2024 Aging and Disability Mortality Review Panel Annual Report

Required by:
22 MRS § 264, sub-§6(B)
PL 2024, c.398, Pt. MMMM, §2

Prepared by: Department of Health and Human Services
Maine Center for Disease Control and Prevention, in partnership with

Maine's Aging and Disability Mortality Review Panel

EXECUTIVE SUMMARY

This annual report prepared by the Maine Center for Disease Control and Prevention in partnership with Maine's Aging and Disability Mortality Review Panel provides a summary of mortality and morbidity data pertaining to the adult home and community-based waiver populations and recommendations for system improvements aimed at reducing death and serious injury to members receiving these waiver services, pursuant to 22 MRS § 264. This report describes the related activities for this report year (November 2023 - November 2024), including procedures for data collection and reporting, and rulemaking required by statute. As of this report, the panel coordinator completed 55 comprehensive investigations, including 33 deaths and 21 serious injuries, and referred to the Aging and Disability Mortality Review Panel, a total of 13 deaths and one case of serious injury.

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 2024. (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

[1] https://www.maine.gov/sos/cec/rules/10/ch101.htm

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.

Under section 1915(c), successful waivers must provide assurances to Centers for Medicare and Medicaid Services (CMS) that the state has implemented necessary safeguards to protect the health and welfare of participants receiving services. By establishing the Aging and Disability Mortality Review Panel, Maine has strengthened its system for safeguarding the HCBS member population.

Depending on a member's eligibility and waiver service, the service provider who is selected by the member/guardian may be licensed or unlicensed and may be 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.

RELATED ACTIVITIES

Panel members convened four times during the report year and participated in the comprehensive reviews of 14 cases referred by the panel coordinator and discussed further in this report.

Panel Membership in 2024
- Brenda Gallant, Executive Director, Long-term Care Ombudsman Program
  - Replaced by Gretchen Zeh-Higgins, Associate Director, November 2024
- 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
- Patricia K. Poulin, Assistant Attorney General, Office of the Attorney General

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

    - Replaced by Gregg Bernstein, Assistant Attorney General, November 2024
- Jennifer Putnam, Executive Director, Waypoint
- Katrina Ringrose, Deputy Director, Disability Rights Maine
    - Replaced by Barrett Littlefield, Developmental Services Advocate, November 2024
- Taylor Slemmer, Medicolegal Death Investigator, Office of the Chief Medical Examiner

In accordance with 22 MRS § 264(4), in 2024, the Panel selected a chairperson, Jennifer Putnam, to serve in that role until November 2025.

Due to a 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. The panel coordinator is actively working with Maine CDC, the DHHS Commissioner and the Panel to identify and recruit for this panel seat.

Rulemaking

DHHS is obligated to adopt routine technical rules to implement the requirements under 22 MRS §264 and 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. Rulemaking performed by the Maine CDC is in accordance with 5 MRS Chapter 375: Maine Administrative Procedure Act §8001 - §11008 and the agency will administer the rule once adopted.

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. In early 2024, Sections 18, 20, 21 and 29 transitioned to a reportable events system called Evergreen from the previous system, EIS. The panel coordinator has been given access to Evergreen to review deaths and serious injuries via an internal report, and may review service authorizations, reportable events, and person-centered plans in detail as needed to validate the circumstances surrounding incidents and the quality of care provided to the waiver member.

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

The panel coordinator has established a process to request and receive, as authorized, external records necessary to conduct a more comprehensive review of those HCBS member injuries and deaths which, on initial examination, are unexpected or unexplained, premature, potentially preventable, or suspicious. The determination of a death requiring additional investigation is based on review of the initial report provided by OADS, the death certificate, and an examination of records available in the Evergreen and MeCare Systems. Additional information is sought by the panel coordinator to determine the need for full, comprehensive panel review, including reports provided by direct service providers, care coordinators, case managers, medical records, police and EMS reports, APS investigations, and reports from OCME. Serious injuries that undergo panel coordinator investigation are due to a lack an adequate detail in the initial report to explain the injury, or if there is any concern for or evidence of abuse or neglect; the panel

coordinator attends closely to reports involving individuals who are unable to provide their own account of the event or injury. In addition, the coordinator conducts voluntary interviews, typically with family members or guardians, to assist in further investigation. As of this report, the panel coordinator had completed 55 comprehensive investigations in 2024, including 33 deaths and 21 serious injuries. Several are pending further investigation.

