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ONE HUNDRED AND THIRTIETH LEGISLATURE
COMMITTEE ON HEALTH AND HUMAN SERVICES

MEMORANDUM

TO: Senator Anne M. Carney, Chair
Representative Thom Harnett, Chair
Joint Standing Committee on Judiciary

FROM: Senator Ned Claxton, Chair *NC (ATB)*
Representative Michele Meyer, Chair *MM (ATB)*
Joint Standing Committee on Health and Human Services

DATE: March 15, 2021

SUBJECT: Public Record Exception Review
Proposed language in the biennial budget creating the Aging and Disability Mortality Review Panel

The Joint Standing Committee on Health and Human Services is requesting the Joint Standing Committee on Judiciary's review, pursuant to 1 MRSA §434, of a confidentiality provision included in a proposed amendment to the biennial budget, LD 221. The Governor's proposed budget, on page A-251, includes the creation of a Public Health Nurse Consultant position within the Center for Disease Control and Prevention to oversee a mortality review panel although the language establishing the panel was left out of the budget proposal. This committee voted unanimously to support the proposed position as well as the attached language establishing the Aging and Disability Mortality Review Panel (with the blessing of the Department of Health and Human Services). We understand that it is the Appropriations and Financial Affairs Committee that has jurisdiction over the budget. We have communicated with the AFA committee through the analyst, Maureen Dawson, and have been assured that in the interests of expediency, it makes the most sense for us to request Judiciary review and provide the information in this memorandum. We also want to let you know that we have LD 716 in our possession which also establishes the panel.

The issue of establishing an Aging and Disability Mortality Review Panel arose in the 129th Legislature. In 2019, the Joint Standing Committee on Health and Human Services voted unanimously to establish such a panel in LD 1377 (as part of a larger bill). In 2020, a majority of the committee voted for an identical proposal as proposed in LD 2126 (the supplemental budget). LD 1377 remained on the appropriations table at the time of adjournment and the proposal was not included in the enacted Public Law, chapter 616 given the need to expediently adjourn. Our proposed language is almost identical to the sections of LD 1377 and LD 2126 establishing the panel with the sole exception of a change to the definition of "adults receiving services" to reflect that the department is planning to apply for a new waiver with the Centers for Medicare and Medicaid Services. The change in definition does not change the number of individuals for which a death would be reviewed by the panel.

Section 1 of the bill, which proposes to enact 22 MRSA §264, establishes an Aging and Disability Mortality Review Panel. This panel is being established, in part, as a response to an investigation by the federal Office of Inspector General in 2017, that determined that Maine was not complying with requirements for oversight and investigation of critical incidents, including deaths, of adult MaineCare members with developmental disabilities or autism receiving services in the community. (These are MaineCare members receiving Section 21 services.) The Department of Health and Human Services and the Joint Standing Committee on Health and Human Services agreed that a panel should be established to review deaths and serious injuries of all MaineCare members receiving home and community based services under 42 CFR, Part 441. This would cover all MaineCare members receiving these services under a waiver or a State Plan Amendment rather than only Section 21 individuals. This is in line with federal Centers for Medicare and Medicaid Services recommendations.

The panel coordinator, who is an employee of the Department of Health and Human Services, will review all deaths and serious injuries of MaineCare adults receiving home and community based services and select cases that need further review. Those cases will include unexpected, premature or preventable deaths or serious injuries and those in which the systems of care may be problematic. Further review of cases is then conducted by the panel. The intent of the panel is to improve systems of care for MaineCare adults receiving home and community based services. The panel coordinator will have access to records that are both public (e.g. death certificates) and confidential (e.g. health care information and personal treatment plans). The panel coordinator will also conduct interviews but not include family names or identification of the person who was injured or has died. The panel coordinator retains custody of records.

The panel will issue an annual report that assesses factors contributing to mortality of MaineCare adults receiving home and community based services, strengths and weaknesses of the delivery system, recommendations to reduce mortality, recommendations to improve the systems of care, and anything else that may be relevant. This report is a public document. In the proposed section 264, subsection 8, records held by the panel coordinator and the panel are confidential to the same extent as the record would otherwise be confidential. Interviews conducted by the panel coordinator and proceedings of the panel are confidential. This subsection triggers this review by the Judiciary Committee. The language is as follows:

8. Confidentiality. Records held by the panel coordinator or the panel are confidential to the same extent they are confidential while in the custody of the entity that provided the record to the panel coordinator or the panel. Records relating to interviews conducted pursuant to subsection 5, paragraph E by the panel coordinator and proceedings of the panel are confidential and are not subject to subpoena, discovery or introduction into evidence in a civil or criminal action. The Commissioner shall disclose conclusions of the panel upon request, but may not disclose information, records or data that are otherwise classified as confidential.

