Aging and Disability Mortality Review Panel

2025 Annual Report

11/20/2024 to 11/17/2025

Required by:

PL 2024, c. 398, pt. MMMM, §2
22 M.R.S. § 264, sub-§6(B)

Submitted by:
Maine Department of Health and Human Services
Maine Center for Disease Control and Prevention

Table of Contents

EXECUTIVE SUMMARY

This annual report is prepared by the Maine Center for Disease Control and Prevention in partnership with Maine's Aging and Disability Mortality Review Panel, pursuant to 22 MRS § 264. This report provides a summary of mortality and morbidity data pertaining to the adult home- and community-based waiver populations, as well as adults subject to public guardianship, and recommendations for system improvements aimed at reducing death and serious injury to members of these populations. Also included in this report is information about the related activities, procedures established for data collection and reporting, and rulemaking required by statute.

Methodology

The Aging and Disability Mortality Review Panel is established to review patterns of death and serious injury among adults receiving certain services through Maine's Office of Aging and Disability Services. According to statute, the panel coordinator is authorized to access records pertaining to the care for "adults receiving services." The individual's records (i.e. injury reports, case notes, certificate of death, etc) are reviewed by the panel coordinator who may refer cases to the Panel for further review. Record systems maintained by Maine's Office of Aging and Disability Services (OADS) are a primary source of information for the population specified in law. As directed, data is collected by the designated panel coordinator and entered into the statewide mortality database. At least quarterly, the Panel convenes to review case information and identify and investigate mortality trends to make recommendations about the strengths/ weaknesses in the care system.

The panel coordinator determines the date of extracting data from the statewide mortality review database for compiling information for the annual report. This 2025 report includes data entered for the past year, up to November 17, 2025. To comply with recent statutory amendments enacted by the 132nd Legislature, all future reports will also reflect Panel reviews of reported deaths of and serious injuries to adults under public guardianship, specifically.

Highlights

- As of this report, the panel coordinator completed 83 comprehensive investigations, including 67 deaths and 16 serious injuries, and referred to the Aging and Disability Mortality Review Panel a total of 8 deaths and one serious injury.
- Public Law 2025 c. 127 amended the definition of "Adults receiving services" by adding adults subject to public guardianship services to the reviews authorized under 22 M.R.S. § 264, and it also broadened the panel membership.
- Data trends show Section 19 waiver recipients, the older of the waiver groups, most often experience deaths caused by chronic or terminal illness.
- Panel recommends quarterly communications to providers about the more common risks to the health and safety of adult receiving services.
- A charter is being developed to outline conduct of the Panel and member responsibilities.

- DHHS Division of Licensing and Certification (DLC) presented to the Panel on its oversight of providers according to new DLC rules, which include medication administration record reviews as a system improvement effort.

Full Report

INTRODUCTION

The Aging and Disability Mortality Review Panel (the 'Panel') is a multidisciplinary panel established in Maine law by the 130th Legislature (Public Law 2021, chapter 398) to review the patterns of death of and serious injury to all Maine adults receiving home and community-based waiver services (HCBS) under 42 Code of Federal Regulations, Part 441. In 2025, legislation expanded the scope of the Panel to include review of death of and serious injury to adults subject to public guardianship under Title 18-C M.R.S., Article 5.

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 for protecting adults receiving services. The Panel is required to meet at least four times per year and to submit, annually, 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. (22 M.R.S. § 264).

BACKGROUND

Home And Community-Based Waiver Services

Under a waiver program, a state can waive certain Medicaid program requirements, allowing the state to provide home- and community-based 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 the Office of Aging and Disability Services (OADS).

- 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] 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. By establishing the Aging and Disability Mortality Review Panel, the State has strengthened our system for safeguarding the HCBS member population.

Depending on a member's eligibility and the waiver program, 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. The choice of setting where residential services may be provided includes 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 investigations conducted by DHHS Division of Licensing and Certification, regular program site visits, adult protective services (APS) investigations, 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.

Public Guardianship Services

In Maine, Probate Courts may appoint a guardian for an adult who, due to incapacity, cannot manage essential health, safety, or self-care needs. A public guardian is appointed only when an individual cannot effectively communicate, process or manage decision-making safely and independently, and no less restrictive alternatives or private guardian has been identified.