Cases Referred for Panel Review

The panel coordinator refers to the Panel those deaths and serious injuries which, after initial investigation, remain poorly explained or are potentially preventable and any death or serious injury in which the circumstances are suspected to be related to systemic issues of access to or quality of care. Case summaries are compiled for and shared to the Panel in a deidentified manner (22 MRS § 264, sub-§ 5).

In 2024, the Panel met four times and reviewed the comprehensive investigations of 13 deaths and one serious injury.

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).

At the time of this report, there were 208 active members in this waiver. During this report year, no cases of death or serious injury to members of Section 18 have met criteria for referral to the Panel for comprehensive review.

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, nonemergency transportation/escort and care coordination. Section 19 currently serves approximately 2800 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.

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, often family members, who provide services under the Participant-Directed Option will demonstrate their competency for all required tasks to the member or

representative.

There were 15 deaths and 4 serious injuries to Section 19 members which underwent comprehensive investigation by the panel coordinator in 2024. Of those, 7 deaths were referred to the Panel for their review, as of this report.

Panel Findings and Recommendations:
Cases reviewed by the Panel in 2024 included four individuals who died of acute intoxication, the combined effects of a variety of substances which included fentanyl in each case. This is a known trend in Maine and is being explored in depth by the Governor's opioid response work. Panel members commented that some of these individuals may have been trying to manage their chronic pain and recommended the consideration of undertreatment of chronic pain as a possible etiology of overdose risk.

The Panel observed, too, that the death certificate—an important source of public health data—may tell an incomplete story when the cause of death is listed as acute intoxication but does not list other significant conditions, such as cancer. That was the case in each of the four examples above. Each of these individuals were living with conditions associated with chronic pain—as well as other health and mental health conditions that were not mentioned on the death certificate.

Cases reviewed by the Panel involved personal support services provided by friends or family paid by Medicaid waiver funds. For many people, this option is critical to the ability to continue to live in the community, rather than in a facility. However, the Panel identified that a gap in oversight—or a conflict of interest—can occur when the recipient of services is not capacitated and able to direct their own care. The Panel suggests the review of regulations related to self-directed care to ensure that there is always someone providing in-person oversight in such cases.

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 were 41 individuals being served through this waiver at the time of this report. During this report year, no cases of death or serious injury to members of Section 20 met criteria for referral to the Panel.

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 October 2024, OADS reported 3,425 persons served by Section 21.

In 2024, there were 16 deaths and 12 serious injuries in Section 21 which underwent comprehensive investigation by the panel coordinator. Four of those cases were referred to the Panel for their review, including one serious injury.

Panel Findings and Recommendations:

The Panel reviewed cases which again emphasized the need for improved support around individuals with intellectual disability, chronic medical, and mental health conditions. In one case, residential facility staff were tasked with the acute management of escalating mental health behaviors of an individual and appear to have overlooked worsening health status, which lead to death. In another case, staff appeared to delay seeking treatment for new and bizarre behaviors in a member, which were medical in nature, and lead to the member's death at the group home.

In particular, unlicensed two bed homes are not required to employ a nurse. The Panel observed, in their reviews, how often staff are either unprepared or untrained for the acuity of mental health and medical needs of their clients; and there are not always nursing or medical providers on staff or available to readily consult. One recommendation by the Panel is for each direct service provider be made aware of members' individual health and mental health conditions to ensure these needs can be met, especially in a time of crisis or emergency, and that these providers also have 24/7 access to a consulting provider. The Panel recommended that Maine adopt the use of a triage service such as Station MD and pay provider agencies to use it, suggesting a pilot project comparing emergency department use before and during the use of Station MD[3] initially if cost is a concern. The panel anticipates that this would result in clear cost saving and reduced death and serious injury. The panel also identified the need for a uniform documentation system, like an electronic medical record, to be used in group homes. Consistency in documentation would improve the ability for the State to audit those records for quality and completion.

An injury case was reviewed by the Panel which highlighted the frequency of antipsychotic use in individuals being served by home and community-based services. Given that residential facilities are often the default care providers for medically and behaviorally complex individuals who also carry disability diagnoses, more study about the use of antipsychotics in this population is recommended.