Reviewing the statutory criteria for the proposed exception to public records, we have the following comment.

A. Need to collect the information. The panel coordinator collects information and conducts interviews under 22 MRSA §264, sub-§5, ¶¶D and E of the proposed amendment. With the exception of the interviews, these records already exist. Some of these records are public but many are not – especially health care information. Interviews are voluntary and require permission by the person who has been injured or the guardian of the person who has died. In order to determine whether a death or serious injury was suspicious or preventable, the panel coordinator must collect all pertinent information to make a determination of whether a referral to the panel is necessary.

B. Value in maintaining information. Maintenance of the information collected under sub-§5, ¶¶D and E is essential for the panel coordinator and the panel to meet its responsibilities of ensuring the safety of vulnerable individuals on MaineCare receiving home and community based

and to provide information to the Department of Health and Human Services and the Legislature to improve systems. The panel coordinator retains custody of all records under the proposed amendment.

C. Federal and state law. Health care providers and the Department of Health and Human Services, as a repository of any medical records, must follow the federal Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule (Privacy Rule), which protects individually identifiable health care information. State laws also ensure health care information and other related personal records are confidential. 22 MRSA §1711-C outlines who may access such confidential health care information. In this amendment, health care information may be released to the panel coordinator under proposed 22 MRSA §1711-C, sub-§6, ¶V. State law also protects the rights of individuals with intellectual disabilities under 34-B MRSA §§5605 and 1207 by determining medical information and personal care plans of these individuals are confidential records.

D. Balancing the individual's privacy rights and the public interest. The proposed exception protects the privacy rights of MaineCare adults receiving home and community based services by retaining the confidentiality of any documents held by the panel coordinator or the panel that are already confidential. The panel releases a report that is available to the public that is intended to improve systems of care. The Commissioner of Health and Human Services is also authorized to disclose conclusions of the panel as long as the information released is not confidential. We believe that this is a necessary and appropriate balance of the individual's interest and the public interest.

E. Balancing the effect of disclosure on business competition against the public interest. We are unaware of any connection between this information and competitive disadvantages of any business in this State.

F. Interfering in public negotiations. We are unaware of any connection between this information and negotiations involving a public body.

G. Balancing the public interest and potential jeopardy to public safety or a member of the public. It is not necessary to disclose medical information, plans of care or other confidential information to the public. However, the purpose of the panel is to improve the safety of individuals on MaineCare receiving home and community based services.

H. Narrowness of the exception. The exception to public access has been drawn to appropriately protect individual privacy while permitting the panel to issue a report to the public examining systems level information.

I. Any other criteria that assist the review committee in determining the value of the proposed exception as compared to the public's interest in the record protected by the proposed exception.

Thank you for reviewing this proposed public records exception. If you have any questions, please don't hesitate to contact us.

cc: Maureen Dawson, OFPR

Amendment related to lines 269-270 – Aging and Disability Mortality Review Panel:

Sec. 1. 5 MRSA §12004-J, sub-§19 is enacted to read:

19.

<u>Aging and Disability</u>	<u>Aging and Disability Mortality Review Panel</u>	<u>Not Authorized</u>	<u>22 MRSA §264</u>
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Sec. 2. 22 MRSA §264 is enacted to read:

§264. Aging and Disability Mortality Review Panel

1. Panel established. The Aging and Disability Mortality Review Panel, referred to in this section as "the panel," is established to review deaths of and serious injuries to all adults receiving services.

2. Definitions. As used in this section, unless the context otherwise indicates, the following terms have the following meanings.

A. "Adults receiving services" means adults receiving home-based and community-based services under 42 Code of Federal Regulations, Part 441.

B. "Panel coordinator" means an employee of the Maine Center for Disease Control and Prevention who is appointed by the commissioner. The panel coordinator must be a registered nurse, nurse practitioner, physician assistant or physician licensed or registered in this State and who has completed a nationally certified training program for conducting critical incident, including death, investigations or will complete the training within 6 months of appointment as panel coordinator.