State guardianship is governed by the Maine Uniform Guardianship, Conservatorship and Protective Proceedings Act (Title 18-C M.R.S., article 5). OADS is authorized to act as public guardian and/or conservator for adults who are adjudicated incapacitated. Acting in the best interest of the individual, a public guardian may assist with decisions concerning medical care, residential placement, and sometimes finances.

The deaths of individuals under public guardianship have recently faced intense scrutiny following investigations into the state's oversight and reporting practices[3], prompting a 2025 law

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

[3] The Maine Monitor: Eight deaths raise questions about oversight of Maine's public guardianships, Sept. 10, 2023 https://themainemonitor.org/eight-deaths-raise-questions-about-oversight-of-maines-public-guardianships/

change to increase accountability. To comply with the recently amended statute, the panel coordinator will report on reports of deaths of and serious injury to individuals under public guardianship as identified by OADS record system.

PANEL MEMEBERSHIP AND ACTIVITY

Panel membership experienced several changes due to term expirations and other shifts. Three additional panel seats were added in 2025, including representation from Adult Protective Services. (PL 2025, c. 127). The Panel convened a membership recruitment committee this year with the focus of this subgroup being to identify and recruit a person with lived experience and a primary care provider, to comply with the recent statutory change. In accordance with 22 MRS § 264(4), in 2025, the Panel selected a chairperson, Lauren Michalakes, to serve in that role until November 2026. Current membership is listed below.

Panel Membership

- Gregg Bernstein, Assistant Attorney General, State of Maine Office of the Attorney General
- Mel Clarrage, Independent Living Specialist, Alpha One, replaced Thomas Newman, Executive Director, Alpha One, September 2025
- Gina Googins, Associate Director, State of Maine Adult Protective Services, joined September 2025
- Julie Guerrette, Maine Health, joined October 2025
- Heather Hyatt, Associate Director, State of Maine DHHS Division of Licensing and Certification
- Jen Jello, State Director, Neurorestorative replaced Cara Orton, Director of Brain Injury Programs, River Ridge Center September 2025
- Allison Knight, Homeward Bound Transition Manager, Maine Long-Term Care Ombudsman Program replaced Gretchen Zeh-Higgins, Associate Director, Maine Long-term Care Ombudsman Program, June 2025
- Barrett Littlefield, Developmental Services Advocate, Disability Rights Maine
- Lauren Michalakes, Program Consultant, State of Maine DHHS Office of Aging and Disability Services
- Jennifer Putnam, Executive Director, Waypoint
- Taylor Slemmer, Medicolegal Death Investigator, State of Maine Office of the Chief Medical Examiner
- Beth Sullivan, Executive Director, Granite Bay Services replaced Kelly Osborn, Senior Vice President of Client Services, Goodwill Northern New England September 2025

Over the past year, the panel convened four times and participated in the review of nine cases referred by the panel coordinator. Results of those reviews are discussed later in this report. In addition to case reviews, the Panel worked on a charter to help establish simple procedural guidelines, outline member responsibilities, and provide orientation to new panel members.

In July, representatives from the Panel met with OADS leadership to present the 2024 annual report and discuss findings. As a result of that meeting and following a presentation to OADS staff by panel member Dr. Lauren Michalakes regarding the particular health risks experienced by individuals with intellectual and developmental disabilities (IDD), an initiative to provide a quarterly communication to service providers was discussed. This communication would offer information specific to identifying and reducing the risk of commonly fatal and potentially avoidable conditions such as aspiration, dehydration, constipation, seizures and sepsis, known as the Fatal Five[4], and represents an opportunity for Maine CDC to team with OADS on this project.

In September 2025, Maine's Division of Licensing and Certification (DLC) published concurrent emergency and routine technical rulemaking to establish modernized licensing requirements for agencies that provide services funded in whole or in part by the Department, to an adult with an intellectual disability, autism spectrum disorder, a related condition or an acquired brain injury. (34-B MRS §§ 1203-B). Providers, including case management services, employment supports, and residential services, meeting the statutory criteria will be licensed as Home and Community Support Service (HCSS) agencies and subject to DLC oversight and applicable rules. The Panel invited member and DLC staff, Heather Hyatt, to present the new rule, Home and Community Support Service Agencies Licensing Rule, (10-144 CMR chapter 108). DLC and OADS worked together to dramatically increase the number of agencies and group homes licensed to ensure quality of care and create system improvements. The rule includes important systemic improvements such as requiring staff or contracted registered nurse review of medication administration records and training of staff.