[3] Station MD is an online physician service serving individuals with intellectual and/or developmental disabilities (I/DD) and other vulnerable populations through a telemedicine platform; https://stationmd.com/

The Panel observed, again, that cause of death data on death certificates would benefit from increased scrutiny. The Panel reviewed cases of death in which the cause was listed only as the disability diagnosis (such as Down Syndrome or Cerebral Palsy). In those situations, the public health system is unable to extrapolate and learn about health conditions and risks which might have contributed to those deaths. When the disability is not mentioned at all, the opportunity to identify high risk populations, and to collect important data about causes of death and related conditions in these populations is lost. In 70% of death certificates of those in Sections 21 and 29, no disability diagnosis or information was listed under other significant conditions.

As a way to reinforce the importance of this source of data, it has been suggested by the Panel that those authorized to complete and file death certificates undergo a death certificate training and that this be a requirement for a certifying health care provider with each license renewal. A representative from DHHS Electronic Data, who met with the Panel in August to discuss the Database Application for Vital Events (DAVE) system, referenced an available training offered by the CDC's National Center for Vital Statistics[4].

In addition to the discussion about death certificate completion, the Panel invited a presentation by OADS Disability and Brain Injury Services regarding START training[5]. OADS made 1,000 seats available to direct service providers and care coordinators for this training to improve member outcomes.

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 October 2024, OADS reported 3,064 persons served by Section 29.

In 2024, there were 3 deaths and 4 serious injuries which underwent comprehensive investigation by the panel coordinator. Of those, 2 deaths were referred to the Panel for their review.

Panel Findings and Recommendations:

The cases reviewed by the Panel mirrored concerns identified earlier: the system of care is often asked to manage our most complex members in settings, and by direct service providers, who are unprepared or untrained for the individual's level of acuity. And when an individual is hospitalized, there is pressure to discharge, even when the level of care to which they are returning is no longer be appropriate. The Panel suggests exploring increasing the number of beds in care settings, such as intermediate care facilities, which are licensed and intended to address active treatment needs.

Additionally, the Panel was struck by the death of a very young adult which was unexpected but was not referred to the Office of the Chief Medical Examiner. As a result, the Panel suggests that the convening a group of people with expertise to propose recommended legislation related to which cases are referred to the OCME.

[4] https://www.cdc.gov/nchs/nvss/handbooks-and-guides.htm
[5] https://iod.unh.edu/national-center-start-services

HCBS MEMBER DEATH AND SERIOUS INJURY DATA

State HCBS Mortality Database

The panel coordinator is charged with developing and maintaining a state HCBS mortality database. The panel coordinator's compiling of information about HCBS member deaths and serious injuries into a datasheet began on July 1, 2022, aligning with the start of State Fiscal Year 2023. The Maine CDC is working to establish a server engine database. Data field structure has been provided to IT and cost estimates are pending at this time. Data reported from sources including Maine CDC Office of Data, Records and Vital Statistics and OADS will continue to be held in a secure manner and managed by the panel coordinator. Data from reports completed for 2022 (July-December 2022) and 2023 (January 2023-November 2023) are included in this 2024 report.

Deaths of HCBS waiver participants

There were 378 deaths of members receiving waiver services reported between January 1, 2024 and November 20, 2024 when data for this annual report was gathered. This report also includes 93 deaths which occurred late November - December 2023, after data for the 2023 annual report was gathered, bringing the total reported to 471 unique cases. The Panel suggests amending the statutory deadline for this report to align with the State Fiscal Year period to allow reporting to reflect analyses of deaths and injury occurring during the year.

The panel coordinator completed a preliminary investigation of each death, reviewing data reported from sources including OADS and death certificates. 45 cases of death of members were categorized as unexpected or unexplained and underwent, or are undergoing a comprehensive investigation to determine if a full panel review is warranted. As of this report, 13 cases of death were referred to and reviewed by the Panel at their quarterly meetings. Two cases of death of Section 21 members in 2024 are currently in review with the panel coordinator and, as of the time of this report, the need for referral to the Panel is not yet determined, therefore, these cases are not included in analyses.

