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Date: (Filing No. H-)

HEALTH AND HUMAN SERVICES

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**STATE OF MAINE
HOUSE OF REPRESENTATIVES
128TH LEGISLATURE
SECOND REGULAR SESSION**

COMMITTEE AMENDMENT “ ” to H.P. 1164, L.D. 1676, Bill, “An Act To Reestablish the Office of Advocacy within the Department of Health and Human Services”

Amend the bill by striking out the title and substituting the following:

'An Act To Establish an Independent Oversight Panel To Review Deaths of and Serious Injuries to Persons with Intellectual Disabilities or Autism'

Amend the bill by striking out everything after the enacting clause and before the summary and inserting the following:

'Sec. 1. 5 MRSA §12004-J, sub-§18 is enacted to read:

18.

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

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

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

Sec. 3. 22 MRSA §1711-C, sub-§6, ¶U, as enacted by PL 2017, c. 203, §4, 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

COMMITTEE AMENDMENT

1 this paragraph, "panel coordinator" has the same meaning as in section 261,
2 subsection 1, paragraph E and "deceased person" has the same meaning as in section
3 261, subsection 1, paragraph B-; and

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

5 V. To the panel coordinator, appointed under Title 34-B, section 1972, subsection 1,
6 of the Panel To Review Deaths of and Serious Injuries to Persons with Intellectual
7 Disabilities or Autism, established in Title 5, section 12004-J, subsection 18, for the
8 purposes of reviewing health care information of a person with an intellectual
9 disability or autism receiving adult developmental services as defined in Title 34-B,
10 section 1001, subsection 1-A who has died or experienced a serious injury in the last
11 12 months.

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

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

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

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

27 **Sec. 7. 22 MRSA §3474, sub-§3, ¶E** is enacted to read:

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

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

32 **SUBCHAPTER 9**

33 **PANEL TO REVIEW DEATHS OF AND SERIOUS INJURIES TO**
34 **PERSONS WITH INTELLECTUAL DISABILITIES OR AUTISM**

35 **§1971. Panel To Review Deaths of and Serious Injuries to Persons with Intellectual**
36 **Disabilities or Autism**

37 The Panel To Review Deaths of and Serious Injuries to Persons with Intellectual
38 Disabilities or Autism, referred to in this subchapter as "the panel," is established to
39 conduct comprehensive, multidisciplinary reviews of cases of death of or serious injury to

1 persons with intellectual disabilities or autism receiving adult developmental services in
2 the State as described in this subchapter.

3 **§1972. Panel membership; compensation; staffing**

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

5 A. The commissioner shall appoint a member to the panel who is an employee of the
6 Maine Center for Disease Control and Prevention within the department and who is a
7 registered nurse. The member appointed pursuant to this paragraph is the panel
8 coordinator.

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

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

14 (1) A representative of the judicial branch;

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

17 (3) A law enforcement officer; and

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

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

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

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

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

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

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

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

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

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

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

34 **2. Terms.** The term of office of each member of the panel appointed under
35 subsection 1, not including the panel coordinator and the member appointed pursuant to
36 subsection 1, paragraph B, is 3 years. A member serves until a successor is appointed. A

1 vacancy must be filled as soon as practicable by appointment for the unexpired term.
2 Members may be reappointed.

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

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

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

13 **§1973. Initial review by the panel coordinator**

14 The panel coordinator shall conduct an initial review of any death of or serious injury
15 to a person with an intellectual disability or autism receiving adult developmental
16 services to determine whether to refer a case to the panel for a review. The panel
17 coordinator shall refer a case to the panel if the panel coordinator determines that any of
18 the following circumstances exist:

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

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

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

24 **4. Other issues.** Other issues related to the case indicate the case should be
25 reviewed.

26 **§1974. Access to information and records**

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

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

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

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

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

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

4 F. Death certificates;

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

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

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

19 **§1975. Cases referred to the panel by others**

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

27 **§1976. Monthly report**

28 The panel coordinator shall compile a monthly report that includes a list of all cases
29 of death of or serious injury to a person with an intellectual disability or autism receiving
30 adult developmental services reviewed by the panel coordinator, a list of all cases the
31 panel coordinator has referred for review to the panel and a list of all cases referred
32 pursuant to section 1975. For each case referred for review, the report must include the
33 name of the person receiving adult developmental services who has died or experienced
34 serious injury, the name of the guardian, the status of guardianship and a short description
35 of the circumstances of the death or serious injury that occurred. The panel coordinator
36 shall provide the monthly report to the panel, the department and the Maine
37 Developmental Services Oversight and Advisory Board, established in Title 5, section
38 12004-J, subsection 15. The monthly report compiled pursuant to this section is not a
39 public record as defined in Title 1, section 402, subsection 3.

40 **§1977. Review by the panel**

41 **1. Cases reviewed by the panel.** The panel shall review all cases of death of or
42 serious injury to a person with an intellectual disability or autism receiving adult

1 developmental services that are referred by the panel coordinator or are referred pursuant
2 to section 1975; all medical examiner cases pursuant to Title 22, section 3025, subsection
3 1, paragraph E that pertain to a person with an intellectual disability or autism who
4 received adult developmental services; all cases from the last 12 months that are reported
5 incidents pursuant to section 5604-A; and all cases of death or serious injury that are
6 being reviewed by the Maine Developmental Services Oversight and Advisory Board,
7 established in Title 5, section 12004-J, subsection 15. The panel may also choose to
8 review any other case from the monthly report of the panel coordinator under section
9 1976.