Gregg Bernstein from the Attorney General's office presented to the Panel regarding the work of the Health Crimes Unit (HCU). The Panel discussed ways that DLC, APS and HCU work together to investigate high priority complaints and ensure collaboration. The panel coordinator and Dr. Michalakes toured a six-person group home run by Waypoint Maine where they were able to hear from staff about the use of a telephonic medical triage service, Station MD. The service has reduced unnecessary emergency department visits and has provided staff with enhanced decision-making support.

[4] https://www.relias.com/blog/fatal-five-overview

Legislation and Rulemaking

DHHS is obligated to adopt routine technical rules to implement the requirements under 22 M.R.S. § 264 to clarify the collection and reporting of mortality information, including maintaining a state mortality database for death and serious injury reviews, managing individually identifiable health information, providing direction for conducting interviews, and avoiding conflicts of interest.. Rulemaking by Maine CDC is conducted in accordance with 5 MRS Chapter 375: Maine Administrative Procedure Act §8001 - §11008.

In 2025, Maine CDC was consulted on legislation presented by OADS to expand the charge of the Panel to review all deaths and serious injuries for adults subject to public guardianship, whether or not they are enrolled in HCBS programs. The legislation passed and, going forward, this report will specify public guardianship status for cases reviewed. Additionally, according to this legislation, panel membership will be broadened by adding a member of the general public with lived experience as an adult receiving services and, specifically, a DHHS representative for adult protective services. (PL 2025, c. 127).

The panel celebrated recent state legislation which requires a license for every agency that provides a residential care facility, regardless of size, a setting for an adult with an intellectual disability, autism spectrum disorder, or an acquired brain injury. It also requires a license for any facility of any size which is receiving MaineCare reimbursements. Additionally, rule changes require any agency that is responsible for medication administration to retain a registered nurse to assure compliance with the rule.

Rules established pursuant to 22 M.R.S. § 264(9) for the panel will reflect "Adults receiving services" as meaning adults receiving home-based and community-based services under 42 Code of Federal Regulations, Part 441 and adults subject to public guardianship under Title 18-C, Article 5.

Aging and Disability Mortality Review Process

The Aging and Disability Mortality Review Panel Coordinator, who is 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. Beginning September 23, 2025, reporting will include deaths and serious injury events for those under public guardianship regardless of waiver status.

Each report undergoes a preliminary review by the panel coordinator including an examination of records available in the Evergreen and MeCare Systems used by OADS and to which the panel coordinator has been granted access. As authorized, the panel coordinator may review service authorizations, reportable events, and person-centered care plans in detail as needed to validate the circumstances surrounding incidents and the quality of care being provided.

As outlined by statute, the panel coordinator has established a process to request and receive additional records necessary to conduct a more comprehensive review of those injuries and deaths which, on preliminary examination, suggest systemic issues of service access or quality and/or potentially could have been avoided. Additional information may include reports provided by direct service providers, care coordinators and case managers, medical records, police and emergency medical services (EMS) reports, APS investigations and reports from the Office of the Chief Medical Examiner (OCME). Serious injuries which undergo a more thorough investigation are those which lack adequate detail in the initial report to explain the injury, might have been preventable, or those where 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 completed 83 comprehensive investigations in 2025, including 67 deaths and 16 serious injuries, which includes 17 individuals identified as receiving public guardianship services concurrent with a waiver service. Several cases are pending further investigation, including 17 cases of individuals identified as receiving public guardianship services, only. These cases will be included in the subsequent annual report.

Panel Reviews and Findings

The panel coordinator refers to the panel those deaths and serious injuries which, after 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).

Section 18 Cases

Home and Community Based Services Section 18 waiver 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 214 active members on this waiver. In 2025, there were a total of six deaths and two serious injuries reported in Section 18, five (83 percent) of which underwent comprehensive review by the panel coordinator and one death was referred to the panel for their full review. That was a case in which the member experienced an unwitnessed and poorly explained death. After discussion and review of the data presented, the panel could not conclude whether this death was preventable, and OCME reached a similar conclusion, identifying the manner of death as undetermined.

