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Aging and Disability Mortality Review Panel 2023 Annual Report

Required by 22 MRS §264, sub-§6(B)

Submitted April 2024 to the Joint Standing Committee on Health and Human Services

Maine Department of Health and Human Services
Maine Center for Disease Control and Prevention
in partnership with
Maine's Aging and Disability Mortality Review Panel

Aging and Disability Mortality Review Panel
Annual Report 2023

INTRODUCTION

The Aging and Disability Mortality Review Panel (the 'Panel') is a multidisciplinary panel established by Public Law 2021, chapter 398, introduced to the 130th Maine State Legislature as LD 221, to review the patterns of death of and serious injury to all Maine adults receiving home and community-based services (HCBS) under 42 Code of Federal Regulations, Part 441. The Panel is charged with analyzing mortality trends in these populations to identify strengths and weaknesses of the system of care and to recommend to the Commissioner of Maine's Department of Health and Human Services (DHHS) ways to decrease the rate of mortality and improve the system of protection for adults receiving services, including modifications to law, rules, training, policies, and procedures. The Panel is required to meet at least four times per year and, by January 2nd of each year, submit information gathered on cases of reported deaths of and serious injury to adults receiving HCBS and a report of its activities and recommendations to the Governor of Maine, the DHHS Commissioner, and to the joint standing committee of the Legislature having jurisdiction over health and human services matters. This annual report provides a review of the work of the Panel in 2023. (22 MRS § 264.)

BACKGROUND

Under a waiver program, a state can waive certain Medicaid program requirements, allowing the state to provide care for people who might not otherwise be eligible under Medicaid. Through certain waivers, states can target services to people who need long term services and supports. Section 1915(c) of the Social Security Act permits states to offer, under a waiver of statutory requirements, an array of home- and community-based services (HCBS) that an individual may utilize to avoid institutionalization. In Maine, there are five waiver sections as described in the MaineCare Benefits Manual (10-144 CMR chapter 101[1]), Sections 18, 19, 20, 21 and 29, all of which are administered through Maine's Office of MaineCare Services in partnership with Office of Aging and Disability Services.

- Section 18: Home and Community-Based Services for Adults with Brain Injury;
- Section 19: Home and Community Benefits for the Elderly and for Adults with Disabilities;
- Section 20: Home and Community Services for Adults with Other Related Conditions;
- Section 21: Home and Community Benefits for Members with Intellectual Disabilities or Autism Spectrum Disorder; and
- Section 29: Support Services for Adults with Intellectual Disabilities or Autism Spectrum Disorder.

Waiver services are available based on eligibility and can include home support, community support, work support, career planning, assistive technology, durable medical equipment, therapy services, transportation, and respite.

[1] MaineCare Benefits Manual, rule chapter 101: https://www.maine.gov/sos/cec/rules/10/ch101.htm

Under section 1915(c), successful waivers must provide assurances to Centers for Medicare and Medicaid Services that the state has implemented necessary safeguards to protect the health and welfare of participants receiving services.

Depending on a member's eligibility and waiver service, the service provider who is selected by the member/guardian may be licensed or unlicensed, under the oversight of an agency, or be other paid support, and the choice of the setting where residential services may be provided include agency operated group homes or a private residence (i.e.. Family Centered Homes, and Shared Living if the provider is not a related family member), all of which must comply with the HCBS Settings Rule[2] established to ensure all HCBS settings are truly home and community based.

Providers delivering the services described herein are responsible for complying with licensing and other regulatory and contractual requirements, as well as screenings and training requirements, as applicable. In addition to licensing investigation reviews conducted by DHHS Division of Licensing and Certification, regular program site visits and critical incidents, APS and grievance reporting are used to monitor compliance with program standards and serve to identify deficiencies and areas for system improvement. To assure health and safety, providers, who are mandated reporters, are required to report all Reportable Events and all allegations of abuse, neglect, or exploitation. When a Reportable Event occurs, providers are responsible for identifying any root causes and any needed remediation.