C. "Preventable death" means a premature death that could have been avoided.

D. "Serious injury" 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.

E. "Suspicious death" means an unexpected death in which the circumstance or cause is medically or legally unexplained or inadequately explained or a death in which the circumstance or cause is suspected to be related to systemic issues of service access or quality.

3. Composition. The panel consists of up to 15 members and includes health care providers, social service providers, public health officials and other persons with professional expertise on the health and mortality of adults with disabilities and adults who are aging. The commissioner shall appoint the members of the panel unless otherwise specified. At a minimum, the panel consists of the following members:

A. The person who is lead staff attorney for investigations for the Office of the Attorney General or that person's designee;

B. The person who is lead staff attorney for health care crime investigations for the Office of the Attorney General or that person's designee;

- C. A person within the department responsible for licensing and certification;
- D. A person within the department responsible for aging and disability services;
- E. The executive director of the statewide protection and advocacy agency for individuals with disabilities contracted by the department pursuant to Title 5, section 19502 or the executive director's designee;
- F. The executive director of the long-term care ombudsman program as established in section 5106, subsection 11-C or the executive director's designee;
- G. A member of the Maine Developmental Services Oversight and Advisory Board as established in Title 5, section 12004-J, subsection 15 as nominated by that board;
- H. A health care provider who is licensed under Title 32, chapter 36 or 48 and who has expertise and experience in delivering services to individuals with intellectual disabilities or autism nominated by a statewide association representing physicians;
- I. A representative of the developmental service provider community who has expertise regarding community services for individuals with intellectual disabilities or autism;
- J. A representative of the provider community serving older adults and adults with physical disabilities who has expertise in home-based and community-based services;
- K. A representative of the provider community who has expertise in delivering home-based and community-based services to individuals with brain injuries or other related conditions; and
- L. A person who has expertise in forensic pathology.

4. Terms; meetings; chair. The term for each member of the panel is 3 years, except that members serve at the pleasure of the commissioner. A member may serve until a successor has been appointed. Members may be reappointed. A vacancy must be filled as soon as practicable by appointment for the unexpired term. The panel shall meet at least 4 times each year and sufficiently frequently to carry out its duties and to guarantee the timely and comprehensive reviews of all deaths and serious injuries as required in this section. The commissioner or the commissioner's designee shall call the first meeting. The panel shall elect a chair from among its members annually.

5. Panel coordinator; powers and duties. The panel coordinator has the following powers and duties.

A. The panel coordinator shall conduct preliminary reviews of all deaths of and serious injuries to all adults receiving services to determine whether to refer a case to the panel if the panel coordinator determines that any of the following circumstances exist:

- (1) The death or serious injury was unexpected;
- (2) The death was premature;
- (3) The death or serious injury was preventable;
- (4) Issues with the system of care are indicated;
- (5) Facts and circumstances related to the death or serious injury indicate that the department or providers of home-based and community-based services to adults

receiving services could implement actions that would improve the health and safety of those adults receiving services; or

(6) Other issues or facts related to the death or serious injury indicate the case should be reviewed by the panel.

The panel coordinator shall also refer cases based on the need to review particular causes and circumstances of death or serious injury or the need to obtain a representative sample of all deaths.

The panel coordinator shall conduct preliminary reviews within 7 days of the date the death or serious injury was reported. Preliminary reviews of a death may not be officially closed until the death certificate has been received and reviewed by the panel coordinator.

B. The panel coordinator has access to the following records:

(1) Death certificates;

(2) Autopsy, medical examiner and coroner reports;

(3) Emergency medical personnel reports and documentation;

(4) Health care information of an adult receiving services who is deceased pursuant to section 1711-C, subsection 6, paragraph V. For the purposes of this subparagraph, "health care information" has the same meaning as in section 1711-C, subsection 1, paragraph E; and

(5) Notwithstanding any provision of law to the contrary, information or records from the department determined by the panel coordinator to be necessary to carry out the panel coordinator's duties. The department shall provide the panel coordinator with direct access to the information or records or provide the information or records necessary and relevant as soon as is practicable upon oral or written request of the panel coordinator. Records that must be provided include, but are not limited to, the following:

(a) Personal plans and treatment plans of an adult receiving services when that adult is deceased or injured;

(b) Service plans and agreements developed on behalf of an adult receiving services;

(c) Documents from providers of home-based and community-based services and case managers;

(d) Documents related to an adult protective case or investigation; and

(e) Reports relating to incidents or reportable events of an adult receiving services that occurred in the 12 months prior to the adult's death or serious injury.