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

15 **3. Review.** A review of a case conducted by the panel is intended to be a thorough
16 evaluation of circumstances surrounding the death of or serious injury to a person with an
17 intellectual disability or autism receiving adult developmental services, including the
18 overall care of the person, quality of life issues, the death or serious injury event and
19 medical care preceding the event. The review must also include any determination of
20 whether the case is suspicious.

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

24 **§1978. Report of findings**

25 After a review of all materials related to a case of death of or serious injury to a
26 person with an intellectual disability or autism receiving adult developmental services
27 reviewed by the panel pursuant to section 1977, the panel shall make findings and
28 recommendations and submit those findings and recommendations in a report to the
29 commissioner and to the Maine Developmental Services Oversight and Advisory Board,
30 established in Title 5, section 12004-J, subsection 15. The report must identify trends and
31 patterns in deaths or serious injuries that indicate necessary systemic changes and reforms
32 in the delivery of services to reduce adverse outcomes for persons with intellectual
33 disabilities or autism receiving adult developmental services as well as recommendations
34 for corrective actions. All personally identifying information must be removed from the
35 report before it is submitted to the commissioner and the Maine Developmental Services
36 Oversight and Advisory Board.

37 **§1979. Legislative reports**

38 **1. Annual report.** The panel shall provide to the joint standing committee of the
39 Legislature having jurisdiction over health and human services matters an annual report
40 by January 30th with data regarding the number of deaths of and serious injuries to
41 persons with intellectual disabilities or autism receiving adult developmental services, the
42 number of cases reviewed by the panel, the number of cases determined suspicious,
43 actions taken on recommendations submitted to the commissioner and the Maine

1 Developmental Services Oversight and Advisory Board, established in Title 5, section
2 12004-J, subsection 15, and a summary of findings and recommendations.

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

9 **§1980. Confidentiality**

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

14 **Sec. 9. Initial appointments; staggered terms.** Notwithstanding the Maine
15 Revised Statutes, Title 34-B, section 1972, subsection 2, of the initial appointments to the
16 Panel To Review Deaths of and Serious Injuries to Persons with Intellectual Disabilities
17 or Autism, the Governor shall appoint one member to serve an initial term of one year, 2
18 members to serve an initial term of 2 years and one member to serve an initial term of 3
19 years; the President of the Senate shall appoint 2 members to serve an initial term of one
20 year, one member to serve an initial term of 2 years and one member to serve an initial
21 term of 3 years; and the Speaker of the House of Representatives shall appoint one
22 member to serve an initial term of one year, one member to serve an initial term of 2
23 years and 2 members to serve an initial term of 3 years.

24 **Sec. 10. Appropriations and allocations.** The following appropriations and
25 allocations are made.

26 **HEALTH AND HUMAN SERVICES, DEPARTMENT OF**
27 **Maine Center for Disease Control and Prevention 0143**

28 Initiative: Provides funding for one Health Services Consultant position to be the panel
29 coordinator for the Panel To Review Deaths of and Serious Injuries to Persons with
30 Intellectual Disabilities or Autism.

31	GENERAL FUND	2017-18	2018-19
32	POSITIONS - LEGISLATIVE COUNT	0.000	1.000
33	Personal Services	\$0	\$84,899
34	All Other	\$0	\$6,286
35			
36	GENERAL FUND TOTAL	\$0	\$91,185
37			

38 **SUMMARY**

39 This amendment, which is the majority report of the committee, replaces the bill. It
40 establishes the Panel To Review Deaths of and Serious Injuries to Persons with

1 Intellectual Disabilities or Autism. The panel consists of 14 members, including a panel
2 coordinator who is an employee of the Department of Health and Human Services, Maine
3 Center for Disease Control and Prevention and is a registered nurse and a member
4 appointed by the Maine Developmental Services Oversight and Advisory Board. Other
5 members of the panel are appointed by the Governor, the President of the Senate and the
6 Speaker of the House of Representatives. Terms are for 3 years, and members receive
7 expenses if they are not already compensated by their employers. The panel coordinator
8 must review all cases of death of and serious injury to persons with intellectual
9 disabilities or autism receiving adult developmental services and determine those that
10 require further review by the panel. Other individuals may refer cases to the panel, and
11 the panel may choose additional cases from the list of cases provided by the panel
12 coordinator. The panel has access to records necessary for the review. The panel must
13 provide reports to the Commissioner of Health and Human Services and the Maine
14 Developmental Services Oversight and Advisory Board with findings and
15 recommendations. The panel is required to provide reports to the Legislature on an
16 annual basis and may provide trend analyses to the Legislature as necessary. Legislative
17 reports are public documents.

18 The amendment also adds an appropriations and allocations section.

19 **FISCAL NOTE REQUIRED**

20 **(See attached)**