In response to audits by Department of Health and Human Services (HHS) Office of Inspector General (OIG) Reports, United States Government Accountability Office (GAO) Reports, and Centers for Medicare and Medicaid Services (CMS), the need for a multidisciplinary incident management system was identified which would augment and coordinate with the existing robust system for safeguarding those populations here in Maine. Please refer to the first annual report provided by the Panel for a thorough outline of the efforts of the State's Adult Protective Services (APS), Office of Aging and Disability Services (OADS) and the Maine Center for Disease Control and Prevention (Maine CDC).

RELATED ACTIVITIES

Panel members convened four times during the report year and participated in the comprehensive reviews of 13 cases referred by the panel coordinated and discussed further in this report.

Panel Membership

- Brenda Gallant, Executive Director, Long-term Care Ombudsman Program
- Heather Hyatt, Associate Director, DHHS Division of Licensing and Certification
- Lauren Michalakes, Program Consultant, DHHS Office of Aging and Disability Services
- Thomas Newman, Executive Director, Alpha One
- Cara Orton, Director of Brain Injury Programs, River Ridge Center
- Kelly Osborn, Senior Vice President of Client Services, Goodwill Northern New England

[2] HCBS Final Regulation Medicaid.gov: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/home-community-based-services-final-regulation/index.html

- Patricia K. Poulin, Assistant Attorney General, Office of the Attorney General
- Jennifer Putnam, Executive Director, Waypoint
- Katrina Ringrose, Deputy Director, Disability Rights Maine
- Taylor Slemmer, Medicolegal Death Investigator, Office of the Chief Medical Examiner

In accordance with 22 MRS § 264(4), the Panel selected a chairperson, Katrina Ringrose, in November 2022 to serve for a year. In November 2023, the Panel selected Patricia Poulin to serve in that role for the upcoming year.

Due to a recent resignation, there is an opening on the panel awaiting appointment. Per statute, this seat is to be filled by a licensed health care provider with experience and expertise delivering services to individuals with intellectual disabilities or autism.

Rulemaking

DHHS is obligated to adopt routine technical rules to implement the requirements under 22 MRS §264 to clarify the collection and reporting of HCBS member mortality information, including maintaining a state mortality database for HCBS member death and serious injury reviews and managing individually identifiable health information, and to provide direction to conducting interviews and avoiding conflicts of interest. The Maine CDC is taking lead and will administer the rule as authorized when adopted. Rulemaking is in accordance with 5 MRS Chapter 375: Maine Administrative Procedure Act §8001 - §11008.

Aging and Disability Mortality Review Process

The Aging and Disability Mortality Review Panel Coordinator, who is department staff within the Maine CDC, continues to work closely with OADS and APS to ensure receipt of every case of death and serious injury occurring to members receiving HCBS services. Sections 18, 20, 21 and 29 share a reportable events system called EIS (Enterprise Information System). A spreadsheet of reportable events is sent electronically from OADS to the panel coordinator, daily. The coordinator has been given access to EIS and may review service authorizations, reportable events, and person-centered plans in detail as needed to perform a more comprehensive review of reported incidents.

Section 19 incidents are reported by OADS via secure email as they occur. The panel coordinator has been given access to MaineCare, the system used by Section 19, and may view authorizations, assessments and care plans as needed.

As outlined by statute, the panel coordinator has established a process to request and receive external records necessary to conduct a preliminary review of all serious HCBS member injuries and deaths. In addition, the coordinator conducts voluntary interviews to assist in investigating further any cases deemed to be unexpected or unexplained, premature, preventable, or suspicious.

