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No. 1377

H.P. 998

House of Representatives, March 26, 2019

**An Act To Enhance and Improve the Maine Developmental Services
Oversight and Advisory Board and To Establish an Independent
Oversight Panel To Review Deaths of and Serious Injuries to
Persons with Intellectual Disabilities or Autism**

Reference to the Committee on Health and Human Services suggested and ordered printed.

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-§18** is enacted to read:

3 **18.**

4 <u>Intellectual</u>	<u>Panel To Review</u>	<u>Expenses for</u>	<u>34-B MRSA §1971</u>
5 <u>Disability or</u>	<u>Deaths of and</u>	<u>uncompensated</u>	
6 <u>Autism</u>	<u>Serious Injuries to</u>	<u>members</u>	
7	<u>Persons with</u>		
8	<u>Intellectual</u>		
9	<u>Disabilities or</u>		
10	<u>Autism</u>		

11 **Sec. 2. 22 MRSA §1711-C, sub-§6, ¶T**, as amended by PL 2017, c. 203, §3, is
12 further amended to read:

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

14 **Sec. 3. 22 MRSA §1711-C, sub-§6, ¶U**, as enacted by PL 2017, c. 203, §4, is
15 amended to read:

16 U. To a panel coordinator of the maternal, fetal and infant mortality review panel
17 pursuant to section 261, subsection 4, paragraph B-1 for the purposes of reviewing
18 health care information of a deceased person and a mother of a child who died within
19 one year of birth, including fetal deaths after 28 weeks of gestation. For purposes of
20 this paragraph, "panel coordinator" has the same meaning as in section 261,
21 subsection 1, paragraph E and "deceased person" has the same meaning as in section
22 261, subsection 1, paragraph B-; ~~and~~

23 **Sec. 4. 22 MRSA §1711-C, sub-§6, ¶V** is enacted to read:

24 V. To the panel coordinator, appointed under Title 34-B, section 1972, subsection 1,
25 of the Panel To Review Deaths of and Serious Injuries to Persons with Intellectual
26 Disabilities or Autism, established in Title 5, section 12004-J, subsection 18, for the
27 purposes of reviewing health care information of a person with an intellectual
28 disability or autism receiving adult developmental services as defined in Title 34-B,
29 section 1001, subsection 1-A who has died or experienced a serious injury in the last
30 12 months.

31 **Sec. 5. 22 MRSA §3474, sub-§3, ¶C**, as corrected by RR 1991, c. 2, §80, is
32 amended to read:

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

35 **Sec. 6. 22 MRSA §3474, sub-§3, ¶D**, as corrected by RR 1991, c. 2, §81, is
36 amended to read:

37 D. An advocacy agency conducting an investigation under chapter 961, United
38 States Public Law 88-164, Title I, Part C or United States Public Law 99-319,

1 regarding a developmentally disabled person or mentally ill person who is or who,
2 within the last 90 days, was residing in a facility rendering care or treatment, when a
3 complaint has been received by the agency or there is probable cause to believe that
4 that individual has been subject to abuse or neglect, and that person does not have a
5 legal guardian or the person is under public guardianship. The determination of
6 which information and records are relevant to the investigation is made by agreement
7 between the department and the agency;

8 **Sec. 7. 22 MRSA §3474, sub-§3, ¶¶E to G** are enacted to read:

9 E. The panel coordinator, appointed under Title 34-B, section 1972, subsection 1, of
10 the Panel To Review Deaths of and Serious Injuries to Persons with Intellectual
11 Disabilities or Autism, established in Title 5, section 12004-J, subsection 18;

12 F. The Maine Developmental Services Oversight and Advisory Board, established in
13 Title 5, section 12004-J, subsection 15. A copy of the final report of any
14 investigation under this chapter related to a person receiving adult developmental
15 services as defined in Title 34-B, section 1001, subsection 1-A must be disclosed
16 under this paragraph. The department may as necessary redact the name of a reporter
17 and other information that may identify a reporter when necessary to protect the
18 reporter's request for anonymity; and

19 G. The guardian of a person receiving adult developmental services as defined in
20 Title 34-B, section 1001, subsection 1-A or, if the person does not have a guardian,
21 the person receiving adult developmental services. A copy of the final report of any
22 investigation under this chapter related to that person must be disclosed under this
23 paragraph. The department may refuse to disclose a report to a guardian if the
24 guardian is the subject of or the target of the investigation and may redact the name
25 of a reporter and other identifying information when necessary to protect the
26 reporter's request for anonymity.