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 2,800 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.

In 2025, there were a total of 354 deaths and 55 serious injuries reported in Section 19 of which 10 deaths (3 percent) and four injuries (7 percent) underwent comprehensive investigation by the panel coordinator in 2025. As of this report, 1 death was referred to the panel for their review.

The case reviewed by the panel involved an older adult whose cause and manner of death were listed as undetermined by the Office of the Chief Medical Examiner. Medical records reviewed indicated that the individual had multiple chronic health conditions limiting their ability to perform activities of daily living. They had been diagnosed with dementia by a primary care provider but continued to act as their own guardian. They were receiving in-home care from a family member who was paid by a service care agency through the Section 19 waiver. The case was referred to the panel due to their condition upon death.

The individual had no in-person health care visits in the six months prior to death; their primary care provider met with the client twice during that time via telehealth. Five months prior to the death, a care coordinator from the agency performed an in-person visit and documented less-than-ideal living conditions. In the year prior to death, there had been no reports to adult protective services regarding this individual.

The panel concluded that this death was not preventable due to severe underlying medical illness, but that the client may have died sooner than necessary. And a referral to hospice might have provided a more comfortable death. This case also echoes previous panel observations

regarding the need to review SCA rules/requirements to ensure that there is adequate oversight and direct observation of the services that are being provided by the paid family caregiver.

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 42 individuals being served through this waiver at the time of this report. There were no deaths or serious injuries reported in Section 20 in 2025.

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 when 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 2025, OADS reported 3,052 persons served by Section 21.

In 2025, there were 67 deaths and 24 serious injuries reported, of which 33 (49 percent) deaths and 10 (42 percent) serious injuries underwent comprehensive investigation by the panel

coordinator. Seven of those cases were referred to the panel for their review, including one serious injury.

The panel reviewed four deaths of individuals receiving Section 21 supports in which choking played a role. There were notable differences observed in how group homes assessed individuals for choking risk, which is known to be more common in individuals with intellectual and developmental disabilities[5]. One recommendation offered by the panel—especially since many group homes do not have full-time nursing or medical personnel on staff—is for the development of a standardized medical or "red alert" face sheet to be used by all group homes as part of the person-centered plan. This page would list all of the individuals' health conditions and potential risks, like choking, as well as prevention guidance for staff.

A regrettable and well-known fact: people with intellectual and developmental disabilities die 10-20 years younger than those without IDD[6]—and the panel's data confirms this. In 2025, the average age at death of those members in Sections 21 and 29 was 58 years compared to 77 for all Mainers[7]. Although this group was more likely to die from an accident or acute illness than their counterparts in Section 19, 63 percent of individuals in Sections 21 and 29 died from either chronic illness or a terminal condition. And research shows that these populations may experience more challenges accessing appropriate and disability-sensitive health care[8]. An opportunity exists to educate health care providers about providing more inclusive and wholistic care—and to disseminate trainings which have already been developed.[9]

In a death reviewed by the panel, deemed preventable, an individual's known significant medical history was unknown or underappreciated by the group home, and critical medications did not transfer with him upon admission. In another case where an individual was living with medically and psychiatrically complicated conditions, day-to-day care was a significant challenge for direct service provider staff. In both situations, the group homes would have benefited from access to a medical triage service and standardized admission protocols and documentation.

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

[5] Manduchi, B., Walshe, M., Burke, É., Carroll, R., McCallion, P., & McCarron, M. (2021). Prevalence and risk factors of choking in older adults with intellectual disability: Results from a national cross-sectional study. *Journal of Intellectual & Developmental Disability*, *46*(2), 126–137. https://doi.org/10.3109/13668250.2020.1763278

[6] Cooper, S.-A., Allan, L., Greenlaw, N., McSkimming, P., Jasilek, A., Henderson, A., McCowan, C., Kinnear, D., & Melville, C. (2020). Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down syndrome: cohort study with record linkage. *BMJ Open*, *10*(5), e036465. https://doi.org/10.1136/bmjopen-2019-036465

[7] https://www.cdc.gov/nchs/data-visualization/state-life-expectancy/index_2021.htm

[8] Anders Larrabee Sonderlund, Fereshteh Baygi, Sondergaard, J., & Trine Thilsing. (2024). Advancing health equity for populations with intellectual disabilities: A systematic review of facilitators and barriers to implementation of health checks and screening. SSM. Health Systems, 2, 100009–100009. https://doi.org/10.1016/j.ssmhs.2024.100009

[9] https://www.maineddc.org/dd-health-videos

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 November 2025, OADS reported 2,936 people served by Section 29.