State HCBS Mortality Database

The panel coordinator is charged with developing and maintaining a state HCBS mortality database. This database has been developed as a spreadsheet, and the compiling of HCBS member deaths began on July 1, 2022, aligning with the start of State Fiscal Year 2023. The

panel coordinator is partnering with Maine CDC and OADS to establish a server engine database. At this time, the data field structure has been provided to IT and awaits funding. Funding for work on the database is being explored interdepartmentally. Data reported from sources including Maine CDC Office of Data, Records and Vital Statistics and OADS will continue at this time to be held in a secure spreadsheet and managed by the panel coordinator.

Cases Referred for Panel Review

Following a preliminary review, the panel coordinator refers to the Panel those deaths which are medically or legally unexplained, or inadequately explained, and any death in which the circumstances or cause is suspected to be related to systemic issues of access to or quality of care. In addition, deaths or serious injuries which are deemed to have been possibly preventable after a comprehensive review are referred to the Panel. Case summaries are compiled for and shared to the Panel in a deidentified manner (22 MRS § 264, sub-§ 5).

The determination of expected or unexpected/unexplained death is based on initial report and death certificate. Additional information is sought by the panel coordinator as needed to determine the need for full, comprehensive panel review including reports provided by direct service providers, care coordinators and case managers, family members and guardians, medical records, police and EMS reports, APS investigations and reports from OCME.

In 2023, the Panel met four times and reviewed the comprehensive investigations of 13 deaths. An additional 36 cases underwent comprehensive investigation by the panel coordinator; there remain nine in progress as of this report. Sixteen cases of serious injury were investigated by the panel coordinator with four in progress. Several cases in review are expected to be referred to the Panel in 2024.

Section 18 Cases

Home and Community Based Services waiver Section 18 provides services for adults with brain injury. Criteria include diagnosis of an acquired brain injury and an assessment by a neuropsychologist or other qualified health care provider with evidence of potential for rehabilitation. Services may include assistive technology, home/work supports, employment services, self-care/home management reintegration, community/work reintegration, care coordination, work and social engagement skill building, and career planning. Members complete an assessment called a MAPI (Mayo-Portland Adaptability Inventory which helps assure the member's health and safety in a community setting). There are currently 191 active members in this waiver. No cases of death or serious injury to members of Section 18 have met criteria for referral to the Panel for comprehensive review as of this report.

<u>Recommendations:</u> None.

Section 19 Cases

Section 19 is also called Home and Community Benefits for the Elderly and Adults with Disabilities. Individuals approved for Section 19 services are those who meet criteria for nursing home level of care or need skilled nursing services. Services may include assistive technology, personal care, nursing, respite, emergency response systems, environmental modifications, non-

emergency transportation/escort and care coordination. Section 19 currently serves approximately 2450 members.

Section 19 members may benefit from paid in-home services to assist with activities of daily living; eligibility for services is determined by a nursing assessment. The assessment includes an initial plan of care and the individual is referred to a Service Care Agency (SCA). The SCA then assigns a care coordinator. Care coordinators monitor the health and welfare of the member and assist with locating the services and staffing for which the member is authorized. Most deaths of individuals receiving adequate in-home care provided under Section 19 waiver are from expected causes.

Individuals who are approved for personal support services under the Section 19 waiver may choose to receive those services through a licensed home health agency; or they may elect the Participant-Directed Option. Agency staff, according to the MaineCare benefits manual, undergo a background check and complete specified training Attendants who provide services under the Participant-Directed Option will demonstrate their competency for all required tasks to the member or representative.

However, staffing is not guaranteed and unstaffed personal support services hours for these individuals are an on-going issue, especially in certain areas of the State. In one case of death to a member receiving Section 19 services, reviewed in detail by the Panel, staffing was found to be inconsistent and possibly a contributing factor.

When staffing is a challenge, care coordinators assist members to identify natural (unpaid) supports in collaboration with the member's health care provider. Care coordinators are not charged with supervising the in-home care provided to members and frequently members receiving Section 19 services are medically complex or severe. In two cases of death to Section 19 members reviewed by the Panel, both very medically complicated, the Panel noted medical issues had been occurring for the member for several days prior to medical care being sought.

