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H.P. 526

House of Representatives, March 5, 2021

**An Act To Enhance and Improve the Maine Developmental Services
Oversight and Advisory Board and To Establish the Aging and
Disability Mortality Review Panel**

Received by the Clerk of the House on March 3, 2021. Referred to the Committee on Health and Human Services pursuant to Joint Rule 308.2 and ordered printed pursuant to Joint Rule 401.

A handwritten signature in cursive script that reads "R. B. Hunt".

ROBERT B. HUNT
Clerk

Presented by Representative MADIGAN of Waterville.

1 **Be it enacted by the People of the State of Maine as follows:**

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

3 **19.**

4 Aging and Aging and Disability Not Authorized 22 MRSA §264
5 Disability Mortality Review Panel

6
7 **Sec. 2. 22 MRSA §264** is enacted to read:

8 **§264. Aging and Disability Mortality Review Panel**

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

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

14 A. "Adults receiving services" means adults receiving home-based and community-
15 based services under a waiver granted by the United States Department of Health and
16 Human Services, Centers for Medicare and Medicaid Services in accordance with 42
17 Code of Federal Regulations, Part 441.

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

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

25 D. "Serious injury" means a bodily injury that involves a substantial risk of death,
26 unconsciousness, extreme physical pain, protracted and obvious disfigurement or
27 protracted loss or impairment of the function of a body part or organ or mental faculty.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

13 (1) Death certificates;

14 (2) Autopsy, medical examiner and coroner reports;

15 (3) Emergency medical personnel reports and documentation;

16 (4) Health care information of an adult receiving services who is deceased
17 pursuant to section 1711-C, subsection 6, paragraph V. For the purposes of this
18 subparagraph, "health care information" has the same meaning as in section
19 1711-C, subsection 1, paragraph E; and

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

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

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

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

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

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

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

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

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

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

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

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

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

24 E. A case of death of or serious injury to an adult receiving services may be referred
25 to the panel coordinator by the commissioner, the statewide protection and advocacy
26 agency for individuals with disabilities contracted by the department pursuant to Title
27 5, section 19502, a member of the panel or any other person who presents credible
28 evidence that a death or serious injury warrants referral to the panel as determined by
29 preliminary review by the panel coordinator.

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

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

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

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

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

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

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

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

7 (a) Expected due to a known terminal illness;

8 (b) Associated with a known chronic illness;

9 (c) A sudden unexpected death;

10 (d) Due to an unknown cause;

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

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

14 (g) Due to suspicious or unusual circumstances; and

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

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

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

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

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

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

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

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

36 B. The panel shall submit an annual report, no later than January 2nd of each year
37 beginning in 2022, to the Governor, the commissioner, the joint standing committee of
38 the Legislature having jurisdiction over health and human services matters and the
39 Maine Developmental Services Oversight and Advisory Board established in Title 5,
40 section 12004-J, subsection 15. The report must contain the following:

- 1 (1) Factors contributing to the mortality of adults receiving services;
- 2 (2) Strengths and weaknesses of the system of care;
- 3 (3) Recommendations for the commissioner to decrease the rate of mortality of
4 adults receiving services;
- 5 (4) Recommendations about methods to improve the system for protecting adults
6 receiving services, including modifications to law, rules, training, policies and
7 procedures; and
- 8 (5) Any other information the panel considers necessary for the annual report.

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

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

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

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

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

36 **Sec. 3. 22 MRSA §1711-C, sub-§6, ¶T,** as amended by PL 2017, c. 203, §3, is
37 further amended to read:

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

39 **Sec. 4. 22 MRSA §1711-C, sub-§6, ¶U,** as enacted by PL 2017, c. 203, §4, is
40 amended to read:

41 U. To a panel coordinator of the maternal, fetal and infant mortality review panel
42 pursuant to section 261, subsection 4, paragraph B-1 for the purposes of reviewing

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

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

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

13 **Sec. 6. 22 MRSA §3474, sub-§3, ¶C**, as corrected by RR 1991, c. 2, §80, is
14 amended to read:

15 C. A grand jury on its determination that access to those records is necessary in the
16 conduct of its official business; ~~and~~

17 **Sec. 7. 22 MRSA §3474, sub-§3, ¶D**, as corrected by RR 1991, c. 2, §81, is
18 amended to read:

19 D. An advocacy agency conducting an investigation under chapter 961, United States
20 Public Law 88-164, Title I, Part C or United States Public Law 99-319, regarding a
21 developmentally disabled person or mentally ill person who is or who, within the last
22 90 days, was residing in a facility rendering care or treatment, when a complaint has
23 been received by the agency or there is probable cause to believe that that individual
24 has been subject to abuse or neglect, and that person does not have a legal guardian or
25 the person is under public guardianship. The determination of which information and
26 records are relevant to the investigation is made by agreement between the department
27 and the agency-; and

28 **Sec. 8. 22 MRSA §3474, sub-§3, ¶E** is enacted to read:

29 E. The Maine Developmental Services Oversight and Advisory Board established in
30 Title 5, section 12004-J, subsection 15. Access is limited to aggregate data regarding
31 investigations under this chapter relating to persons receiving adult developmental
32 services as defined in Title 34-B, section 1001, subsection 1-A. Data must be provided
33 at least quarterly. The determination of aggregate data to be provided is made by
34 agreement between the department and the Maine Developmental Services Oversight
35 and Advisory Board.

36 **Sec. 9. 34-B MRSA §1223, sub-§6**, as enacted by PL 2007, c. 356, §7 and affected
37 by c. 695, Pt. D, §3, is amended to read:

38 **6. Budget.** The Department of Administrative and Financial Services shall administer
39 the budget of the board. The board shall provide to the ~~commissioner~~ Commissioner of
40 Administrative and Financial Services a proposed budget in accordance with a schedule
41 agreed to by the chair and the ~~commissioner~~ Commissioner of Administrative and Financial
42 Services. The ~~department~~ Department of Administrative and Financial Services shall
43 include in its estimate of expenditure and appropriation requirements filed pursuant to Title

1 5, section 1665 sufficient funds, listed in a separate account as a separate line item, to
2 enable the board to perform its duties.

3 **Sec. 10. 34-B MRSA §1223, sub-§10**, as amended by PL 2013, c. 310, §1, is
4 further amended to read:

5 **10. Access to information.** The board is entitled to access to information from the
6 department necessary to carry out its functions. Except as provided in paragraphs D and
7 E, information provided pursuant to this subsection may not contain personally identifying
8 information about a person with intellectual disabilities or autism.

9 A. ~~The~~ Within existing resources, the department shall provide the board, on a
10 schedule to be agreed upon between the board and the department, reports on case
11 management, reportable events, adult protective and rights investigations, unmet
12 needs, crisis services, quality assurance, quality improvement, budgets and other
13 reports that contain data about or report on the delivery of services to or for the benefit
14 of persons with intellectual disabilities or autism, including reports developed by or on
15 behalf of the department and reports prepared by others about the department.

16 B. ~~The~~ Within existing resources, the department, when requested by the board or
17 pursuant to a written agreement with the board, shall release to the board information
18 pertaining to alleged abuse, exploitation or neglect or an alleged dehumanizing practice
19 or violation of rights of a person with intellectual disabilities or autism.

20 D. The board may examine confidential information in individual records with written
21 permission of the person or that person's guardian. If the person or that person's
22 guardian provides the board with written permission to examine confidential
23 information, the board must maintain the confidentiality of the information as required
24 by section 1207.

25 E. ~~The~~ A member of the board or the board's staff may receive and examine
26 confidential information when otherwise authorized to do so by law, including but not
27 limited to when serving on a committee established by the department or other entity
28 for which access to such information is necessary to perform the function of the
29 committee.

30 **Sec. 11. Data assessment report.** The Maine Developmental Services Oversight
31 and Advisory Board established in the Maine Revised Statutes, Title 5, section 12004-J,
32 subsection 15 shall include in its annual report provided to the Legislature pursuant to Title
33 34-B, section 1223, subsection 9, paragraph D an assessment of the adequacy of the
34 aggregate data provided pursuant to Title 22, section 3474, subsection 3, paragraph E to
35 the board's ability to carry out its functions and duties established in Title 34-B, section
36 1223, subsections 8 and 9.

37 **Sec. 12. Department data assessment report.** The Department of Health and
38 Human Services shall report to the joint standing committee of the Legislature having
39 jurisdiction over health and human services matters no later than January 15, 2022 an
40 assessment of the adequacy of the aggregate data provided pursuant to the Maine Revised
41 Statutes, Title 22, section 3474, subsection 3, paragraph E to the Maine Developmental
42 Services Oversight and Advisory Board established in Title 5, section 12004-J, subsection
43 15.

