NEBRASKA

DEPT. OF HEALTH AND HUMAN SERVICES

DIVISION OF DEVELOPMENTAL DISABILITIES

Mortality Annual Report

FY 2021

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Liberty Healthcare Corporation

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Executive Summary

This annual report provides an overview of the mortalities of participants supported by the Department of Health and Human Services Developmental Disabilities Division (DHHS-DDD) services that occurred between July 15, 2021, and June 30, 2022. 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 **520** deaths reported resulting in a crude mortality rate of **47.21** per 1000 population.
- There were **72** deaths of participants receiving Comprehensive Developmental Disabilities (CDD) waiver services (individuals designated with an intellectual or developmental disability), for a crude mortality rate of **15.73** per 1000 population.
- The strongest predictors of mortality were 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/Developmental Disabilities Adult Day (DDAD) waiver programs was **55.93** years.
- The average age at death for individuals receiving services from the Aged and Disabled (AD) and the Traumatic Brain Injury (TBI) waiver programs was **74.97** years.
- Among CDD/DDAD waiver participants, **39.7%** of mortalities were classified as unexpected, while among the AD/TBI waiver participants, **8.2%** were classified as unexpected deaths.
- **Cardiovascular disease** continues to be the leading cause of death (25.6%) in both the participants in AD and CDD populations, followed closely by **Respiratory System diseases** (24.6%).
- Hospice supports were provided in **49.4%** of expected deaths 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 of 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 2021 and July 2022, the mortality review process has evolved, resulting in the following improvements:

- A more robust mortality nurse investigation process;
- Collection of multiple additional data sets related to mortality and quality of services;
- Comprehensive analysis of data related to mortalities leading to the discovery of relationships and patterns that point to opportunities for systemic improvements in services;
- An enhanced Mortality Review Committee that includes external stakeholders and advocates;

- A process for generation and submission of recommendations for improvements that are data-driven, designed to improve the quality of services, and prevent avoidable participant deaths;
- A process for developing and reporting the summary and analysis of data on a monthly, quarterly and annual basis.

Additional improvements and enhancements are planned in the coming year that include standardizing the process for submitting notifications of death, further enhancing and refining the data collection and analysis processes to yield more trending and predictability capacity, and implementing a more robust technical assistance and remediation process geared toward enhancing improvements in service quality.

Critical Components of the Mortality Review Process

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

Notification of Death Reporting System

Currently, the Notification of Death process varies among the waiver groups and the Beatrice State Developmental Center:

- When an Individual receiving Medicaid HCBS Comprehensive Developmental Disabilities Waiver (CDD) or Developmental Disabilities Adult Day Waiver (DDAD) services passes away, the provider makes a verbal report to the Service Coordinator as soon as possible and fills out A Death of a Participant General Event Report (GER) in Therap within 24 hours.
- When an individual is receiving Medicaid HCBS Aged and Disabled Waiver (A/D) services or Traumatic Brain Injury Waiver (TBI) services, the Local Agency/Service Coordinator makes a verbal or written report by telephone or e-mail to the HCBS Waiver Unit Staff Assistant by the next business day. They also complete a Local Level Incident Form in CONNECT within ten (10) days of becoming aware of the death.
- When an Individual is residing at Beatrice State Developmental Center (BSDC), notifications will be made according to Beatrice State Developmental Center Operational Guideline Death at BSDC or Death Away from BSDC accordingly and a GER will be completed.

A goal in the coming year is to have deaths of participants across all waiver programs reported via the Therap system by completing a “Death of A Participant” General Event Report (GER). This will streamline and standardize not only the method and platform by which deaths are reported, but will also standardize the data reported and collected on death notification forms, increasing the reliability of data analyzed about mortalities.

Triage Process

Liberty’s Mortality Review Nurse Investigator triages (screens) each notification of death to determine if it 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 will be expedited. An expedited review will be prioritized ahead of non-expedited reviews. Expedited deaths are always prioritized to be completed within 45 calendar days following triage. Non-Expedited deaths are reviewed as work on expedited deaths permits, but may not be completed within 45 calendar days of triage depending on the volume of death notices received.

If the initial triage review reveals potential signs of abuse/neglect or exploitation, the mortality nurse investigator alerts the DHHS-DDD Quality Administrator to the immediate concerns that may need to be addressed.

Nurse Mortality Review

To start the 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, and receipt of those documents is tracked and the documents are organized in preparation for the review.

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

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

The nurse mortality investigator completes the review using the documents received and completes the mortality review brief electronically, entering all appropriate data about the mortality. The investigator determines whether each mortality case:

- Is sent to the Mortality Review Committee for review;
- Requires recommendations or remediation to be sent to the provider;
- Requires a 2nd Level Physician Review;
- Should be closed with no further 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, 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 the questions about the mortality listed above.

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 DHHS-DDD 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 the 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 DHHS-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 (IDD) 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 DHHS-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 DHHS-DDD Quality Administrator (or designee), and then sent to the applicable provider, SC or BSDC. Liberty, in collaboration with the Quality Unit of DHHS-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, and Reporting of Mortality Data

Multiple sets of data are collected and stored during triage and 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 conditions

Additional data elements are being added to the data collection system as new questions emerge from data analysis.

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.