Recommendations:
As a result of three Section 19 comprehensive reviews in 2023, the Panel identified the need for more frequent assessment of members with complex medical needs—particularly those with co-occurring medical and behavioral health conditions—as well as increased training and oversight of personal care providers, especially paid family members.

Section 20
This HCBS waiver program is also known as Home and Community Based Services for Adults with Other Related Conditions (sometimes referred to as ORC) and may serve individuals living with cerebral palsy or seizure disorders, or conditions found to be closely related to Intellectual Disabilities. A qualifying condition must have been present prior to age 22 and be likely to continue indefinitely. Eligibility for services is determined by an independent nursing assessment. Members of this waiver program meet the medical eligibility criteria for admission to an intermediate care facility for individuals with intellectual disabilities (ICF/IID) and choose to receive services in the community instead. Services may include care coordination, community/home and work support, personal care services, employment services, assistive technology, communication aids, consultative services (speech, occupational/physical/behavioral

or psychological therapy, specialized equipment, and care coordination. There are currently 43 individuals being served through this waiver. No cases of death or serious injury to members of Section 20 met criteria for referral to the Panel as of this report.

Recommendations: None.

Section 21

Home and Community Benefits for Members with Intellectual Disabilities (ID) or Autism Spectrum Disorder (ASD) is the formal name for the Section 21 HCBS waiver. Persons authorized for this comprehensive waiver are adults who are living with an Intellectual Disability or Autism Spectrum Disorder or Rett Syndrome who meet medical eligibility criteria for admission to an ICF/IID. Eligibility is determined by completing a BMS-99—a tool which assesses the individual's functioning as it relates to living in the community. Once approved for waiver services and awarded Section 21 funding, and there is an opening, the provider selected by the member or member's guardian develops a Service Implementation Plan to define how services will be provided for the individual, taking into consideration needs for health and safety. Case management is not a covered waiver service under Section 21 though this service may be available through another program.

Services are wide-ranging and may include assistive technology, career planning, communication aids, community support, counseling, consultative services (OT, PT, speech and language, behavioral, psychological), crisis assessment, crisis intervention services, employment specialist services, home accessibility adaptations, home support-family centered support, home support, non-medical transportation, non-traditional communication assessments, shared living, specialized medical equipment and supplies, and work support. As of May 2023, OADS reported 3,353 persons served by Section 21 with 1985 individuals waiting for available funding; of those waiting, 285 had no other coverage/services.

In 2023, the Panel reviewed 10 comprehensive death investigations of Section 21 members. Two of those cases involved accidental death in the community while in the care of direct service providers. One of those individuals had a very specific safety plan in place for the residential setting, but not in the community setting.

Comprehensive case reviews involving a completed suicide and the death of a member shortly after a brief hospitalization associated with an acute mental health exacerbation raised questions about the appropriateness of settings for individuals who experience both mental illness and developmental disabilities. When an opening in a residential setting occurs, any Section 21 member seeking initial placement or relocation can be moved in regardless of whether it is an ideal setting. Other cases reviewed by the Panel suggested that direct service personnel may not always be prepared to manage the acuity of both medical and behavioral/mental health conditions with which members present or which arise under their care.

Similar to findings in Section 19, direct service providers in shared living and residential settings struggled at times to appreciate illness acuity or respond quickly enough. Several of these deaths were potentially preventable with earlier recognition and intervention.

Recommendations:
The Panel suggested more robust healthcare training to help direct service providers to spot the signs and symptoms of potentially preventable causes of death. These include choking, aspiration, constipation/bowel obstruction, seizures, dehydration, and sepsis[3]. An example of such a training can be found here: https://replacingrisk.com/idd-staff-training/the-fatal-five-fundamentals/.

