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Date: (Filing No. H- )

**HEALTH AND HUMAN SERVICES**

Reproduced and distributed under the direction of the Clerk of the House.

**STATE OF MAINE  
HOUSE OF REPRESENTATIVES  
129TH LEGISLATURE  
FIRST REGULAR SESSION**

COMMITTEE AMENDMENT “ ” to H.P. 998, L.D. 1377, Bill, “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”

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

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

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

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

**18.**

<u>Aging and Disability</u>	<u>Aging and Disability</u>	<u>Not Authorized</u>	<u>22 MRSA §264</u>
	<u>Mortality Review</u>		
	<u>Panel</u>		

**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 a waiver granted by the United States Department of Health and Human Services, Centers for Medicare and Medicaid Services in accordance with 42 Code of Federal Regulations, Part 441.

**COMMITTEE AMENDMENT**

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

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

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

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

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

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

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

25           C. A person within the department responsible for licensing and certification;

26           D. A person within the department responsible for aging and disability services;

27           E. The executive director of the statewide protection and advocacy agency for  
28           individuals with disabilities contracted by the department pursuant to Title 5, section  
29           19502 or the executive director's designee;

30           F. The executive director of the long-term care ombudsman program as established  
31           in section 5106, subsection 11-C or the executive director's designee;

32           G. A member of the Maine Developmental Services Oversight and Advisory Board  
33           as established in Title 5, section 12004-J, subsection 15 as nominated by that board;

34           H. A health care provider who is licensed under Title 32, chapter 36 or 48 and who  
35           has expertise and experience in delivering services to individuals with intellectual  
36           disabilities or autism nominated by a statewide association representing physicians;

37           I. A representative of the developmental service provider community who has  
38           expertise regarding community services for individuals with intellectual disabilities  
39           or autism;

40           J. A representative of the provider community serving older adults and adults with  
41           physical disabilities who has expertise in home-based and community-based services;

1           K. A representative of the provider community who has expertise in delivering  
2           home-based and community-based services to individuals with brain injuries or other  
3           related conditions; and

4           L. A person who has expertise in forensic pathology.

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

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

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

19                   (1) The death or serious injury was unexpected;

20                   (2) The death was premature;

21                   (3) The death or serious injury was preventable;

22                   (4) Issues with the system of care are indicated;

23                   (5) Facts and circumstances related to the death or serious injury indicate that the  
24                   department or providers of home-based and community-based services to adults  
25                   receiving services could implement actions that would improve the health and  
26                   safety of those adults receiving services; or

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

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

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

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

37                   (1) Death certificates;

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

39                   (3) Emergency medical personnel reports and documentation;

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

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

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

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

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

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

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

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

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

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

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

38                   (4) The panel coordinator may delegate the responsibility to conduct interviews  
39                   pursuant to this paragraph to a registered nurse, physician assistant, nurse  
40                   practitioner or physician licensed or registered in this State and who has  
41                   completed a nationally certified training program for conducting critical incident

1 investigations. If the interview pertains to a preventable death or suspicious  
2 death, the person conducting the interview must have professional training or  
3 experience in bereavement services.

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

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

9 E. A case of death of or serious injury to an adult receiving services may be referred  
10 to the panel coordinator by the commissioner, the statewide protection and advocacy  
11 agency for individuals with disabilities contracted by the department pursuant to Title  
12 5, section 19502, a member of the panel or any other person who presents credible  
13 evidence that a death or serious injury warrants referral to the panel as determined by  
14 preliminary review by the panel coordinator.

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

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

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

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

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

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

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

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

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

35 (b) Associated with a known chronic illness;

36 (c) A sudden unexpected death;

37 (d) Due to an unknown cause;

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

33                U. To a panel coordinator of the maternal, fetal and infant mortality review panel  
34                pursuant to section 261, subsection 4, paragraph B-1 for the purposes of reviewing  
35                health care information of a deceased person and a mother of a child who died within  
36                one year of birth, including fetal deaths after 28 weeks of gestation. For purposes of  
37                this paragraph, "panel coordinator" has the same meaning as in section 261,  
38                subsection 1, paragraph E and "deceased person" has the same meaning as in section  
39                261, subsection 2, paragraph B; and

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

41                V. To a panel coordinator of the Aging and Disability Mortality Review Panel  
42                pursuant to section 264, subsection 5, paragraph B, subparagraph (4) for the purposes  
43                of reviewing health care information of an adult receiving services who is deceased in

1 accordance with section 264, subsection 5, paragraph A. For purposes of this  
2 paragraph, "panel coordinator" has the same meaning as in section 264, subsection 2,  
3 paragraph B.