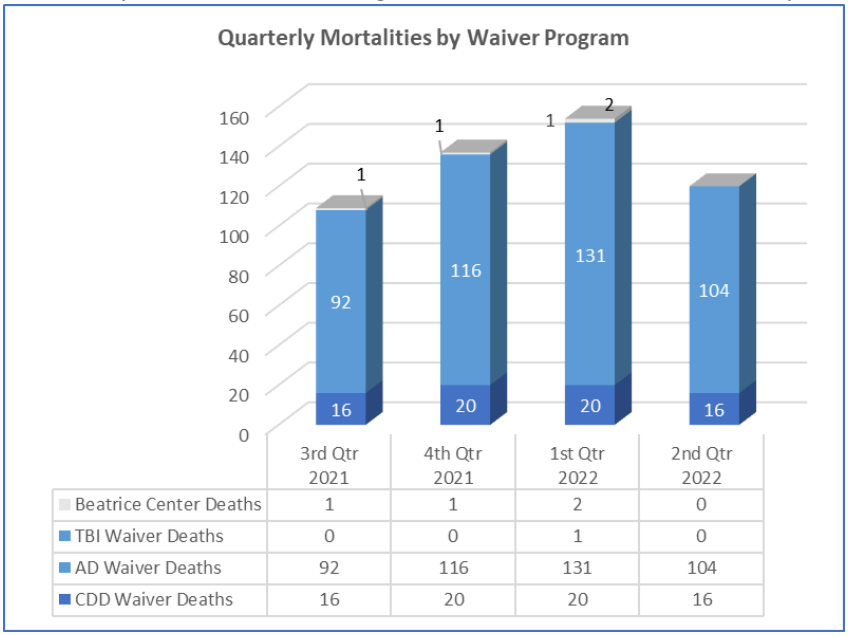
Analysis of All DHHS-DDD Mortalities

Overall Mortality Rate

Between July 15, 2021, and June 30, 2022, a total of **520** deaths occurred across all waiver programs and the Beatrice State Developmental Center, resulting in an overall crude mortality rate of **47.21** per 1,000.

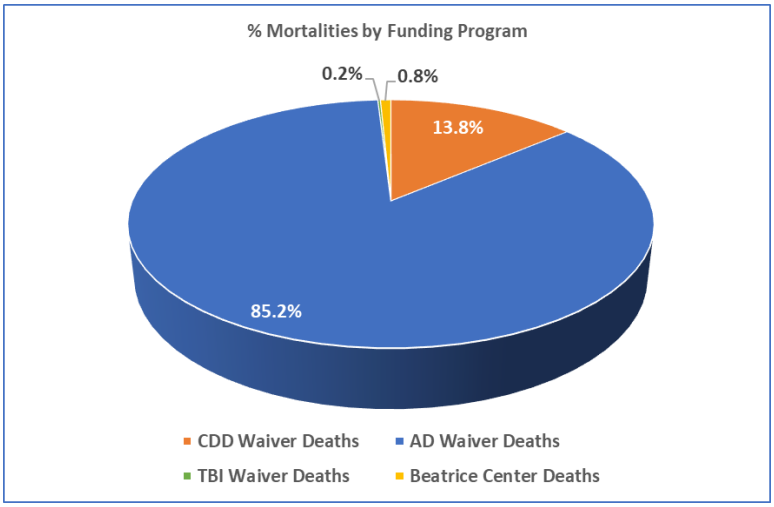
The overall mortality rate is not very useful for evaluating the mortality rate for the population of individuals with intellectual and developmental disabilities (IDD) because it includes a large percentage of the aging population receiving services from the Aging and Disabled (AD) waiver program. The AD waiver program serves 6,438 individuals, 4,053 (63%) of whom are 60 years and older, most of whom are likely 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 is a sizeable cohort of individuals with a designation of Intellectual and Developmental Disabilities receiving AD waiver services, we were unable to accurately determine that designation for all mortalities in this report. Moving forward, that will be a data point that will be collected in mortality reviews to report data about all of the IDD population.

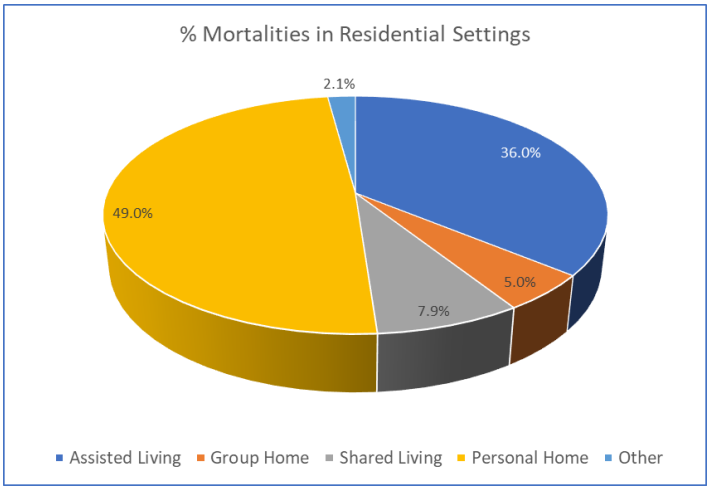


The chart on the left illustrates the mortalities by quarter for the past year as well as by the waiver program.

The chart on the right illustrates the percentage of mortalities by HCBS Waiver.