C. The panel coordinator may conduct voluntary interviews with parties that may have relevant information for a preliminary review pursuant to paragraph A, including a guardian of or family of or the provider of services to the adult receiving services who has died or experienced serious injury, in accordance with this paragraph.

(1) For interviews pertaining to serious injury of an adult receiving services, prior to conducting any interview, the panel coordinator shall obtain the permission of the adult or the adult's guardian, if the adult cannot consent.

(2) For interviews pertaining to preventable death or suspicious death of an adult receiving services, prior to conducting any interview, the panel coordinator shall obtain the permission of the adult's personal representative if one was appointed or, if there is no personal representative, the adult's guardian if the adult had a guardian.

(3) The purpose of an interview is limited to gathering information or data for the panel, provided in summary or abstract form without family names or identification of the adult receiving services.

(4) The panel coordinator may delegate the responsibility to conduct interviews pursuant to this paragraph to a registered nurse, physician assistant, nurse practitioner or physician licensed or registered in this State and who has completed a nationally certified training program for conducting critical incident investigations. If the interview pertains to a preventable death or suspicious death, the person conducting the interview must have professional training or experience in bereavement services.

(5) A person conducting an interview under this paragraph may make a referral for bereavement counseling if indicated and desired by the person being interviewed.

D. The panel coordinator shall endeavor to minimize the burden imposed on health care providers, hospitals and service providers.

E. A case of death of or serious injury to an adult receiving services may be referred to the panel coordinator by the commissioner, the statewide protection and advocacy agency for individuals with disabilities contracted by the department pursuant to Title 5, section 19502, a member of the panel or any other person who presents credible evidence that a death or serious injury warrants referral to the panel as determined by preliminary review by the panel coordinator.

F. The panel coordinator shall prepare a summary and abstract of relevant trends in deaths of the population of adults receiving services for comparison to cases reviewed by the panel pursuant to subsection 6.

G. The panel coordinator shall prepare a review summary or abstract of information regarding each case, as determined to be useful to the panel and at a time determined to be timely, without the name or identifier of the adult receiving services who is deceased or who has experienced a serious injury to be presented to the panel.

H. The panel coordinator shall, in conjunction with the department, establish and maintain a state mortality database that includes, but is not limited to, the following:

(1) Name, age, sex, race or ethnicity and type of disability or condition of the adult receiving services who is deceased;

(2) Community-based service received by the adult receiving services who is deceased and the name of the service provider;

(3) Description of the events leading to the death of the adult receiving services and the immediate circumstances of the death;

(4) Location of the death, such as the home of the adult receiving services, community setting, hospital or hospice;

(5) Immediate and secondary causes of death of an adult receiving services, including if the death was:

(a) Expected due to a known terminal illness;

(b) Associated with a known chronic illness;

(c) A sudden unexpected death;

(d) Due to an unknown cause;

(e) Due to an accident, including the type of accident;

(f) Due to a self-inflicted injury or illness, including suicide or serious self-injurious behavior;

(g) Due to suspicious or unusual circumstances; and

(h) Due to suspected or alleged neglect, abuse or criminal activity;

(6) Whether an autopsy was conducted and a narrative of any findings from the autopsy;

(7) Findings of the preliminary reviews of all deaths by the panel coordinator pursuant to paragraph A;

(8) Findings of the comprehensive reviews by the panel pursuant to subsection 6; and

(9) Recommendations pursuant to subsection 6, paragraph B issued by the panel and information related to the implementation of those recommended corrective actions.

I. The panel coordinator shall determine the records that are made available to the panel for the purposes of reviewing cases of death or serious injury. The panel coordinator shall maintain custody of all records.

6. Panel; powers and duties. The panel shall conduct comprehensive multidisciplinary reviews of data presented by the panel coordinator, with a particular focus on preventable deaths, suspicious deaths and serious injuries.