The Panel has identified an opportunity for improved review and ongoing oversight of the complex medical and behavioral/mental health needs of waiver eligible members, especially as they age, including specific training to ensure service providers have an understanding of how to best address those complex needs of members served, as well as a commitment to report and respond to emerging health issues with expedience. The inaccessibility of mental and behavioral health care is a persistent challenge, and the panel recommends that the State consider how to increase access to medical and nurse case management services.

Section 29
Section 29 is designated as Support Services for Adults with Intellectual Disabilities or Autism Spectrum Disorder. Similar to Section 21—individuals receiving services must be adults with a diagnosis of ID or ASD who meet medical eligibility criteria for admission to an ICF/IID. Section 29 provides funding for limited service which may include access to assistive technology, career planning, community support, employment specialist services, home accessibility adaptations, non-medical transportation, shared living, and home support—quarter hour/remote. As with Section 21, Section 29 does not include case management services. As of May 2023, OADS reported 2,804 persons served by Section 29 with 186 individuals waiting for a funded opening; of those waiting, 86 had no other coverage/services. No cases of death or serious injury to members of Section 29 met criteria for referral to the Panel as of this report. As such, there are also no recommendations in this report.

HCBS MEMBER DEATH AND SERIOUS INJURY DATA

Deaths of HCBS waiver participants
There were 360 deaths of members receiving waiver services reported between 1/1/23 and 11/16/23 when data for the annual report was gathered. The panel coordinator completed a preliminary investigation of each death, reviewing data reported from sources including OADS and death certificates. 44 cases of death of members, and 19 serious injuries were categorized as unexpected or unexplained and underwent, or are undergoing, a comprehensive investigation to determine if these require full panel review. 13 cases of death were referred to and reviewed by the Panel at their quarterly meetings.

Note: data reported for 2022 represents only a partial year.

[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7710575/

Deaths by waiver section

Waiver	2022 (partial year)	2023
Section 18	1	4
Section 19	148	285
Section 20	0	1
Section 21	33	58
Section 29	3	12
Total	185	360

Waiver participant deaths by age

Age Group	2022 (partial year)	2023
<19	1 (1%)	0 (0%)
20-29	3 (2%)	8 (2%)
30-39	3 (2%)	7 (2%)
40-49	11 (6%)	16 (4%)
50-59	18 (10%)	46 (13%)
60-69	60 (31%)	88 (24%)
70-79	38 (20%)	86 (24%)
>80	51 (28%)	109 (31%)
Total	185 (100%)	360 (100%)

Average age at death by HCBS waiver section

Waiver	2022 (partial year)	2023
Section 18	68	52.6
Section 19	72.12	71.79
Section 20	N/A	40
Section 21	59.32	62.62
Section 29	45.5	57.7

Waiver participant deaths by gender

Gender	2022 (partial year)	2023
Female	111 (60%)	202 (56%)
Male	74 (40%)	158 (44%)
Other/Trans.	0 (0%)	0 (0%)
Total	185 (100%)	360 (100%)

Waiver participant deaths by race/ethnicity

Race/Ethnicity	2022 (partial year)	2023
African American	0 (0%)	5 (1%)
Asian	1 (1%)	3 (1%)
Hawaiian/Pacific Islander	0 (0%)	1 (<1%)
Hispanic	2 (1%)	2 (1%)
Not listed	7 (4%)	0 (0%)
Native American	0 (0%)	2 (1%)
Other	5 (3%)	0 (0%)
White	170 (91%)	343 (95%)
Total	185 (100%)	360 (100%)

Waiver participant deaths by type

Type	2022 (partial year)	2023
Accident	5 (3%)	12 (3%)
Acute illness	13 (7%)	22 (6%)
Known chronic illness	85 (46%)	173 (49%)
Known terminal illness	66 (36%)	116 (32%)
Self-inflicted	0 (0%)	2 (1%)
Unknown*	16 (8%)	35 (9%)
Total	185 (100%)	360 (100%)