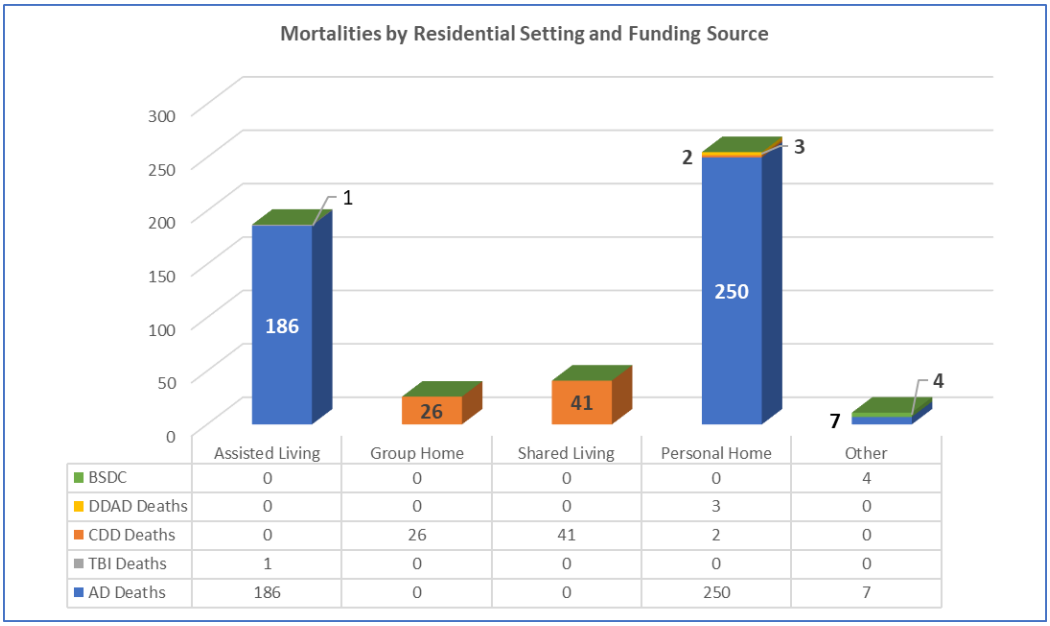


Mortality and Residential Setting



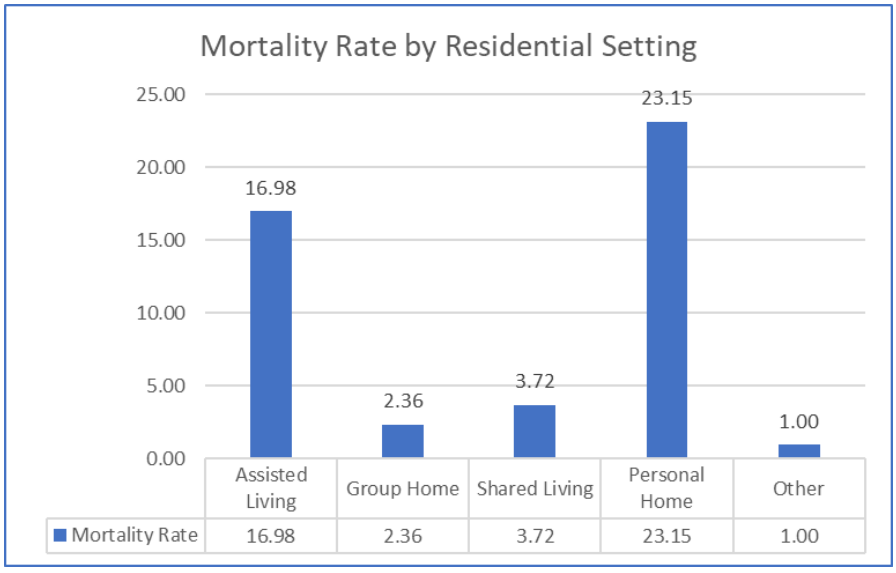
Almost half (49%) of participants who died were residing in their own homes immediately prior to death and 98% of those individuals were receiving AD waiver services.

Assisted Living settings accounted for 36% 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 TBI services.



The "Other" category includes four mortalities who were residing in BSDC, one AD waiver death that occurred in a nursing facility, and six (6) mortalities for which the residential category was listed as "other" or was unknown due to the information not being available before July 1, 2022.

The chart on the right illustrates the crude mortality rate for each residential setting. The highest mortality rates were for Personal Home and Assisted Living settings. Almost all (98% and 99.5% respectively) were participants receiving AD waiver services, while all (100%) of the Group Home and Shared Living participants who expired were receiving services from the CDD waiver program.



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 such 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

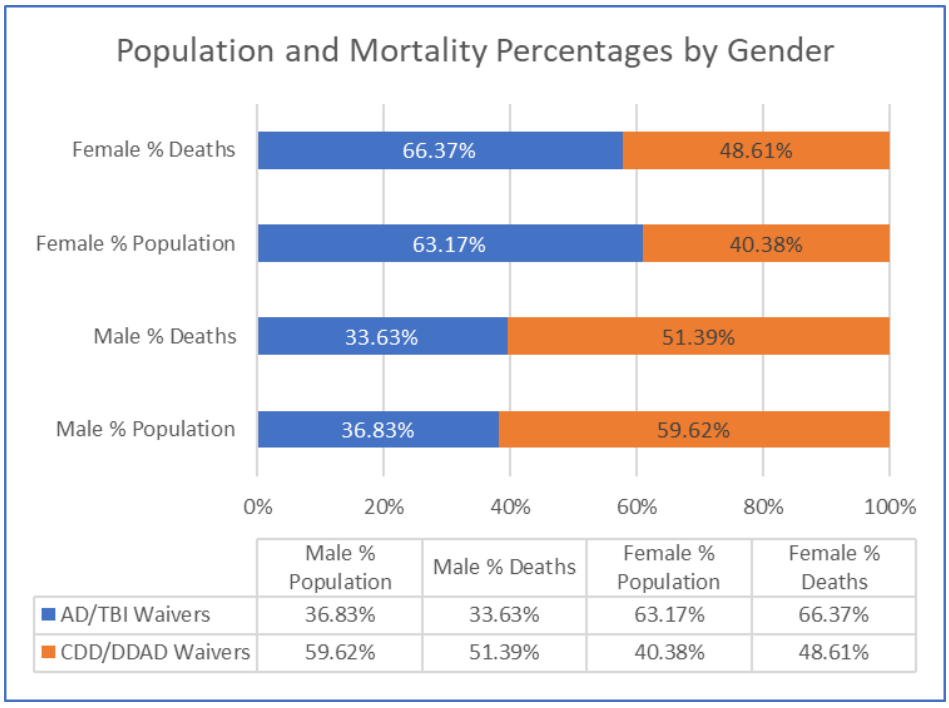
Gender	% Waiver Population	Waiver Population Totals	% of Waiver Deaths	Total Waiver Deaths	Waiver Mortality Rate by Gender
Male	36.83%	2371	33.63%	149	62.84
Female	63.17%	4067	66.37%	294	72.29

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	59.62%	2729	51.39%	37	13.56
Female	40.38%	1848	48.61%	35	18.94

The higher mortality rate for the AD/TBI waivers is a result of the predominance of older individuals in that population. In both of the waiver programs, females have a higher mortality rate than males.