27 **Sec. 8. 34-B MRSA §1223, sub-§1**, as amended by PL 2011, c. 542, Pt. A, §66,
28 is further amended to read:

29 **1. Composition.** The Maine Developmental Services Oversight and Advisory
30 Board, as established by Title 5, section 12004-J, subsection 15 and referred to in this
31 section as "the board," consists of 15 members appointed by the Governor from a list of
32 nominees proposed by the board pursuant to procedures established in the ~~rules~~ bylaws of
33 the board adopted in accordance with department rules adopted pursuant to subsection 11.

34 A. The board shall submit nominees to the Governor in writing at least 90 60 days
35 prior to the expected date of each vacancy. If within 60 days after a nomination is
36 submitted to the Governor the Governor does not appoint the nominee or notify the
37 board that the nomination is denied, the nominee is a member of the board upon a
38 vote in favor of the nominee by a majority of the members of the board.

39 B. In making nominations, the board shall endeavor to ensure adequate
40 representation at all times from different service regions of the State and from
41 ~~interested stakeholder groups, including but not limited to:~~ interested in the welfare of
42 and quality of delivery of services to persons with intellectual disabilities or autism in
43 the State.

1 ~~(1) The protection and advocacy agency designated pursuant to Title 5, section~~
2 ~~19502;~~

3 ~~(2) A statewide coalition that works to support and facilitate the ability of local~~
4 ~~and statewide self-advocacy organizations to network with each other and with~~
5 ~~national organizations;~~

6 ~~(3) A nonprofit organization that serves teens and young adults in the State with~~
7 ~~emotional and intellectual disabilities;~~

8 ~~(4) A statewide coalition that works to support and facilitate the ability of local~~
9 ~~and statewide self-advocacy organizations to network with each other and with~~
10 ~~national organizations; and~~

11 ~~(5) The Maine Developmental Disabilities Council.~~

12 C. In making the nominations and appointments, the board and the Governor shall
13 endeavor to ensure that ~~at least 8 of the members of the board are~~ persons with
14 intellectual disabilities or autism or family members, guardians or allies of persons
15 with intellectual disabilities or autism who receive services funded by the Department
16 of Health and Human Services are represented on the board. ~~Of these members, at~~
17 ~~least 4 must be persons with intellectual disabilities or autism, referred to in this~~
18 ~~section as "self-advocates."~~

19 ~~Members of the board must include stakeholders involved in services and supports for~~
20 ~~persons with intellectual disabilities or autism in the State and other individuals interested~~
21 ~~in issues affecting persons with intellectual disabilities or autism. Employees of the~~
22 ~~Department of Health and Human Services may not be appointed as members of the~~
23 ~~board.~~

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

26 **6. Administration and budget.** The Department of Administrative and Financial
27 Services shall administer the budget of the board. The board shall provide to the
28 ~~commissioner~~ Commissioner of Administrative and Financial Services a proposed budget
29 in accordance with a schedule agreed to by the chair and the ~~commissioner~~ Commissioner
30 of Administrative and Financial Services. The ~~department~~ Department of Administrative
31 and Financial Services shall include in its estimate of expenditure and appropriation
32 requirements filed pursuant to Title 5, section 1665 sufficient funds, listed in a separate
33 account as a separate line item, to enable the board to perform its duties.

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

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

40 A. ~~The~~ Within existing resources, the department shall provide the board, on a
41 schedule to be agreed upon between the board and the department, reports on case

1 management, reportable events, adult protective and rights investigations, unmet
2 needs, crisis services, quality assurance, quality improvement, budgets and other
3 reports that contain data about or report on the delivery of services to or for the
4 benefit of persons with intellectual disabilities or autism, including reports developed
5 by or on behalf of the department and reports prepared by others about the
6 department.

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

11 D. The board may examine confidential information in individual records with
12 written permission of the person or that person's guardian. If the person or that
13 person's guardian provides the board with written permission to examine confidential
14 information, the board must maintain the confidentiality of the information as
15 required by section 1207.

