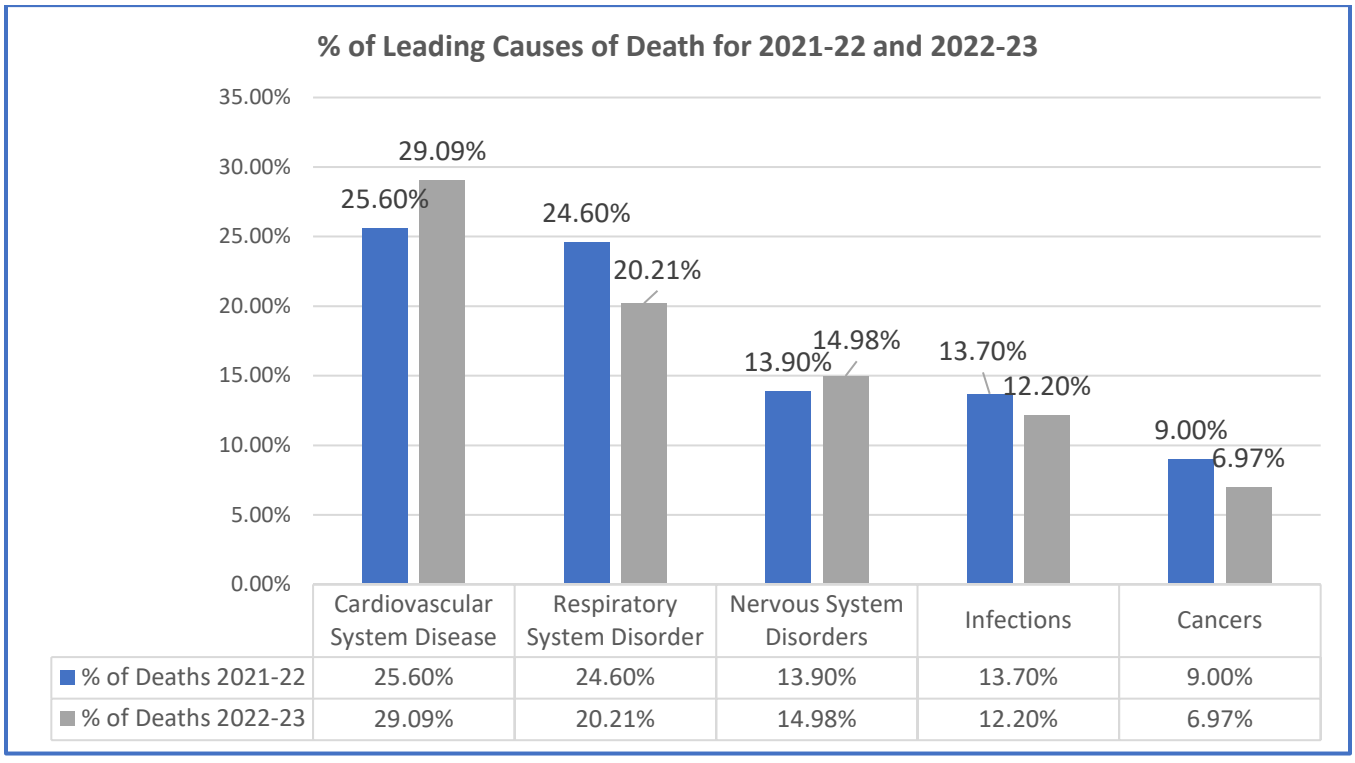
When comparing 2021-22 and 2022-23 unexpected CDD deaths by age ranges, 65.39% of all unexpected deaths occurred by the age of 60 in 2021-22 and 72.5% of all unexpected deaths occurred by the age of 60 in 2022-23. This represents a 7% increase in unexpected deaths before the age of 60 in the past year, as illustrated in the graph below.



	0-19	20-29	30-39	40-49	50-59	60-69	70-79	80+
% Unexpected Deaths 2021-22	3.85%	0.00%	19.23%	23.08%	19.23%	26.92%	7.69%	0.00%
% Unexpected Deaths 2022-23	0.00%	24.10%	10.30%	17.20%	20.70%	24.10%	3.40%	0.00%

Leading Causes of Death

The top-ranking causes of death did not change from 2021-22 to 2023-23 years, but the percentages did show some marginal change, as shown in the chart below.



	Cardiovascular System Disease	Respiratory System Disorder	Nervous System Disorders	Infections	Cancers
% of Deaths 2021-22	25.60%	24.60%	13.90%	13.70%	9.00%
% of Deaths 2022-23	29.09%	20.21%	14.98%	12.20%	6.97%

Benchmarks

Mortality Rate Comparisons

Benchmarks are standards by which similar items can be compared and can provide valuable context for data analysis. There are few relative benchmarks (data from other state agencies) available for use in comparing mortality data for persons with IDD and when data does exist, there may be differences in the way the data is reported and analyzed.

Caution should be used in comparing mortality rates across populations that may differ in terms of inclusion criteria for services. States vary in eligibility and enrollment criteria, yielding unlike populations which may complicate meaningful comparisons of mortality rates. The population in Nebraska that receives services from waiver programs is quite different in age composition and designation of Intellectual and Developmental Disabilities compared to other state agencies that primarily support persons with IDD. We have chosen to compare the mortality rates and average age at death for the CDD/DDAD waiver mortalities in order to have a more meaningful comparison with other state IDD support systems.

A comparison of crude mortality rates and average ages at death is listed in the table below:

Metric	NE CDD/DDAD Waiver Population	2020 GA IDD Population	2022 VA IDD Population	2022 NE General Population	2021 US General Population
Crude Mortality Rate	15.58/1000	16.2/1000	23.6/1000	9.21/1000	8.79/1000
Average Age at Death	53.63 years	54.40 years	54 years	80.0 years	76.4 years

While the Nebraska IDD crude mortality rate is better than in the states of Georgia and Virginia, the IDD population continues to have a higher mortality rate when compared to the general populations of both Nebraska and the United States, and the average age at death is about the same as the IDD populations in Georgia and Virginia. The average age at death for the Nebraska IDD population is more than 20 years lower than the general population in Nebraska and the U.S.