A. The panel shall review all cases of death or serious injury that are referred by the panel coordinator. A review of a case by the panel is a comprehensive evaluation of the circumstances surrounding the death of or serious injury to an adult receiving services, including the overall care of the adult, quality of life issues, the death or serious injury event and the medical care that preceded and followed the event.

B. The panel shall submit an annual report, no later than January 2nd of each year beginning in 2021, to the Governor, the commissioner, the joint standing committee of the Legislature having jurisdiction over health and human services matters and the Maine Developmental Services Oversight and Advisory Board established in Title 5, section 12004-J, subsection 15. The report must contain the following:

(1) Factors contributing to the mortality of adults receiving services;

(2) Strengths and weaknesses of the system of care;

(3) Recommendations to the commissioner to decrease the rate of mortality of adults receiving services;

(4) Recommendations about methods to improve the system for protecting adults receiving services, including modifications to law, rules, training, policies and procedures; and

(5) Any other information the panel considers necessary for the annual report.

C. The panel shall offer a copy of the annual report under paragraph B to any party who granted permission for an interview conducted by the panel coordinator pursuant to subsection 5, paragraph C.

D. Following the submission of the annual report to the commissioner and the joint standing committee of the Legislature having jurisdiction over health and human services matters pursuant to paragraph B, the report must be released to the public.

7. Access to information and records. In any case subject to review by the panel under subsection 6, upon oral or written request of the panel, notwithstanding any provision of law to the contrary, a person that possesses information or records that are necessary and relevant to a panel review shall as soon as practicable provide the panel with the information or records. Persons disclosing or providing information or records upon request of the panel are not criminally or civilly liable for disclosing or providing information or records in compliance with this subsection.

8. Confidentiality. Records held by the panel coordinator or the panel are confidential to the same extent they are confidential while in the custody of the entity that provided the record to the panel coordinator or the panel. Records relating to interviews conducted pursuant to subsection 5, paragraph C by the panel coordinator and proceedings of the panel are confidential and are not subject to subpoena, discovery or introduction into evidence in a civil or criminal action. The commissioner shall disclose conclusions of the panel upon request but may not disclose information, records or data that are otherwise classified as confidential.

9. Rulemaking. The department shall adopt rules to implement this section, including rules on collecting information and data, selecting and setting any limits on the number of terms for the members of the panel, managing and avoiding conflicts of interest of members, collecting and using individually identifiable health information and conducting reviews. adopted pursuant to this subsection are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

Sec. 3. 22 MRSA §1711-C, sub-§6, ¶T is amended to read:

T. To a lay caregiver designated by an individual pursuant to section 1711-G; and

Sec. 4. 22 MRSA §1711-C, sub-§6, ¶U, is amended to read:

U. To a panel coordinator of the maternal, fetal and infant mortality review panel pursuant to section 261, subsection 4, paragraph B-1 for the purposes of reviewing health care information of a deceased person and a mother of a child who died within one year of birth, including fetal deaths after 28 weeks of gestation. For purposes of this paragraph, "panel coordinator" has the same meaning as in section 261, subsection 1, paragraph E and "deceased person" has the same meaning as in section 261, subsection 2, paragraph B-; and

Sec. 5. 22 MRSA §1711-C, sub-§6, ¶V is enacted to read:

V. To a panel coordinator of the Aging and Disability Mortality Review Panel pursuant to section 264, subsection 5, paragraph B, subparagraph (4) for the purposes of reviewing health care information of an adult receiving services who is deceased in accordance with section 264, subsection 5, paragraph A. For purposes of this paragraph, "panel coordinator" has the same meaning as in section 264, subsection 2, paragraph B.

Sec. 6. Initial appointments; staggered terms. All appointments to the Aging and Disability Mortality Review Panel established in the Maine Revised Statutes, Title 22, section 264 must be made no later than 90 days after the effective date of this Act. Notwithstanding Title 22, section 264, subsection 4, of the initial appointments to the Aging and Disability Mortality Review Panel, the Commissioner of Health and Human Services shall appoint 2 members to serve an initial term of one year, 2 members to serve an initial term of 2 years and 2 members to serve an initial term of 3 years.

SUMMARY

This amendment establishes the Aging and Disability Mortality Review Panel to review deaths of and serious injuries to all adults receiving home-based and community-based services under a State Plan Amendment or a waiver approved by the United States Department of Health and Human Services, Centers for Medicare and Medicaid Services.