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

21 F. The department shall ensure that the executive director of the board has direct
22 access to a record in the possession of the department that is maintained pursuant to
23 section 5470-B, subsection 7 or section 5605, subsection 15. The permission of the
24 person who is the subject of the record is not required prior to access to the record
25 under this paragraph. The executive director may not disseminate personally
26 identifying information in the record without first obtaining written permission
27 pursuant to paragraph D. Within existing resources, the department shall provide
28 training to the executive director that is adequate to enable the executive director to
29 access such a record. If the executive director position of the board is vacant, the
30 chair of the board has access to records under this paragraph for as long as the
31 executive director position of the board is vacant.

32 G. Within existing resources, the department shall notify the board of any report to
33 the medical examiner pursuant to Title 22, section 3478 made by the department or of
34 which the department is aware that pertains to a person receiving adult developmental
35 services.

36 H. The executive director of the board may directly access the records of an
37 investigation into a suspicious death conducted by the department or by a medical
38 examiner or a mortality review conducted by the maternal, fetal and infant mortality
39 review panel established pursuant to Title 22, section 261 pertaining to a deceased
40 person who was receiving adult developmental services at the time of the person's
41 death. The executive director may not disseminate personally identifying information
42 from the investigation or mortality review without first obtaining the written
43 permission of the deceased person's guardian or from the personal representative of
44 the deceased person's estate. If the executive director position of the board is vacant,
45 the chair of the board has access to records under this paragraph for as long as the

1 executive director position of the board is vacant. This paragraph does not authorize
2 the disclosure of a record generated by a hospital and provided to the department or
3 the maternal, fetal and infant mortality review panel that is otherwise confidential,
4 including, but not limited to, a sentinel event record, a root cause analysis and a
5 professional competency review. As used in this paragraph, "sentinel event" has the
6 same meaning as in Title 22, section 8752, subsection 4-A and "root cause analysis"
7 has the same meaning as in Title 22, section 8752, subsection 3-B.

8 **Sec. 11. 34-B MRSA c. 1, sub-c. 9** is enacted to read:

9 **SUBCHAPTER 9**

10 **PANEL TO REVIEW DEATHS OF AND SERIOUS INJURIES TO**
11 **PERSONS WITH INTELLECTUAL DISABILITIES OR AUTISM**

12 **§1971. Panel To Review Deaths of and Serious Injuries to Persons with Intellectual**
13 **Disabilities or Autism**

14 The Panel To Review Deaths of and Serious Injuries to Persons with Intellectual
15 Disabilities or Autism, referred to in this subchapter as "the panel," is established to
16 conduct comprehensive, multidisciplinary reviews of cases of death of or serious injury to
17 persons with intellectual disabilities or autism receiving adult developmental services in
18 the State as described in this subchapter.

19 **§1972. Panel membership; compensation; staffing**

20 **1. Membership.** The panel consists of 14 members as provided in this subsection.

21 A. The commissioner shall appoint a member to the panel who is an employee of the
22 Maine Center for Disease Control and Prevention and who is a registered nurse. The
23 member appointed pursuant to this paragraph is the panel coordinator.

24 B. The Maine Developmental Services Oversight and Advisory Board, established in
25 Title 5, section 12004-J, subsection 15, shall appoint a member to the panel. The
26 board may appoint a new member to the panel annually or as the board determines
27 necessary.

28 C. The Governor shall appoint 4 members to the panel as follows:

29 (1) A representative of the judicial branch;

30 (2) A physician licensed under Title 32, chapter 36 or chapter 48 who is a
31 primary care physician;

32 (3) A law enforcement officer; and

33 (4) A provider of community services to persons with intellectual disabilities or
34 autism in the State.

35 D. The President of the Senate shall appoint 4 members to the panel as follows:

1 (1) A nurse licensed in the State with expertise in intellectual disabilities or
2 autism;

3 (2) A person licensed to practice law in the State working in the public sector;

4 (3) A person with expertise in forensic pathology; and

5 (4) A person with expertise in the field of community mental health.

6 E. The Speaker of the House of Representatives shall appoint 4 members to the panel
7 as follows:

8 (1) A person with expertise in the field of public health;

9 (2) A person licensed to practice law in the State working in the private sector;

10 (3) A person employed by a university or who is a doctoral candidate in a
11 relevant area of study; and

12 (4) A provider of community services to persons with intellectual disabilities or
13 autism in the State.

14 **2. Terms.** The term of office of each member of the panel appointed under
15 subsection 1, not including the panel coordinator and the member appointed pursuant to
16 subsection 1, paragraph B, is 3 years. A member serves until a successor is appointed. A
17 vacancy must be filled as soon as practicable by appointment for the unexpired term.
18 Members may be reappointed.