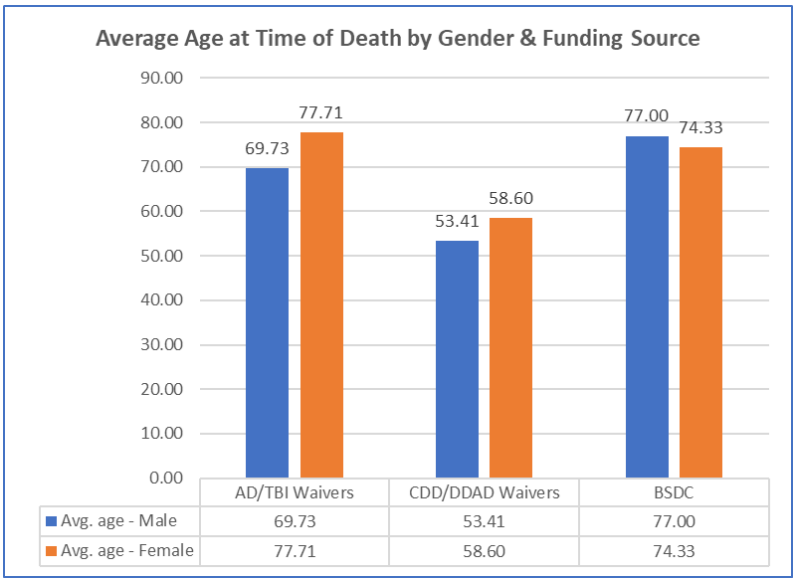
While the percentage of mortalities by gender was similar to the gender percentages in the population of the AD/TBI waiver programs, the percentage of mortalities by gender in the CDD/DDAD waivers was slightly more disparate as shown in the chart below.



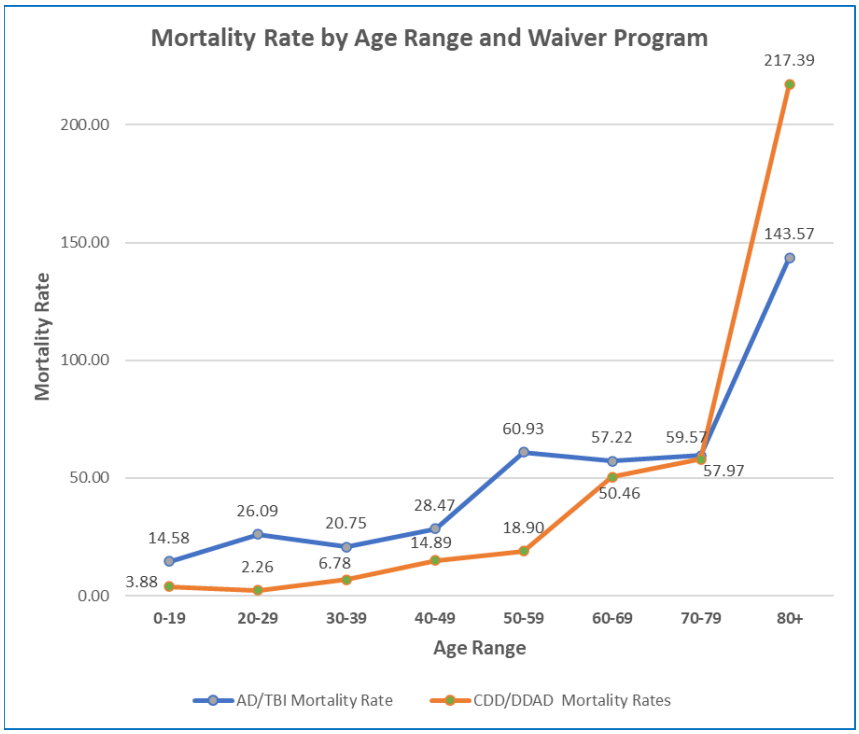
Mortality and Age

The average age at death across all waivers was **72.23** years. The average age at death for the CDD/DDAD waiver mortalities was **55.93** years. The average age at death for the AD/TBI waiver mortalities was **74.97**.

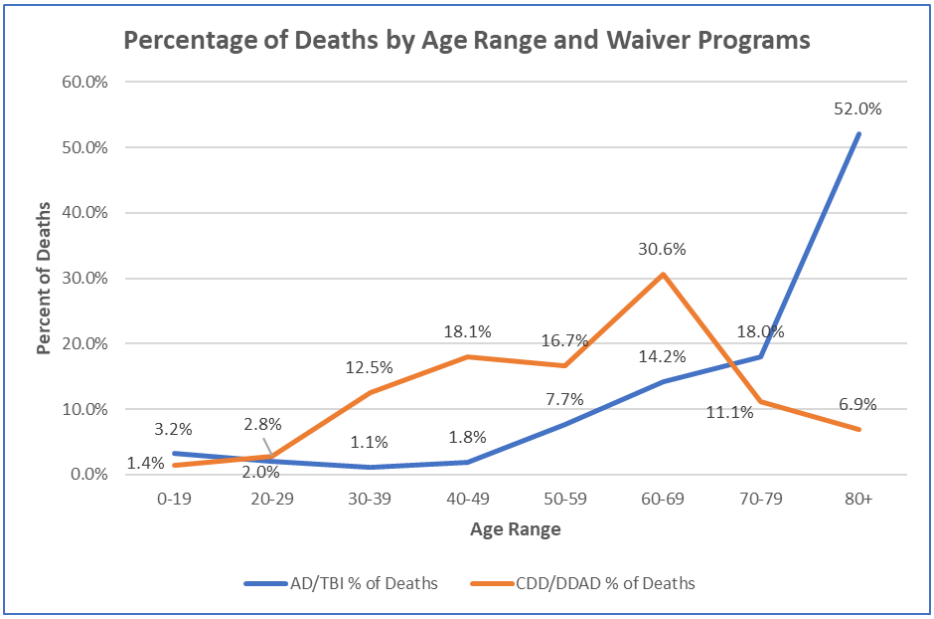
The following chart illustrates the average age at death by gender for each of the waiver groups or funding sources:



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 both waiver program populations by the 5th decade of life.