In 2025, there were 12 deaths and 3 serious injuries reported in Section 29, of which 2 deaths underwent comprehensive investigation by the panel coordinator. There were no deaths or serious injuries which met criteria for panel review in 2025.

Public Guardianship

Prior to the statutory change requiring reviews of deaths of and serious injury to, individuals under public guardianship, specifically, the panel coordinator included this data element in the case record in the state mortality database, when available. Of the cases reviewed by the panel coordinator during this reporting period, 17 waiver recipients also received public guardianship services. Between the effective date of the new law and the data pull for this report, 17 cases of death were entered for non-waiver individuals under public guardianship. No reports of serious injury were made to the panel coordinator for this group. Deaths of and serious injury to "Adults receiving services" will be reported categorically and analysis will identify which service or services the individual was receiving.

DEATH AND SERIOUS INJURY DATA

State Mortality Database

The panel coordinator is charged with developing and maintaining a state mortality database. This database has been developed as a spreadsheet, and the compiling of case records began on July 1, 2022, aligning with the start of State Fiscal Year 2023. Maine CDC has explored the development of a server engine database and found this cost-prohibitive at this time.

Maine CDC supported adding to the law that reviews under the authority of 22 M.R.S. § 264 include public guardianship services, in addition to waiver services. The panel coordinator will continue to work in partnership with OADS to ensure identification and referral of cases that involve individuals under public guardianship and, with input from the Panel, the data will be configured to provide statistics for this population.

Deaths of Adults Receiving Services

There were 456 deaths of members receiving waiver services or subject to public guardianship reported between 11/20/2024 and 11/17/2025 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, APS and death certificates or OCME reports. Because individuals under public guardianship were recently added to the law governing the panel's activities, data for this category is limited at the time of this report and will be explored further in future reports. 67 (15 percent) cases of death of members were categorized as unexpected or

unexplained and underwent, or are undergoing, a comprehensive investigation to determine if these require full panel review. Eight (2 percent) cases of death were referred to and reviewed by the panel at their quarterly meetings.

Service Recipient Deaths and Panel Referrals by Service (N:456)

Waiver	**2022 Report***		**2023 Report**		**2024 Report**		**2025 Report**	
Waiver	Deaths	Panel Referrals	Deaths	Panel Referrals	Deaths	Panel Referrals	Deaths	Panel Referrals
Section 18	1	0	4	0	1	0	6	1
Section 19	148	1	285	3	389	7	354	1
Section 20	0	0	1	0	0	0	0	0
Section 21	33	1	58	10	67	4	67	6
Section 29	3	10	12	0	12	2	12	0
Total	185	2	360	13	471	13	439**	8
Public Guardianship/ Non-Waiver							17***	0

**Note: data reported for 2022 represents only a partial year.*
***Counts include individuals who also received public guardianship services.*
****Partial Data. Data collection required per PL 2025, c. 127, effective September 24, 2025.*

Of the total 439 cases of death of individuals receiving waiver services, 17 also received public guardianship services.

Service Recipient Deaths By Age (N:456)

Age Group	**2022***	**2023**	**2024**	**2025**
<19	1 (1%)	0 (0%)	0 (0%)	0 (0%)
20-29	3 (2%)	8 (2%)	12 (3%)	6 (2%)
30-39	3 (2%)	7 (2%)	8 (1%)	8 (2%)
40-49	11 (6%)	16 (4%)	25 (5%)	34 (8%)
50-59	18 (10%)	46 (13%)	65 (14%)	64 (14%)
60-69	60 (31%)	88 (24%)	116 (25%)	115 (25%)
70-79	38 (20%)	86 (24%)	101 (21%)	92 (20%)
>80	51 (28%)	109 (31%)	144 (31%)	134 (29%)
Total	185 (100%)	360 (100%)	471 (100%)	456 (100%)