***pending receipt of death certificate or undergoing investigation by Office of the Chief Medical Examiner*

Accident types

Type	2022 (partial year)	2023
Acute intoxication	1	3
Choking	1	1
Drowning	1	0
Fall	1	2
Hanging	0	1
Motor vehicle accident	1	1
Trauma	0	4

Waiver participant deaths by Maine county

County	2022 (partial year)	2023
Androscoggin	16	23
Aroostook	16	17
Cumberland	32	67
Franklin	5	7
Hancock	4	10
Kennebec	12	31
Knox	2	10
Lincoln	1	8
Oxford	7	25
Penobscot	36	63
Piscataquis	2	4
Sagadahoc	1	2
Somerset	9	35
Waldo	6	10
Washington	12	15
York	24	32
Out of state	1	3

Death trends

The large majority (93%) of persons receiving Section 19 waiver services died of known chronic or terminal illness; 76% of persons receiving Section 21/29 services died of known chronic or terminal illness. It was more common for people receiving Section 21/29 services to die of an acute illness compared to people receiving Section 19 services (10 or 14% versus 12 or 4%). The average age of death in people receiving Section 19 services was 72, with a range of 25 years to 101 years. 158 of these members were under the age of 75. In sections 18, 20, 21 and 29, the average age of death was 62, with a range of 23 years to 94. In 58 of these members were under the age of 75.

Premature death in the United States is commonly defined as before age 75[4] but varies by gender, race and other variables[5]. Premature death in persons living with IDD has not been defined.

People with intellectual and developmental disabilities are known to experience earlier deaths than the general population. Data published in 2015 show that the average age at death for people in state intellectual and developmental disabilities systems was 50.4–58.7; from Medicaid claims data that average was found to be 61.2–63.0 years[6]. The average life expectancy in Maine for all people is 77.8[7] compared to age 63.01 for individuals who lived with an intellectual or developmental disability--data culled from the panel database combining deaths reported in Sections 21 and 29; that same group in 2022 showed an average age of death of 57.59.

For 10 Section 21 individuals whose deaths underwent comprehensive investigation by the panel in 2023, the average age at death was 51.8 years. The significance of this observation is not yet known. The Panel will continue to work to identify trends in care, including access to health care, which might offer opportunities to lengthen life expectancies and improve health in these populations.

The Panel also notes that across all waiver sections, death certificates vary widely in how they are completed. The cause of death data to which we have access is that which is listed on the death certificate. The cause(s) of death can include a description which is a challenge to categorize without the help of coding, which happens at National Vital Statistics. Interpretation and analysis of that data is beyond the scope of the Panel at this time pending access to epidemiology and statistics expertise. It may be helpful in the future to access National Center for Health Statistics (NHCS) cause of death codes, as a way to compare to national data. The electronic database that is currently in development stages, could permit the upload of the NHCS codes assigned to deaths in Maine, allowing more meaningful trend analysis. This is being explored.

In the Panel's experience, it is uncommon to find the intellectual or developmental disability with which the person lived listed on their death certificate, even when closely associated with the listed cause of death (e.g., Alzheimer's dementia and Down syndrome). The disability is not

[4] https://www.cancer.gov/publications/dictionaries/cancer-terms/def/premature-death
[5] https://www.cdc.gov/nchs/data/vsrr/vsrr031.pdf
[6] https://onlinelibrary.wiley.com/doi/10.1111/jar.12191
[7] https://www.cdc.gov/nchs/pressroom/states/maine/me.htm

likely the cause of death in individuals with IDD, but those with IDD often have conditions that predispose them to particular medical conditions. And as such, the condition of some forms of IDD should be identified as a significant condition that contributes to but does not cause the death. The panel coordinator is now tracking inclusion of IDD diagnoses on death certificates in the panel database for future exploration.

Since beginning to track this, it was found that of the 70 people in waiver sections 21 and 29 with history of intellectual or developmental disability (IDD), death certificates, an important source of public health data, included mention of their disability as a significant condition only 27% of the time (19 out of 70).

