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REPORT TO THE LEGISLATURE

TO: Joint Standing Committee on Health and Human Services
FROM: Maine Center for Disease Control and Prevention, Maine DHHS
DATE: February 2023
RE: 2022 Annual Report of the Aging and Disability Mortality Review Panel

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INTRODUCTION AND BACKGROUND

The Aging and Disability Mortality Review Panel is a multidisciplinary panel established by Maine law (Public Law 2021, Ch. 398, part MMMM) to review the patterns of death of and serious injury to all Maine adults receiving home- and community-based services 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 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 a report of its activities and recommendations to the Governor, Commissioner, and to the Legislature.

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), sections 18, 19, 20, 21 and 29.

- Section18: 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.

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

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 & 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 for a thorough outline of the efforts of Adult Protective Services (APS), Office of Aging and Disability Services (OADS) and the Maine Center for Disease Control and Prevention (Maine CDC).

IMPLEMENTATION OF THE PANEL

Title 22 MRS §264 specifies the composition for the Aging and Disability Mortality Review Panel and the qualifications of the coordinator. The panel coordinator, employed within the department of Public Health Nursing (PHN), is responsible for identifying and investigating incidents of death and serious injury occurring to HCBS participants and for referring to the Panel, in a de-identified manner, those cases which meet criteria for full review. A panel coordinator, Ann Lovegren, MSN, RN, FNP-BC, was hired and began work at the end of May 2022. In compliance with the requirements of the position, the panel coordinator completed a death investigation training with Labor Relations Alternatives Inc. in July 2022.

The process of identifying Panel members took place over the first half of 2022. The Commissioner then formalized those appointments with a September 1, 2022 start date. The Panel met for the first time on November 1, 2022. A cadence has been established for future meetings and panel members have been notified of meeting dates for the upcoming year.

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, Office of Aging and Disability Services
- Thomas Newman, Executive Director, AlphaOne
- Cara Orton, Director of Brain Injury Programs, RiverRidge Center
- Kelly Osborn, Senior Vice President of Client Services, Goodwill Northern New England
- Patricia K. Poulin, Assistant Attorney General, State of Maine Office of the Attorney General
- Jennifer Putnam, Executive Director, Waban Projects
- Katrina Ringrose, Deputy Director, Disability Rights Maine
- Matthew Siegel, Child and Adolescent Psychiatrist, Maine Behavioral Healthcare
- Taylor Slemmer, Medicolegal Death Investigator, State of Maine Office of the Chief Medical Examiner

The Department is actively drafting a routine technical rule to implement the responsibilities of the Aging and Disability Mortality Review Panel and clarify collection and reporting of HCBS member mortality information, including maintaining a state database for HCBS member death and serious injury reviews; selecting and setting any limits on the number of terms for the panel members; avoiding conflicts of interest of members; managing individually identifiable health information; and reporting findings and recommendations following reviews of death and serious injury.

REVIEW PROCESS

The panel coordinator has been working closely with OADS and APS to ensure receipt of every case of death and serious injury occurring in the state. Sections 18, 20, 21 and 29 share a reportable events system called EIS. A spreadsheet of reportable events is emailed daily to the panel coordinator from OADS. 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 secure email. The panel coordinator has been given access to MeCare, the system used by Section 19, and may view authorizations, assessments and care plans as needed. Additionally, the coordinator has been working with APS to ensure that all cases warranting their review are communicated to the coordinator for panel review.

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

HCBS MORTALITY DATABASE

The Aging and Disability Mortality Review Panel coordinator is charged with developing and maintaining a 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 SFY23. The coordinator is partnering with Maine CDC and OADS colleagues to establish a server engine database using SQL and it is expected that data will be migrated to the new system by mid-2023. Other future options include an extension of preexisting systems, such as Evergreen used by APS, and will be explored as well.

CASES REFERRED FOR PANEL REVIEW

Per statute, the panel coordinator must refer 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 preventable after a comprehensive review are referred to the Panel. Case summaries are compiled for and shared to the Panel in a deidentified manner.

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 panel review including reports provided by direct service providers, support coordinators, family members, hospital records, physician reports, hospice, or home health plans of care (when these services were used) and coroners' findings whenever available.

DATA

Deaths of waiver participants

There were 185 deaths of members receiving waiver services reported between 7/1/22 and 12/9/22. The panel coordinator completed a preliminary investigation of each death. 16 cases were categorized as unexpected or unexplained and underwent, or are undergoing, a comprehensive investigation to determine if these require full panel review. And 2 cases were referred to and reviewed by the Panel at their first meeting on 11/2/22. The two cases reviewed by the Panel raised many important questions and illustrated opportunities for increased awareness of cross-departmental operations.