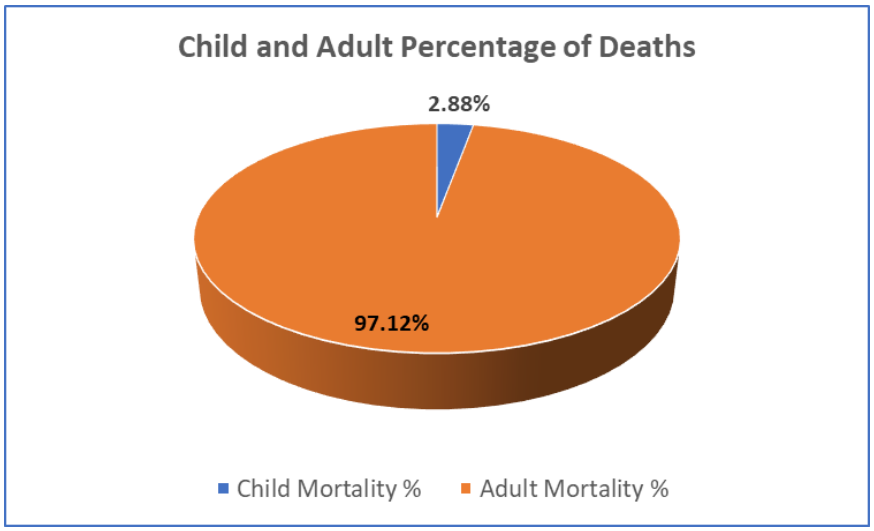


The chart below shows the percentage of deaths for each age range for the AD/TBI and CDD/DDAD waiver programs. For the CDD/DDAD waiver participants, the percentage of deaths peaks during the 6th decade, reflecting the lower life expectancy of the IDD population. In the AD/TBI waiver programs, the percentage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



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

Fifteen (15) children died between 7/15/2021 and 6/30/2022. Fourteen (14) were living in personal homes and were receiving AD waiver services. One (1) child, aged 4 years old, was living in a Shared Living setting and died unexpectedly. He 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 **384** investigations in this reporting period. Investigations yield a much richer set of mortality data than triage screenings, 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 and Unexpected 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.

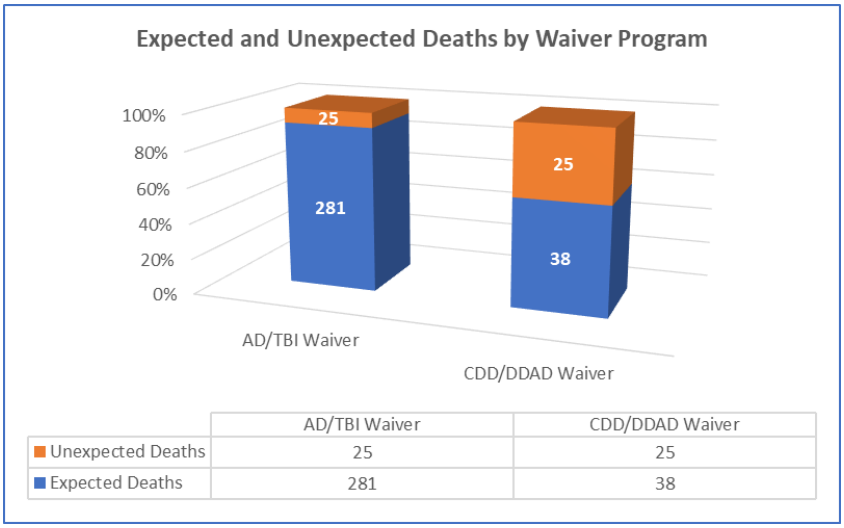
The possible causes of death for an unexpected mortality might include accidental death, sudden acute illness unrelated to pre-existing medical illnesses or conditions, neglect or abuse, or homicide/suicide.

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 wellbeing, and avoid preventable adverse outcomes.

A comparison of expected and unexpected mortalities of the AD/TBI waiver and the CDD/DDAD waiver programs reveals that both sets of programs had the same number of unexpected deaths, but the AD/TBI program had a much larger number of expected deaths due to the large proportion of individuals in the AD/TBI cohort that are over the age of 65 years.

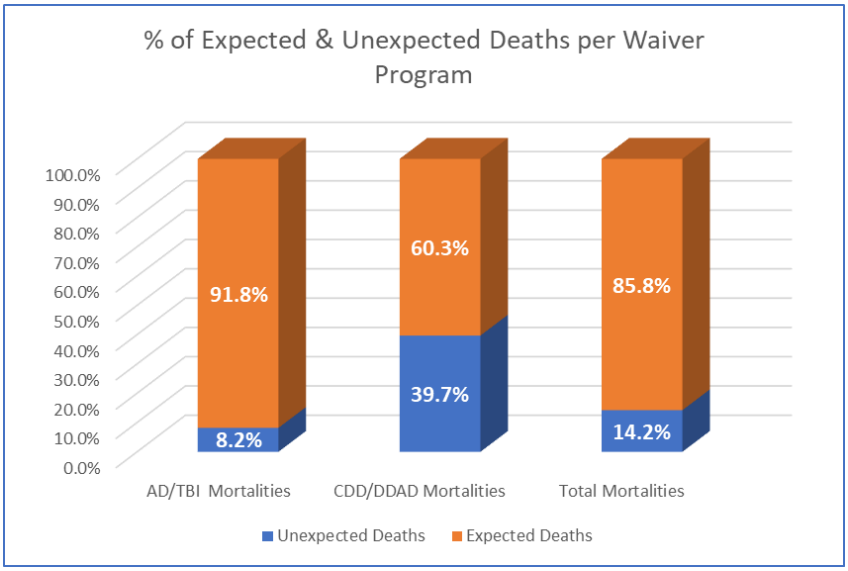
There were only four (4) deaths of participants residing at the BSDC, three (3) of which were unexpected deaths.



	AD/TBI Waiver	CDD/DDAD Waiver
Unexpected Deaths	25	25
Expected Deaths	281	38

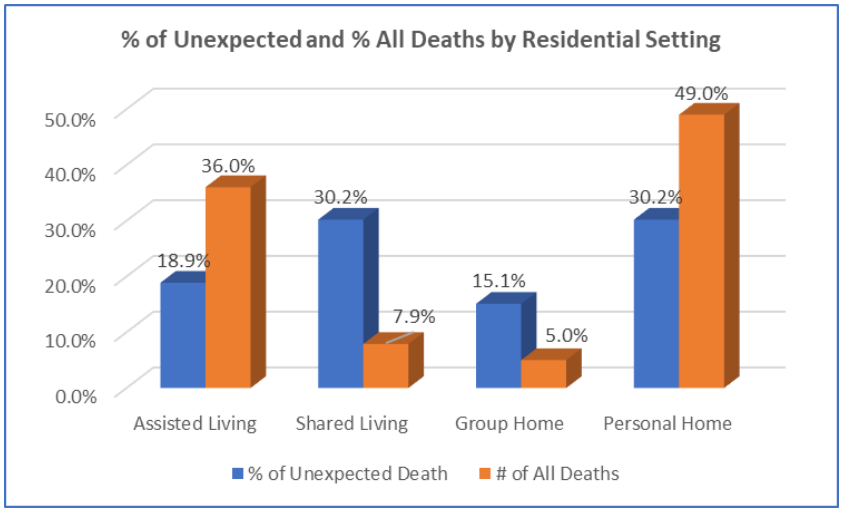
Almost 40% of the CDD/DDAD waiver mortalities were unexpected deaths as compared to only 14.2% of the total deaths that were unexpected.

85.8% 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 had a medical history that included coronary artery disease.



Unexpected Deaths and Residential Setting

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

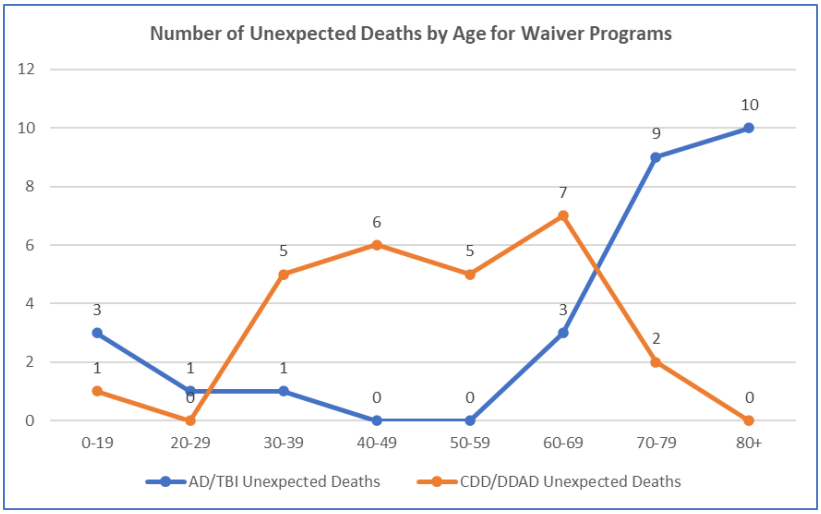


- Almost half (49.7%) of all deaths were participants living in their own homes, but those mortalities accounted for only 30.2% of unexpected deaths.
- Only 8% of all deaths were participants living in a Shared Living setting, but those individuals accounted for 30.2% of unexpected deaths (the same percentage as those who lived in personal homes).
- Only 5.1% of all deaths were participants living in a Group Home setting, but those individuals accounted for 15.1% of all unexpected deaths.

Unexpected Deaths and Age

The graph on the right illustrates the unexpected deaths by age range for the AD/TBI waiver and the CDD/DDAD waiver programs. Note that the CDD/DDAD waiver unexpected mortalities accounted for almost all of the unexpected deaths between the ages of 30 and 59 as compared to the AD/TBI waiver mortalities.

Children (under age 19) accounted for four (4) unexpected deaths.



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.

Midway through the year when we began looking more extensively at unexpected deaths, Liberty noted a prevalence of these conditions, either as pre-existing conditions or as the direct causes of death. We began tracking these closely in the 2nd Quarter of 2022 (April-June). For deaths that occurred in the 2nd Quarter, there were 17 unexpected deaths identified in investigations completed in that quarter, and **70.6%** of those had one or more of the Fatal Five Plus as pre-existing conditions prior to death. Seven (7) mortalities **(41.2%)** in unexpected death investigations completed in that quarter had a Fatal Five Plus condition identified as the primary or secondary cause of death.

Mortalities and Fatal Five Plus Conditions – 2nd Quarter 2022		
Condition	**Incidents in all Investigated Cases for 2nd Quarter Deaths**	**Incidents in 2nd Quarter Unexpected Mortalities**
Aspiration/Choking or History of	10 (12.5%)	5 (29.4%)
Bowel Obstruction or History of	7 (8.75%)	3 (17.65%)
Sepsis	4 (5%)	4 (23.53%)
GERD	26 (32.5%)	6 (35.3%)
Seizures	1 (1.25%)	0
Dehydration	1 (1.25%)	1 (5.9%)
Note: 80 Deaths that occurred in the 2nd Quarter were investigated; 17 Unexpected Deaths were Identified. Some individuals may have had more than one condition.		

The existence of Fatal Five Plus conditions in a substantial percentage of unexpected deaths aligns with the literature that identifies a significant mortality risk for these conditions. We noted that in seven (7) deaths in the 2nd Quarter, Fatal Five Plus conditions (bowel obstruction, sepsis, and aspiration/choking) were directly related to the causes of death.

Mortality and Falls

Literature supports the experience of falls as a predictive factor for mortality, especially in the elderly. The data obtained from DHHS-DDD mortality reviews support that premise. During the reporting period, nearly half **(48.26%)** of all mortalities that were investigated had evidence of 1 or more falls during 6 months preceding the time of death. A similar percentage **(47.37%)** 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.

Abuse, Neglect, and Exploitation

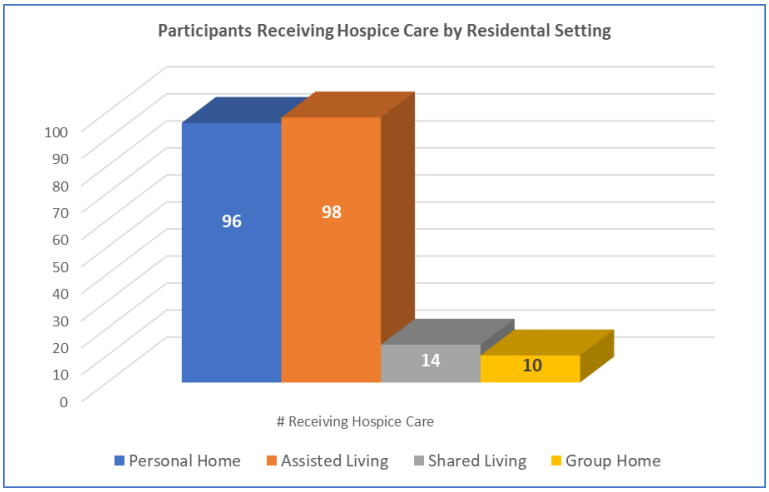
Of the 520 mortalities, **9** cases were found to have suspected abuse or neglect and were referred to Adult Protection Services for investigation. These referrals were either made by DHHS-DDD Mortality Nurse Investigators or by outside entities, such as the hospital in which the participant passed. The referrals represented concerns about delays in recognition of a changing health condition, lack of provision of appropriate healthcare, and 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 individual's death. Additional data about the suspected abuse or neglect cases:

Age	Residential Setting	Type of Death	Waiver Program	Status
29	Personal Home	Expected	AD waiver	Not opened
40	Personal Home	Expected	AD waiver	Not opened
52	Shared Living	Unexpected	CDD waiver	Not opened
66	Group Home	Unexpected	CDD waiver	Unfounded
70	Personal Home	Unexpected	AD waiver	Not opened
71	Assisted Living	Unexpected	AD waiver	Unfounded
74	Assisted Living	Expected	AD waiver	Not confirmed
76	Shared Living	Unexpected	CDD waiver	Substantiated
81	Personal Home	Expected	AD waiver	unfounded

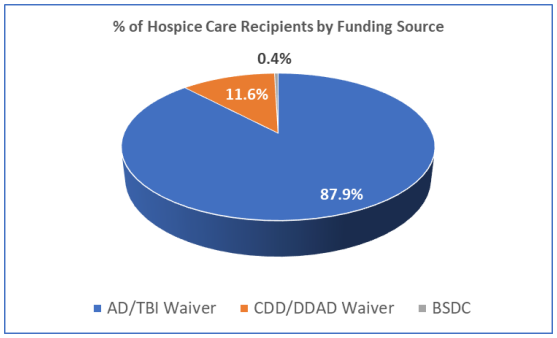
Note: "Not Opened" refers to a case that did not meet the definition of abuse, neglect, or exploitation.

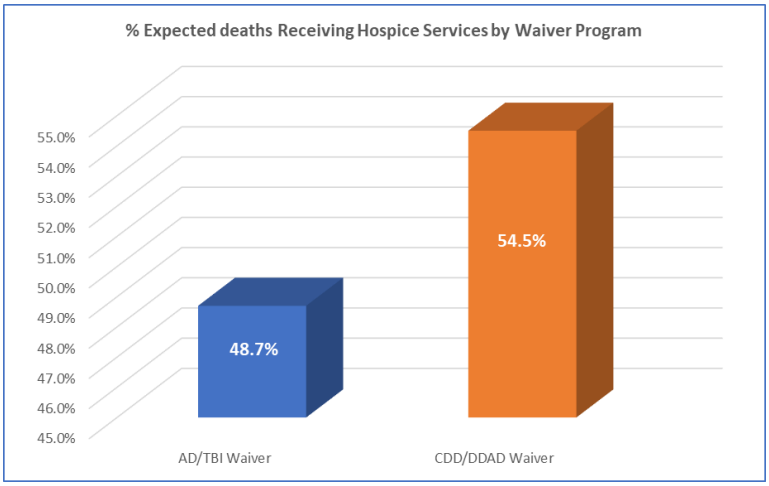
Mortality and Hospice Care

The inclusion of end-of-life planning, including hospice care, for individuals receiving services, has been supported by 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. **224** individuals (43%) were receiving hospice care at the time of their deaths.



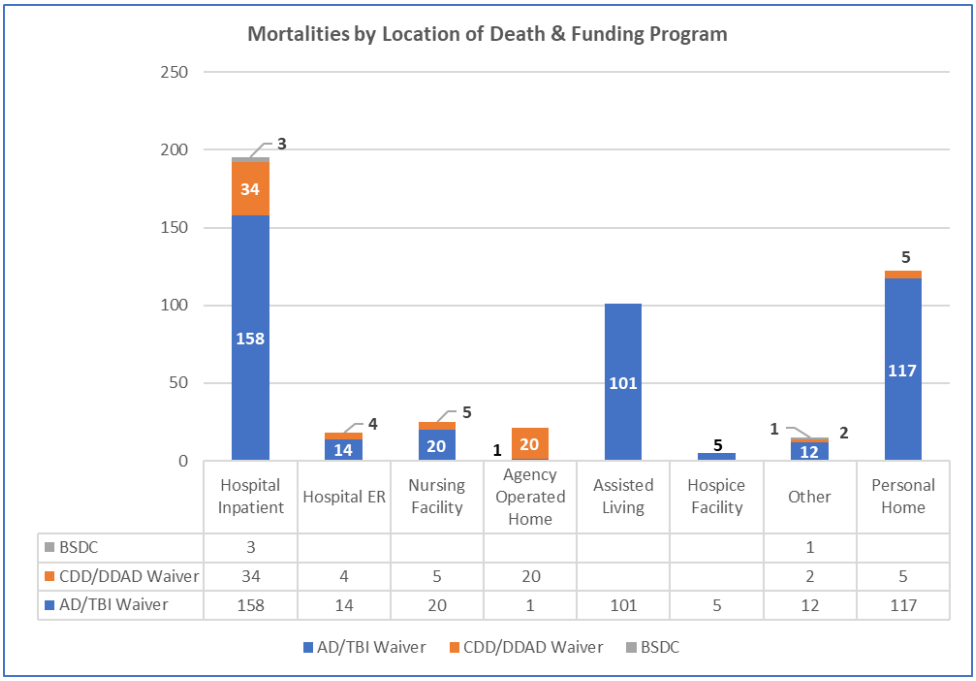
Most (86.7%) of the recipients of hospice care were living in their personal homes and assisted living and receiving AD waiver services.