Member Deaths and Panel Referrals by Waiver Section

	2022 (partial year)		2023 Report		2024 Report	
Waiver	**Deaths**	**Panel Referrals**	**Deaths**	**Panel Referrals**	**Deaths**	**Panel Referrals**
Section 18	1	0	4	0	2	0
Section 19	148	1	285	3	389	7
Section 20	0	0	1	0	0	0
Section 21	33	1	58	10	67	4
Section 29	3	0	12	0	12	2
Total	185	2	360	13	471	13

Member Deaths by Age

Age Group	2022 Report (partial year)	2023 Report	2024 Report
<19	1 (1%)	0 (0%)	0 (0%)
20-29	3 (2%)	8 (2%)	12 (3%)
30-39	3 (2%)	7 (2%)	8 (1%)
40-49	11 (6%)	16 (4%)	25 (5%)
50-59	18 (10%)	46 (13%)	65 (14%)
60-69	60 (31%)	88 (24%)	116 (25%)
70-79	38 (20%)	86 (24%)	101 (21%)
>80	51 (28%)	109 (31%)	144 (31%)
Total	185 (100%)	360 (100%)	471 (1005)

Average Age of Member at Time of Death by HCBS Waiver Section

	2022 Report (partial year)	2023 Report	2024 Report
Waiver	**Avg Age**	**Avg Age**	**Avg Age**
Section 18	68	52.6	54.71
Section 19	72.12	71.79	72.28
Section 20	N/A	40	N/A
Section 21	59.32	62.62	59.59
Section 29	45.5	57.7	53.08

Member Deaths by Gender*

Gender	2022 Report (partial year)	2023 Report	2024 Report
Female	111 (60%)	202 (56%)	302 (64%)
Male	74 (40%)	158 (44%)	169 (36%)
Total	185 (100%)	360 (100%)	471 (100%)

***** *Source: DHHS Data, Research, and Vital Statistics*

Member Deaths by Race/ethnicity

Race/Ethnicity	2022 Report (partial year)	2023 Report	2024 Report
African American	0 (0%)	5 (1%)	8 (2%)
Asian	1 (1%)	3 (1%)	4 (1%)
Hawaiian/Pacific Islander	0 (0%)	1 (<1%)	0 (0%)
Hispanic	2 (1%)	2 (1%)	3 (<1%)
Native American	0 (0%)	2 (1%)	5 (1%)
Other/Unknown*	0 (0%)	0 (0%)	4 (1%)
White	170 (98%)	343 (95%)	447 (95%)
Total	220 (100%)	360 (100%)	471 (100%)

**Other/Unknown means the review awaits the death certificate*

Member Deaths by Type

Type	2022 Report (partial year)	2023 Report	2024 Report
Accident	5 (3%)	12 (3%)	11 (2%)
Acute illness	13 (7%)	22 (6%)	39 (8%)
Acute intoxication/overdose	0	0	4 (1%)
Known chronic illness	85 (46%)	173 (49%)	231 (49%)
Known terminal illness	66 (36%)	116 (32%)	158 (34%)
Self-inflicted	0 (0%)	2 (1%)	1 (<1%)
Undetermined as reported by OCME	0 (0%)	0 (05)	1 (<1%)
Unknown*	16 (8%)	35 (9%)	26 (6%)
Total	185 (100%)	360 (100%)	471 (100%)

**P*ending receipt of death certificate or undergoing investigation by Office of the Chief Medical Examiner as of this report*

Breakout by Member Accident Type

Type	2022 Report (partial year)	2023 Report	2024 Report
Acute intoxication	1	3	2*
Choking	1	1	1
Drowning	1	0	0
Fall	1	2	4
Hanging	0	1	0
Motor vehicle accident	1	1	1
Trauma	0	4	1

**In two cases of acute intoxication (overdose), manner of death was categorized as accidental by the Office of the Chief Medical examiner and included above; in two cases, the manner of death was listed as undetermined*

Member Deaths by Maine County

County	2022 Report (partial year)	2023 Report	2024 Report
Androscoggin	16	23	29
Aroostook	16	17	33
Cumberland	32	67	60
Franklin	5	7	15
Hancock	4	10	10
Kennebec	12	31	58
Knox	2	10	9
Lincoln	1	8	7
Oxford	7	25	27
Penobscot	36	63	73
Piscataquis	2	4	4
Sagadahoc	1	2	8
Somerset	9	35	38
Waldo	6	10	27
Washington	12	15	21
York	24	32	51
Out of state	1	3	1
Total	185	360	471

Death Trends

Since July 2022, when data for the Aging and Disability Mortality Panel began being collected, the majority (89%) of persons receiving Section 19 waiver services died of known chronic or terminal illness as expected; 71% of persons receiving Section 21/29 services died of known chronic or terminal illness. It is more common for people receiving Section 21/29 services to die of an acute illness compared to people receiving Section 19 services (19% compared to 6%). Since data has been collected, the average age of death in people receiving Section 19 services is 73, compared to 60 for those in sections 18, 20, 21, and 29.