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

Average Age of Service Recipient At Time Of Death By Service (N:456)

Service	2022*	2023	2024	2025
Section 18	68	52.6	64.0	55.50
Section 19	72.12	71.79	71.88	71.60
Section 20	N/A	40	N/A	N/A
Section 21	59.32	62.62	58.75	58.94
Section 29	45.5	57.7	54.2	57.45
Public guardianship/Non-waiver			77.21	

*****Note: data reported represents only a partial year.*

Service Recipient Deaths by Gender (N:456)

Gender	2022*	2023	2024	2025
Female	111 (60%)	202 (56%)	302 (64%)	261 (57%)
Male	74 (40%)	158 (44%)	169 (36%)	195 (43%)
Other/Trans.	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Total	185 (100%)	360 (100%)	471 (100%)	456 (100%)

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

Service Recipient Deaths by Race/ethnicity (N:456)

Race/Ethnicity	2022*	2023	2024	2025
African American	0 (0%)	5 (1%)	8 (2%)	6 (1%)
Asian	1 (1%)	3 (1%)	4 (1%)	5 (1%)
Hawaiian/Pacific Islander	0 (0%)	1 (<1%)	0 (0%)	0 (0%)
Hispanic	2 (1%)	2 (1%)	3 (<1%)	0 (0%)
Not listed	7 (4%)	0 (0%)	0 (0%)	0 (0%)
Native American	0 (0%)	2 (1%)	5 (1%)	5 (1%)
Other/Unknown**	5 (3%)	0 (0%)	4 (1%)	0 (0%)
White/Caucasian	170 (91%)	343 (95%)	447 (95%)	440 (97%)
Total	185 (100%)	360 (100%)	471 (100%)	456 (100%)

***Other: listed as biracial; Unknown: not listed in Evergreen, awaiting death certificate.*

Service Recipient Deaths by Type (N:456)

Type	2022*	2023	2024	2025
Accident	5 (3%)	12 (3%)	11 (2%)	18 (4%)
Acute illness	13 (7%)	22 (6%)	39 (8%)	32 (7%)
Acute intoxication/overdose	0	0	4 (1%)	1 (<1%)
Known chronic illness	85 (46%)	173 (49%)	231 (49%)	246 (54%)
Known terminal illness	66 (36%)	116 (32%)	158 (34%)	142 (31%)
Self-inflicted	0 (0%)	2 (1%)	1 (<1%)	1 (<1/%)
Undetermined as reported by OCME	0 (0%)	0 (0%)	1 (< 1%)	3 (1%)
Unknown**	16 (8%)	35 (9%)	26 (6%)	13 (3%)
Total	185 (100%)	360 (100%)	471 (100%)	456 (100%)

Source: DRVS

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

***Cases pending receipt of death certificate or undergoing investigation by Office of the Chief Medical Examiner as of this report.*

Accidental Deaths of Service Recipients by Accident Type

Type	2022*	2023	2024	2025
Acute intoxication	1	3	2	0
Choking	1	1	1	2
Drowning	1	0	0	0
Fall	1	2	2	10
Hanging	0	1	0	0
Motor vehicle accident	1	1	1	3
Trauma	0	4	1	0
Unknown, remote injury	0	0	0	3
Total	5	12	7	18

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

Service Recipient Deaths by Maine County

County	2022*	2023	2024	2025
Androscoggin	16	23	29	40
Aroostook	16	17	33	34
Cumberland	32	67	60	75
Franklin	5	7	15	9
Hancock	4	10	10	17
Kennebec	12	31	58	36
Knox	2	10	9	8
Lincoln	1	8	7	10
Oxford	7	25	27	20
Penobscot	36	63	73	82
Piscataquis	2	4	4	7
Sagadahoc	1	2	8	6
Somerset	9	35	38	30
Waldo	6	10	27	19
Washington	12	15	21	21
York	24	32	51	42
Out of state	1	3	1	0
Total	185	360	471	456

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

Death trends

Data continues to show that individuals who are receiving Section 19 waiver services, and represent an older population, most often experience deaths caused by chronic or terminal illness. Since July 2022, when data collection for the Aging and Disability Mortality Review Panel began, the largest percentage of deaths reported (79 percent) are in this population. And, as noted earlier, more premature deaths in individuals with intellectual and developmental disabilities are seen compared to the total population.