In both the AD/TBI waiver group and the CDD/DDAD waiver group, about half of the expected mortalities were receiving hospice services at the time of death.

Mortalities and Location of Death



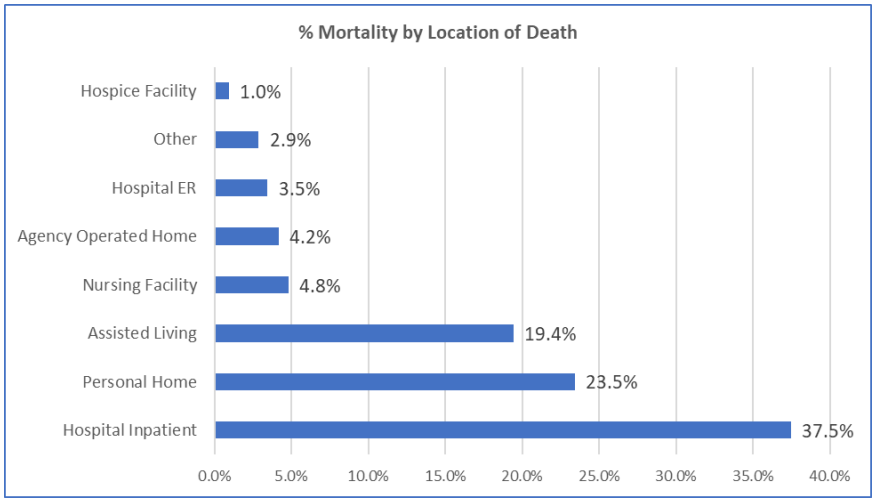
The chart on the left illustrates the Location of Death by Funding Program. The “Agency Operated Home” refers to the combination of Shared Living settings and Group Homes.

The chart on the right shows the % of mortalities by location of death.

41% of mortalities occurred in a hospital setting, either in inpatient or emergency room.

19.4% of mortalities occurred in an Assisted Living setting.

23.5% of mortalities occurred in the individual's personal home.



Mortality Trends

Since this report is the first of its kind for the enhanced Nebraska DHHS-DDD mortality review process, trending is not possible due to the implementation of a new, more robust data collection and analysis system in the past year with which data from previous years is not available. Trending in future years will focus on the following:

- Expected vs. unexpected mortalities
- Mortality rates by residential setting, location of death, and causes of death
- Mortality rates by gender and age
- Percent of hospice support services
- Leading causes of death

In addition to the above, there will likely be additional data points collected that will evaluate the impact of systemic improvement initiatives to improve service delivery and quality of services and will inform and drive future plans for quality improvement.

Leading Causes of Death

477 causes of death were received for the deaths reported 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	25.6%	Sudden cardiac death, Myocardial Infarction, Congestive Heart Failure, Cardiac Arrest, Atherosclerosis, Arrhythmia
Respiratory System Disorder	24.6%	Respiratory disease, Respiratory Failure, Respiratory Condition
Nervous System Disorders	13.9%	Alzheimer's and Dementia, Encephalopathy, Parkinson's, Seizures/Epilepsy, Stroke
Infections	13.7%	Aspiration Pneumonia, Influenza, Pneumonia, Sepsis, UTI, Respiratory Infection, COVID-19
Cancers	9.0%	Breast, Colon, Leukemia, Lung, Lymphoma, Pancreatic
Renal System Disorders	4.1%	(No sub-categories identified)
Gastrointestinal/Digestive System Disorders	3.5%	Bowel Obstruction, GI Bleed, Other GI Disease
External Causes	1.4%	Choking/Aspiration, Falls, Motor Vehicle Accident
Endocrine System Disorder	1.2%	Diabetes, Other
Musculoskeletal Disorders	0.6%	(No sub-categories identified)

Heart disease remains the leading cause of death, but is closely 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, pneumonia, 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 16.95 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	123	10	76.76	60.5
Respiratory Disease	105	24	72.49	56
Nervous System Disorders	62	8	83.81	59.63
Alzheimer's/Dementia	36	3	86.17	70
Infections	48	21	71.38	61.57
Cancers	38	8	72.18	53.38

Analysis of Cancer Deaths

Lung cancer is the most prevalent, comprising almost 30% of all mortalities from cancers. Almost half 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	13	29.5%
Colon	3	6.8%
Breast	2	4.5%
Lymphoma	2	4.5%
Leukemia	2	4.5%
Pancreatic	1	2.3%
Not specified	21	47.7%

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 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 are listed in the table below:

Metric	NE CDD/DDAD Waiver Population	2019 GA IDD Population	2020 CT IDD Population	2020 NE General Population	2020 US General Population
Crude Mortality Rate	15.73/1000	16.2/1000	17.1/1000	8.49/1000	8.95/1000
Average Age at Death	55.93 years	54.40 years	62 years	79.6 years	78.5 years

While the crude mortality rate appears better than in the states of Georgia and Connecticut, 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 population in Georgia, but not as high as the IDD population in Connecticut. 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.