19 **3. Chair.** Every year, the panel shall elect a chair from among its members.

20 **4. Compensation.** Members of the panel not otherwise compensated by their
21 employers or other entities whom they represent are entitled to reimbursement of
22 reasonable expenses incurred in serving on the panel.

23 **5. Panel coordinator duties; staffing.** The panel coordinator shall act as staff to the
24 panel. The panel coordinator may procure specialist expertise when the panel coordinator
25 considers it necessary or when it is requested by the panel. The panel coordinator shall
26 conduct an initial review as described in section 1973 of any death of or serious injury to
27 a person with an intellectual disability or autism receiving adult developmental services.
28 The panel coordinator shall compile reports required pursuant to this subchapter.

29 **§1973. Initial review by the panel coordinator**

30 The panel coordinator shall conduct an initial review of all deaths of or serious injury
31 to persons with intellectual disabilities or autism receiving adult developmental services
32 to determine whether to refer a case to the panel for a review. The panel coordinator shall
33 refer a case to the panel if the panel coordinator determines that any of the following
34 circumstances exist:

35 **1. Unexpected.** The death or serious injury was unexpected;

36 **2. Preventable.** Facts and circumstances indicate that the death or serious injury
37 could have been prevented;

1 **3. System issues.** Issues with the system of care described in section 5003-A are
2 implicated;

3 **4. Health and safety issues.** Facts and circumstances related to the death or serious
4 injury indicate that the department, providers of residential services or providers of day
5 activity programs could implement actions that would improve the health and safety of
6 the persons receiving adult developmental services; or

7 **5. Other issues.** Other issues related to the case indicate the case should be
8 reviewed.

9 **§1974. Access to information and records**

10 **1. Department records.** Notwithstanding any other provision of law, the panel
11 coordinator may access information or records from the department determined by the
12 panel coordinator to be necessary to carry out the panel coordinator's responsibilities.
13 The department shall provide the panel coordinator with direct access to the information
14 or records or provide information or records necessary and relevant as soon as practicable
15 upon oral or written request of the panel coordinator. Records that must be provided
16 include, but are not limited to, the following:

17 A. Personal plans developed pursuant to section 5470-B;

18 B. Service plans and agreements developed pursuant to section 5471;

19 C. Documents from providers of residential services to persons with intellectual
20 disabilities or autism pursuant to chapters 5 and 6 or caseworkers;

21 D. Documents related to any adult protective case or investigation;

22 E. Reports related to a person with an intellectual disability or autism who was
23 receiving adult developmental services of incidents that occurred in the 12-month
24 period prior to the person's death or serious injury;

25 F. Death certificates;

26 G. Health care information related to a person with an intellectual disability or
27 autism who was receiving adult developmental services from the 12-month period
28 prior to the person's death or serious injury. For the purposes of this paragraph,
29 "health care information" has the same meaning as in Title 22, section 1711-C,
30 subsection 1, paragraph E; and

31 H. Records from any autopsy performed on a deceased person.

32 **2. Duty to provide records.** A person that possesses medical records or information
33 that is necessary and relevant to the review under section 1973 shall provide those
34 medical records or information to the panel coordinator as soon as practicable. This
35 subsection does not authorize the disclosure of a record generated by a hospital that is
36 otherwise confidential, including, but not limited to, a sentinel event record, a root cause
37 analysis and a professional competency review. As used in this subsection, "sentinel
38 event" has the same meaning as in Title 22, section 8752, subsection 4-A and "root cause
39 analysis" has the same meaning as in Title 22, section 8752, subsection 3-B.

1 **§1975. Cases referred to the panel by others**

2 A case of death of or serious injury to a person with an intellectual disability or
3 autism receiving adult developmental services may be referred to the panel by the
4 commissioner, the agency designated as the protection and advocacy agency for persons
5 with disabilities pursuant to Title 5, section 19502, a member of the panel or any other
6 person who presents credible evidence, as determined by the panel coordinator, that a
7 death of or serious injury to a person with an intellectual disability or autism receiving
8 adult developmental services warrants review by the panel.