Comparable data for previous years is not available. Data gathered between 7/1/22 and 12/9/22 includes the following:

Deaths by Waiver Section	
Section	*Total*
Section 18	1
Section 19	148
Section 20	0
Section 21	33
Section 29	3
Total	185

As would be expected, the largest number of deaths was experienced in the Section 19 population, largely an older population most of whom carry chronic or terminal diagnoses.

Waiver Participant Deaths by Age		
Age Range	*Total*	*Percent*
<19	1	.1%
20-29	3	.2%
30-39	3	.2%
40-49	11	5.9%
50-59	18	9.7%
60-69	60	32.4%
70-79	38	20.5%
>80	51	27.6%

Waiver Participant Deaths by Gender		
Gender	*Total*	*Percent*
Female	111	60%
Male	74	40%

Waiver Participant Deaths by Race/Ethnicity		
Race/Ethnicity	*Total*	*Percent*
African American	0	0%
Asian	1	.5%
Hispanic	2	1.1%
Native American	0	0%
Not Listed	7	3.8%
Other	5	2.7%
White	170	91.9%

Waiver Participant Deaths by Type	
Type	*Total*
Accident	5
Acute Illness	13
Known Chronic Illness	85
Known Terminal Illness	66
Unknown*	16

Accident Types	
Type	*Total*
Acute Intoxication	1
Choking	1
Drowning	1
Fall	1
Motor Vehicle Accident	1

**pending receipt of death certificate or undergoing investigation by OCME*

Waiver Participant Deaths by Maine County	
County	*Total*
Androscoggin	16
Aroostook	16
Cumberland	32
Franklin	5
Hancock	4
Kennebec	12
Knox	2
Lincoln	0
Oxford	7
Penobscot	36
Piscataquis	2
Sagadahoc	1
Somerset	9
Waldo	6
Washington	12
York	24
Out of State	1

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. 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.

Maine has a robust system for safeguarding our most vulnerable populations which includes the work of Adult Protective Services (APS), a unit within OADS that investigates reports of abuse, neglect, or exploitation, or the substantial risk of abuse, neglect, or exploitation for incapacitated and dependent adults, including individuals with intellectual disabilities or autism. Because the purpose of the Panel is trend-focused and cases are referred in a deidentified manner, the panel coordinator performs a preliminary investigation of serious injury cases and collaborates with APS to ensure that all cases of serious injury which involve restraint use, suspected abuse or neglect, or are suspicious or concerning in any way have been referred to by that office.

Comparable data for previous years is not available. Data gathered between 7/1/22-12/9/22 includes the following:

Serious Injury by Waiver Section	
Section	*Total*
Section 18	2
Section 19	56
Section 20	0
Section 21	96
Section 29	11
Total	165

Waiver Participant Serious Injury by Gender		
Gender	*Total*	*Percent*
Female	98	59.4%
Male	64	38.8%
Other	3	1.8%

Waiver Participant Serious Injury by Race/Ethnicity		
Race/Ethnicity	*Total*	*Percent*
African American	0	0%
Asian	1	.6%
Hispanic	2	1.2%
Native American	2	1.2%
Not Listed	55	33.3%
Other	2	1.2%
White	103	62.4%

Waiver Participant Serious Injury by Type		
Type	*Total*	*Percent*
Accident	87	52.7%
Acute Illness	15	9.1%
Acute Injury	31	18.8%
Known Chronic Illness	4	2.4%
Restraint Use	9	5.5%
Self-Inflicted	12	7.3%
Self-Neglect	1	.6%
Suspected Abuse or Neglect	5	3.0%
Suspicious Circumstances	1	.6%

Accident Types	
Type	*Total*
Burn	1
Fall	77
Motorized Vehicle Accident	3
Seizure Resulting in Injury	6

SUMMARY

In the first several months of its existence, the Aging and Disability Mortality Review Panel, with the full support of OADS and Maine CDC, has established effective data sharing and storage processes. The importance of compiling death and serious injury data from each of the five waiver sections in a central database is heightened by the fact that there are currently two separate systems, EIS and MeCare, in which event reporting occurs. The panel coordinator will continue to work with partners across the State to sharpen the quality of data to identify and react to preventable trends in our HCBS waiver populations.

The Panel has been appointed by the Commissioner and met for the first time in November. The group is engaged and enthusiastic about the mission. Comprehensive reviews of cases of death and serious injury will continue at least quarterly as the Panel refines their processes with the aim of making actionable recommendations to further strengthen Maine's vital system of HCBS care.

Related resources:
The 2018 report is 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[1]. 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.)

[1] https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf