

1	\ B			L.D. 1377
2	Date: 6/14/	119		(Filing No. H-604)
3			IUMAN SERVICE	ES
4	Reproduced a	nd distributed under the d	irection of the Clerk (of the House.
5	Reproduced and distributed under the direction of the Clerk of the House. STATE OF MAINE			
6			PRESENTATIVES	2
0 7		· _		,
8	129TH LEGISLATURE FIRST REGULAR SESSION			
9 10 11 12	COMMITTEE AMENDMENT "A" 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"			
13	Amend the bill by striking out the title and substituting the following:			ollowing:
14 15	'An Act To Enhance and Improve the Maine Developmental Services Oversight and Advisory Board and To Establish the Aging and Disability Mortality Review Panel'			
16 17	Amend the bi	1 by striking out everythi	ing after the enacting	g clause and inserting the
18	'Sec. 1. 5 M	RSA §12004-J, sub-§1	8 is enacted to read:	
19	<u>18.</u>			
20 21 22	Aging and Disability	<u>Aging and Disability</u> <u>Mortality Review</u> <u>Panel</u>	Not Authorized	<u>22 MRSA §264</u>
23	Sec. 2. 22 M	RSA §264 is enacted to	read:	
24		Disability Mortality Rev		
25 26 27	1. Panel esta	blished. The Aging and the panel," is established	Disability Mortality 1	Review Panel, referred to and serious injuries to all
28 29	2. Definitions. As used in this section, unless the context otherwise indicates, the following terms have the following meanings.			
30 31 32 33	based services Human Servic	under a waiver granted b	by the United States I	ne-based and community- Department of Health and tes in accordance with 42

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1 2 3 4 5 6	B. "Panel coordinator" means an employee of the Maine Center for Disease Control and Prevention who is appointed by the commissioner. The panel coordinator must be a registered nurse, nurse practitioner, physician assistant or physician licensed or registered in this State and who has completed a nationally certified training program for conducting critical incident, including death, investigations or will complete the training within 6 months of appointment as panel coordinator.
7	C. "Preventable death" means a premature death that could have been avoided.
8 9 10 11	D. "Serious injury" means a bodily injury that involves a substantial risk of death, unconsciousness, extreme physical pain, protracted and obvious disfigurement or protracted loss or impairment of the function of a body part or organ or mental faculty.
12 13 14 15	E. "Suspicious death" means an unexpected death in which the circumstance or cause is medically or legally unexplained or inadequately explained or a death in which the circumstance or cause is suspected to be related to systemic issues of service access or quality.
16 17 18 19 20	3. Composition. The panel consists of up to 15 members and includes health care providers, social service providers, public health officials and other persons with professional expertise on the health and mortality of adults with disabilities and adults who are aging. The commissioner shall appoint the members of the panel unless otherwise specified. At a minimum, the panel consists of the following members:
21 22	A. The person who is lead staff attorney for investigations for the Office of the Attorney General or that person's designee;
23 24	B. The person who is lead staff attorney for health care crime investigations for the Office of the Attorney General or that person's designee;
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 28 29	E. The executive director of the statewide protection and advocacy agency for individuals with disabilities contracted by the department pursuant to Title 5, section 19502 or the executive director's designee;
30 31	F. The executive director of the long-term care ombudsman program as established in section 5106, subsection 11-C or the executive director's designee;
32 33	<u>G.</u> A member of the Maine Developmental Services Oversight and Advisory Board as established in Title 5, section 12004-J, subsection 15 as nominated by that board;
34 35 36	H. A health care provider who is licensed under Title 32, chapter 36 or 48 and who has expertise and experience in delivering services to individuals with intellectual disabilities or autism nominated by a statewide association representing physicians;
37 38 39	I. A representative of the developmental service provider community who has expertise regarding community services for individuals with intellectual disabilities or autism;
40 41	J. A representative of the provider community serving older adults and adults with physical disabilities who has expertise in home-based and community-based services;

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

L. A person who has expertise in forensic pathology.

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

13 <u>5. Panel coordinator; powers and duties.</u> The panel coordinator has the following
 powers and duties.

15A. The panel coordinator shall conduct preliminary reviews of all deaths of and16serious injuries to all adults receiving services to determine whether to refer a case to17the panel if the panel coordinator determines that any of the following circumstances18exist:

- (1) The death or serious injury was unexpected;
- (2) The death was premature;
- 21 (3) The death or serious injury was preventable;
- 22 (4) Issues with the system of care are indicated;

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

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

29The panel coordinator shall also refer cases based on the need to review particular30causes and circumstances of death or serious injury or the need to obtain a31representative 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:
 - (1) Death certificates;
- 38 (2) Autopsy, medical examiner and coroner reports;
 - (3) Emergency medical personnel reports and documentation;

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1 2 3	(4) Health care information of an adult receiving services who is deceased pursuant to section 1711-C, subsection 6, paragraph V. For the purposes of this subparagraph, "health care information" has the same meaning as in section
4	1711-C, subsection 1, paragraph E; and
5 6 7	(5) Notwithstanding any provision of law to the contrary, information or records from the department determined by the panel coordinator to be necessary to carry out the panel coordinator's duties. The department shall provide the panel
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 13	(a) Personal plans and treatment plans of an adult receiving services when that adult is deceased or injured;
14 15	(b) Service plans and agreements developed on behalf of an adult receiving services;
16 17	(c) Documents from providers of home-based and community-based services 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 24	have relevant information for a preliminary review pursuant to paragraph A, including a guardian of or family of or the provider of services to the adult receiving
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 32	receiving services, prior to conducting any interview, the panel coordinator shall obtain the permission of the adult's personal representative if one was appointed
32 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

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- investigations. If the interview pertains to a preventable death or suspicious death, the person conducting the interview must have professional training or experience in bereavement services.
- (5) A person conducting an interview under this paragraph may make a referral for bereavement counseling if indicated and desired by the person being interviewed.
- D. The panel coordinator shall endeavor to minimize the burden imposed on health care providers, hospitals and service providers.

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

- 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.
 - G. The panel coordinator shall prepare a review summary or abstract of information regarding each case, as determined to be useful to the panel and at a time determined to be timely, without the name or identifier of the adult receiving services who is deceased or who has experienced a serious injury to be presented to the panel.
 - H. The panel coordinator shall, in conjunction with the department, establish and maintain a state mortality database that includes, but is not limited to, the following:
 - (1) Name, age, sex, race or ethnicity and type of disability or condition of the adult receiving services who is deceased;
 - (2) Community-based service received by the adult receiving services who is deceased and the name of the service provider;
- 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,31community 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;
 - (e) Due to an accident, including the type of accident;

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	COMMITTEE AMENDMENT "
1 2	(f) Due to a self-inflicted injury or illness, including suicide or serious self- 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	(6) Whether an autopsy was conducted and a narrative of any findings from the autopsy:
7 8	(7) Findings of the preliminary reviews of all deaths by the panel coordinator pursuant to paragraph A;
9 10	(8) Findings of the comprehensive reviews by the panel pursuant to subsection 6; and
11 12 13	(9) Recommendations pursuant to subsection 6, paragraph B issued by the panel and information related to the implementation of those recommended corrective actions.
14 15 16	I. The panel coordinator shall determine the records that are made available to the panel for the purposes of reviewing cases of death or serious injury. The panel coordinator shall maintain custody of all records.
17 18 19	6. Panel; powers and duties. The panel shall conduct comprehensive multidisciplinary reviews of data presented by the panel coordinator, with a particular focus on preventable deaths, suspicious deaths and serious injuries.
20 21 22 23 24	A. The panel shall review all cases of death or serious injury that are referred by the panel coordinator. A review of a case by the panel is a comprehensive evaluation of the circumstances surrounding the death of or serious injury to an adult receiving services, including the overall care of the adult, quality of life issues, the death or serious injury event and the medical care that preceded and followed the event.
25 26 27 28 29	B. The panel shall submit an annual report, no later than January 2nd of each year beginning in 2021, to the Governor, the commissioner, the joint standing committee of the Legislature having jurisdiction over health and human services matters and the Maine Developmental Services Oversight and Advisory Board established in Title 5, section 12004-J, subsection 15. The report must contain the following:
30	(1) Factors contributing to the mortality of adults receiving services;
31	(2) Strengths and weaknesses of the system of care;
32 33	(3) Recommendations to the commissioner to decrease the rate of mortality of adults receiving services;
34 35 36	 (4) Recommendations about methods to improve the system for protecting adults receiving services, including modifications to law, rules, training, policies and procedures; and (5) Any other information the neural considers recorders for the ensuel we est.
37	(5) Any other information the panel considers necessary for the annual report.

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

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

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

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

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

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

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

Sec. 4. 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 this paragraph, "panel coordinator" has the same meaning as in section 261, subsection 1, paragraph E and "deceased person" has the same meaning as in section 261, subsection 2, paragraph B_{-1} and

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

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

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

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

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

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

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

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

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

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

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

 37
 Sec. 10. 34-B MRSA §1223, sub-§10, as amended by PL 2013, c. 310, §1, is

 38
 further amended to read:

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

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

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

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

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

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

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

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

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

3 HEALTH AND HUMAN SERVICES, DEPARTMENT OF

Maine Center for Disease Control and Prevention 0143 4

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

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CENEDAT FUND 0

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8 GENERAL FUND 2019-20 2	4020-21
9 POSITIONS - LEGISLATIVE COUNT 1.000	1.000
10Personal Services\$24,518	\$25,322
11 All Other \$1,599	\$1,599
12	
13 GENERAL FUND TOTAL \$26,117	\$26,921

Office of MaineCare Services 0129 14

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		FEDERAL EXPENDITURES FUND	2019-20	2020-21
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	2019-20	2020-21
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	۲		-	·
33		Amend the bill by relettering or renumbering any	nonconsecutive P	art letter or

33 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)

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COMMITTEE AMENDMENT

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129th MAINE LEGISLATURE

LD 1377

LR 1467(02)

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 Fiscal Note for Bill as Amended by Committee Amendment " $\mathcal{H}(\mathcal{H}-\mathcal{H})$

Committee: Health and Human Services

Fiscal Note Required: Yes

Fiscal Note

	FY 2019-20	FY 2020-21	Projections FY 2021-22	Projections FY 2022-23
Net Cost (Savings)				
General Fund	\$26,117	\$26,921	\$27,753	\$28,634
Appropriations/Allocations				
General Fund	\$26,117	\$26,921	\$27,753	\$28,634
Federal Expenditures Fund	\$78,351	\$80,763	\$83,259	\$85,902
Revenue				
Federal Expenditures Fund	\$78,351	\$80,763	\$83,259	\$85,902

Fiscal Detail and Notes

The bill includes General Fund appropriations to the Department of Health and Human Services of \$26,117 in fiscal year 2019-20 and \$26,921 in fiscal year 2020-21 for one Public Health Nurse consultant position for the panel coordinator position which would be responsible for preparing monthly and annual reports, acting as the staff person to the panel, conducting an initial review of any deaths or serious injuries and referring a case to the panel for review. Federal Expenditures Fund allocations are also included for the FMAP match.