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

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

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

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

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

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

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

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

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

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

1           A. The Within existing resources, the department shall provide the board, on a  
2 schedule to be agreed upon between the board and the department, reports on case  
3 management, reportable events, adult protective and rights investigations, unmet  
4 needs, crisis services, quality assurance, quality improvement, budgets and other  
5 reports that contain data about or report on the delivery of services to or for the  
6 benefit of persons with intellectual disabilities or autism, including reports developed  
7 by or on behalf of the department and reports prepared by others about the  
8 department.

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

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

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

23           **Sec. 11. Data assessment report.** The Maine Developmental Services Oversight  
24 and Advisory Board established in the Maine Revised Statutes, Title 5, section 12004-J,  
25 subsection 15 shall include in its annual report provided to the Legislature pursuant to  
26 Title 34-B, section 1223, subsection 9, paragraph D an assessment of the adequacy of the  
27 aggregate data provided pursuant to Title 22, section 3474, subsection 3, paragraph E to  
28 the board's ability to carry out its functions and duties established in Title 34-B, section  
29 1223, subsections 8 and 9.

30           **Sec. 12. Department data assessment report.** The Department of Health and  
31 Human Services shall report to the joint standing committee of the Legislature having  
32 jurisdiction over health and human services matters no later than January 15, 2021 an  
33 assessment of the adequacy of the aggregate data provided pursuant to the Maine Revised  
34 Statutes, Title 22, section 3474, subsection 3, paragraph E to the Maine Developmental  
35 Services Oversight and Advisory Board established in Title 5, section 12004-J,  
36 subsection 15.

37           **Sec. 13. Initial appointments; staggered terms.** All appointments to the  
38 Aging and Disability Mortality Review Panel established in the Maine Revised Statutes,  
39 Title 22, section 264 must be made no later than 90 days after the effective date of this  
40 Act. Notwithstanding Title 22, section 264, subsection 4, of the initial appointments to  
41 the Aging and Disability Mortality Review Panel, the Commissioner of Health and  
42 Human Services shall appoint 2 members to serve an initial term of one year, 2 members  
43 to serve an initial term of 2 years and 2 members to serve an initial term of 3 years.

1           **Sec. 14. Appropriations and allocations.** The following appropriations and  
 2 allocations are made.

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

5 Initiative: Provides appropriations for one Public Health Nurse Consultant position within  
 6 the Maine Center for Disease Control and Prevention, office of health equity to design,  
 7 implement and manage the Aging and Disability Mortality Review Panel.

8	<b>GENERAL FUND</b>	<b>2019-20</b>	<b>2020-21</b>
9	POSITIONS - LEGISLATIVE COUNT	1.000	1.000
10	Personal Services	\$24,518	\$25,322
11	All Other	\$1,599	\$1,599
12			
13	GENERAL FUND TOTAL	\$26,117	\$26,921

14           **Office of MaineCare Services 0129**

15 Initiative: Provides allocations for one Public Health Nurse Consultant position within the  
 16 Maine Center for Disease Control and Prevention, office of health equity to design,  
 17 implement and manage the Aging and Disability Mortality Review Panel.

18	<b>FEDERAL EXPENDITURES FUND</b>	<b>2019-20</b>	<b>2020-21</b>
19	POSITIONS - LEGISLATIVE COUNT	1.000	1.000
20	Personal Services	\$73,553	\$75,965
21	All Other	\$4,798	\$4,798
22			
23	FEDERAL EXPENDITURES FUND TOTAL	\$78,351	\$80,763

24           **HEALTH AND HUMAN SERVICES,**  
 25           **DEPARTMENT OF**  
 26           **DEPARTMENT TOTALS**

26		<b>2019-20</b>	<b>2020-21</b>
27			
28	GENERAL FUND	\$26,117	\$26,921
29	FEDERAL EXPENDITURES FUND	\$78,351	\$80,763
30			
31	DEPARTMENT TOTAL - ALL FUNDS	\$104,468	\$107,684
32			

33           Amend the bill by relettering or renumbering any nonconsecutive Part letter or  
 34 section number to read consecutively.

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**SUMMARY**

This amendment replaces the bill. It 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 waiver approved by the United States Department of Health and Human Services, Centers for Medicare and Medicaid Services rather than a panel to review only deaths of or injuries to adults with intellectual disabilities or autism. It removes most of the changes to the Maine Developmental Services Oversight and Advisory Board in the bill. It keeps the provisions related to moving the budget of the board from the Department of Health and Human Services to the Department of Administrative and Financial Services and related to the disclosure of adult protective investigations of individuals with intellectual disabilities or autism to the board.

The amendment also adds an appropriations and allocations section.

**FISCAL NOTE REQUIRED**

**(See attached)**