As noted earlier in this report, a total of 456 deaths were reported in all populations, including those under public guardianship, between November 20, 2024 and November 17, 2025, when data for this report was accessed. To date, 17 deaths of individuals receiving public guardianship services and no waiver services have been reported. The average age of death in this group is 77.21.

Serious injuries to waiver participants and individuals under public guardianship

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 M.R.S. § 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. As of the date of data extraction for this report, no record of serious injury to an adult receiving public guardianship services only, was identified. Of note, the panel reviewed an injury in which a member's witnessed and reported staff-inflicted injury may have been part of a pattern of abuse in that home. The staff person was appropriately terminated by the group home agency.

Serious Injuries by Service

Waiver	2022*	2023	2024	2025
Section 18	2	2	8	2
Section 19	56	62	54	55
Section 20	0	0	0	0
Section 21	96	68	45	25
Section 29	11	11	8	3
Public Guardianship/non-waiver			0	
Total	165	143	115	85

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

Recipient Serious Injury by Gender

Gender	2022*	2023	2024	2025
Female	98 (59%)	90 (63%)	80 (70%)	61 (72%)
Male	64 (39%)	52 (36%)	35 (30%)	24 (28%)
Other/ Trans.	3 (2%)	1 (1%)	0 (0%)	0 (0%)
Total	165 (100%)	143 (100%)	115 (100%)	85 (100%)

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

Waiver Recipient Serious Injury by Race/ethnicity

Race/Ethnicity	2022*	2023	2024	2025
African American	0	2	4	1
Asian	1	1	0	1
Hawaiian/Pacific Islander	0	0	0	0
Hispanic	2	0	1	0
Native American	2	2	1	2
Not listed**	55	33	35	10
Other	2	1	1	1
White/Caucasian	103	105	73	70
Total	165	143	115	85

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

***Race/ethnicity data is from the Evergreen and MeCare systems when it is listed there.*

Waiver Recipient Serious Injury by Type

Type	2022*	2023	2024	2025
Accident	87	* *	0	0
Acute illness	15	6	1	0
Acute injury	31	116	109	79
Known chronic illness	4	4	0	0
Restraint use	9	2	0	0
Self-inflicted	12	7	4	0
Self-neglect	1	0	0	2
Suspected abuse or neglect	5	3	1	3
Suspicious circumstances	1	0	0	1
Total	165	143	115	85

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

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

Waiver Recipient Acute Injury Types

Type	2022*	2023	2024	2025
Allergic reaction	0	0	0	1
Bruise	0	3	3	0
Burn	1	1	0	1
Contusion	0	2	1	0
Fall	77**	13	20	15
Fall with fracture		66	77	54
Fracture without fall	0	0	0	4
Heart problem	0	0	0	1
Heat stroke	0	0	0	1
Laceration	0	11	3	0
Motor vehicle accident	3	4	3	0
Possible blood clot	0	0	0	1
Seizure resulting in injury	6	0	0	0
Self-inflicted	0	2	1	0
Stroke	0	1	0	1
Total	87	116	109	79

**Note: data reported for 2022 represents only a partial year.*
*** Not delineated in 2022.*

SUMMARY

In 2025, the Aging and Disability Mortality Review Panel met four times and completed the in-depth review of eight cases of death and one serious injury to individuals receiving home- and community-based waiver services. The Panel continued to refine their analyses of each case with which they were presented by sharing expertise, knowledge and varying perspectives to identify meaningful recommendations to improve the systems of care.

Specific recommendations made by the panel in 2025 include:

- Collaboration by OADS and Maine CDC on a quarterly prevention newsletter to service providers;
- Development of a standardized medical or “red alert” face sheet to be used by all group homes as part of the person-centered plan;
- Education of health care providers about providing more inclusive and holistic care to individuals with IDD;
- Ensuring access to a medical triage service for group homes lacking health care staff; and
- Requirement of standardized admission protocols and documentation for providers.

The panel will continue to meet quarterly in 2026, or more frequently as needed. Work will continue in 2026 to complete the rulemaking process. Progress on recommendations outlined in this report will be included in the next annual report.

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.)