9 **§1976. Monthly report**

10 The panel coordinator shall compile a monthly report that includes a list of all cases
11 of death of or serious injury to a person with an intellectual disability or autism receiving
12 adult developmental services reviewed by the panel coordinator, a list of all cases the
13 panel coordinator has referred for review to the panel and a list of all cases referred
14 pursuant to section 1975. For each case referred for review, the report must include the
15 name of the person receiving adult developmental services who has died or experienced
16 serious injury, the name of the guardian, the status of guardianship or a protective
17 arrangement instead of guardianship under Title 18-C, Article 5 and a short description of
18 the circumstances of the death or serious injury that occurred. The panel coordinator
19 shall provide the monthly report to the panel, the department and the Maine
20 Developmental Services Oversight and Advisory Board, established in Title 5, section
21 12004-J, subsection 15. The monthly report compiled pursuant to this section is not a
22 public record as defined in Title 1, section 402, subsection 3.

23 **§1977. Review by the panel**

24 **1. Cases reviewed by the panel.** The panel shall review all cases of death of or
25 serious injury to a person with an intellectual disability or autism receiving adult
26 developmental services that are referred by the panel coordinator or are referred pursuant
27 to section 1975; all medical examiner cases pursuant to Title 22, section 3025, subsection
28 1, paragraph E that pertain to a person with an intellectual disability or autism who
29 received adult developmental services; all cases from the last 12 months that are reported
30 incidents pursuant to section 5604-A; and all cases of death or serious injury that are
31 being reviewed by the Maine Developmental Services Oversight and Advisory Board,
32 established in Title 5, section 12004-J, subsection 15. The panel may also choose to
33 review any other case from the monthly report of the panel coordinator under section
34 1976.

35 **2. Records provided to the panel.** The panel coordinator shall determine records as
36 listed in section 1974 that must be made available to the panel for the purpose of
37 reviewing cases of death of or serious injury to persons with intellectual disabilities or
38 autism receiving adult developmental services. The panel coordinator shall maintain
39 custody of all records.

40 **3. Review.** A review of a case conducted by the panel is intended to be a thorough
41 evaluation of circumstances surrounding the death of or serious injury to a person with an
42 intellectual disability or autism receiving adult developmental services, including the

1 overall care of the person, quality of life issues, the death or serious injury event and
2 medical care preceding the event. The review must also include any determination of
3 whether the case is suspicious.

4 **4. Investigations.** A review under this section is subject to and may not interfere
5 with the authority and responsibility of the Attorney General to investigate and prosecute
6 homicides pursuant to Title 5, section 200-A.

7 **§1978. Report of findings**

8 After a review of all materials related to a case of death of or serious injury to a
9 person with an intellectual disability or autism receiving adult developmental services
10 reviewed by the panel pursuant to section 1977, the panel shall make findings and
11 recommendations and submit those findings and recommendations in a report to the
12 commissioner and to the Maine Developmental Services Oversight and Advisory Board,
13 established in Title 5, section 12004-J, subsection 15. The report must identify trends and
14 patterns in deaths or serious injuries that indicate necessary systemic changes and reforms
15 in the delivery of services to reduce adverse outcomes for persons with intellectual
16 disabilities or autism receiving adult developmental services as well as recommendations
17 for corrective actions. All personally identifying information must be removed from the
18 report before it is submitted to the commissioner and the Maine Developmental Services
19 Oversight and Advisory Board.

20 **§1979. Legislative reports**

21 **1. Annual report.** The panel shall provide to the joint standing committee of the
22 Legislature having jurisdiction over health and human services matters an annual report
23 by January 30th with data regarding the number of deaths of and serious injuries to
24 persons with intellectual disabilities or autism receiving adult developmental services, the
25 number of cases reviewed by the panel, the number of cases determined suspicious,
26 actions taken on recommendations submitted to the commissioner and the Maine
27 Developmental Services Oversight and Advisory Board, established in Title 5, section
28 12004-J, subsection 15, and a summary of findings and recommendations.

29 **2. Trend analyses.** The panel may provide to the joint standing committee of the
30 Legislature having jurisdiction over health and human services matters a periodic report
31 with trend analyses if the panel determines that such a report is necessary. Any periodic
32 trend analysis report that is submitted must be developed in conjunction with the
33 commissioner and the Maine Developmental Services Oversight and Advisory Board,
34 established in Title 5, section 12004-J, subsection 15.

35 **§1980. Confidentiality**

36 Any information or record accessed by or provided to the panel coordinator or the
37 panel pursuant to this subchapter that is designated confidential pursuant to state or
38 federal law by the official, agency or other entity providing the information or record
39 must be maintained as confidential by the panel coordinator and the panel.