Serious injuries to waiver participants

Serious injury as defined by the statute means a bodily injury that involves a substantial risk of death, unconsciousness, extreme physical pain, protracted and obvious disfigurement or protracted loss or impairment of the function of a body part or organ or mental faculty. (22 MRS §264, sub-§ 2(D.) The data, as received from each waiver section, includes events or injuries which may not strictly meet these criteria; and it is possible that incidents which do meet criteria are not coded as serious injury in the EIS or MeCare system and are not included in this data. There may be more than one event involving an individual; each event is recorded separately. The process of gathering and filtering data continues to be refined by OADS and Maine CDC in order to offer the most meaningful trend analysis. In 2023, efforts were made to include only those injuries which met these criteria; less serious injuries, such as minor wounds or sprains, were excluded from data unless the event included a concern for abuse or neglect.

Serious injuries by waiver section

Waiver	2022 (partial year)	2023
Section 18	2	2
Section 19	56	62
Section 20	0	0
Section 21	96	68
Section 29	11	11
Total	165	143

Waiver participant serious injury by gender

Gender	2022 (partial year)	2023
Female	98 (59%)	90 (63%)
Male	64 (39%)	52 (36%)
Other/ Trans.	3 (2%)	1 (1%)
Total	165 (100%)	143 (100%)

Waiver participant serious injury by race/ethnicity

Race/Ethnicity	2022 (partial year)	2023
African American	0	2
Asian	1	1
Hispanic	2	0
Native American	2	2
Not listed*	55	33
Other	2	1
White	103	105
Total	165	143

***Data regarding race/ethnicity is gathered from the EIS and MaineCare systems when it is listed there*

Waiver participant serious injury by type

Type	2022 (partial year)	2023
Accident	87	*
Acute illness	15	6
Acute injury	31	116
Known chronic illness	4	4
Restraint use	9	2
Self-inflicted	12	7
Self-neglect	1	0
Suspected abuse or neglect	5	3
Suspicious circumstances	1	0
Total	165 (100%)	143 (100%)

**In 2023, the category of accident was included in acute injury; a second data field was added to narrow down acute injury by type.*

Accident types

Type	2022 (partial year)	2023
Bruise	0	3
Burn	1	1
Contusion	0	2
Fall	77	13
Fall with fracture	Not delineated in 2022	66
Laceration	0	11
Motor vehicle accident	3	4
Seizure resulting in injury	6	0
Self-inflicted	0	2
Stroke	0	1

SUMMARY

In 2023, the Aging and Disability Mortality Review Panel met four times and completed the in-depth review of 13 cases of death of individuals receiving home- and community-based waiver services. By sharing their diverse perspectives and areas of expertise in their analyses of those cases, as well as data and trends, panel members developed increased insights into the strengths and weaknesses of the system of care of adults receiving services. The Panel invited presentations from the Office of Aging and Disability Services to better understand each HCBS waiver section. The Panel continued to make thoughtful recommendations, as discussed in this report, for ways to strengthen the system of protection of the home- and community-based services populations.

The Panel will continue to meet quarterly in 2024, and more frequently if the need arises. Work will continue toward a formal database and the completion of the rulemaking process.

RELATED RESOURCES

Of note, is Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight (https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf), a 2018 joint report issued by the U.S. Department of Health and Human Services, Office of Inspector General (OIG); Administration for Community Living (ACL); and Office for Civil Rights (OCR) to help improve the health, safety, and respect for the civil rights of individuals living in group homes. The joint report provides suggested model practices to the Centers for Medicare and Medicaid Services (CMS) and states for comprehensive compliance oversight of group homes to help ensure better health and safety outcomes. In addition, the Joint Report provides suggestions for how CMS can assist states when serious health and safety issues arise that require immediate attention. (Note in particular, Appendix C Model Practices for State Mortality Reviews.)