Premature death in the United States is commonly defined as death occurring before age 75[6] but varies by gender, race and other variables[7]. 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[8]. In 2024, the average life expectancy in Maine for all people is

[6] https://www.cancer.gov/publications/dictionaries/cancer-terms/def/premature-death
[7] https://www.cdc.gov/nchs/data/vsrr/vsrr031.pdf
[8] https://onlinelibrary.wiley.com/doi/10.1111/jar.12191

76.7[9] compared to age 57.5 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 2023 showed an average age of death of 62.8 and, in 2022, age 58.2.

The Panel continues to note that across all waiver sections, death certificates vary widely in how they are completed. The cause(s) of death can include a description which is a challenge to categorize without the help of coding, which happens at the Office of 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.

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 Evergreen 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.

Since 2023, efforts have been 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.

Member Serious Injuries by Waiver Section

Waiver	2022 Report (partial year)	2023 Report	2024 Report
Section 18	2	2	8
Section 19	56	62	54
Section 20	0	0	0
Section 21	96	68	45
Section 29	11	11	8
Total	165	143	115

[9] https://www.cdc.gov/nchs/pressroom/states/maine/me.htm

Member Serious Injury by Gender

Gender	2022 Report (partial year)	2023 Report	2024 Report
Female	98 (59%)	90 (63%)	80 (70%)
Male	64 (39%)	52 (36%)	35 (30%)
Other/ X	3 (2%)	1 (1%)	0 (0%)
Total	165 (100%)	143 (100%)	115 (100%)

Member Serious Injury by Race/ethnicity

Race/Ethnicity	2022 Report (partial year)	2023	2024
African American	0	2	4
Asian	1	1	0
Hawaiian/Pacific Islander	0	0	0
Hispanic	2	0	1
Native American	2	2	1
Not listed*	55	33	35
Other*	2	1	1
White	103	105	73
Total	165	143	115

**Data regarding race/ethnicity is reported as listed in the Evergreen and MeCare systems*

Member Serious Injury by Type

Type	2022 Report (partial year)	2023 Report	2024 Report
Accident	87	*	0
Acute illness	15	6	1
Acute injury	31	116	109
Known chronic illness	4	4	0
Restraint use	9	2	0
Self-inflicted	12	7	4
Self-neglect	1	0	0
Suspected abuse or neglect	5	3	1
Suspicious circumstances	1	0	0
Total	165	143	115

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

Acute Injury by Type

Type	2022 Report (partial year)	2023 Report	2024 Report
Bruise	0	3	3
Burn	1	1	0
Contusion	0	2	1
Fall	77 *	13	20
Fall with fracture		66	77
Laceration	0	11	3
Motor vehicle accident	3	4	3
Seizure resulting in injury	6	0	0
Self-inflicted	0	2	1
Stroke	0	1	0
Total	87	116	109

** 2022 data did not delineate Fall and Fall with Fracture*

In 2024, the Panel had the opportunity to review an injury sustained by a resident of a group home. The injury was poorly explained, and the reporting lacked a plan for preventing future injuries for this individual with limited verbal ability. The panel coordinator found, too, that the group home organization had a number of APS reports—all were investigated fully, and no evidence of abuse or neglect was found. However, this resident was being treated with two antipsychotic medications, increasing risk for sedation and possible falls, with no clear indication other than sleep disruption. This mirrors quality data from OADS regarding the use of antipsychotic medication in individuals in sections 21 and 29. The Panel recommends continued study of this issue.

SUMMARY

During this report period, the Aging and Disability Mortality Review Panel met four times and completed the in-depth review of 13 cases of death of and one serious injury to 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 continues 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 2025 and more frequently if the need arises. Work will continue toward a formal database and the final adoption of rules by the Department.

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-andhttps://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdfpublications/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.