NEIL ABERCROMBIE GOVERNOR OF HAWAII



LORETTA J. FUDDY, A.C.S.W., M.P.H. DIRECTOR OF HEALTH

> In reply, please refer to: File:

STATE OF HAWAII DEPARTMENT OF HEALTH P.O. Box 3378 HONOLULU, HAWAII 96801-3378

LATE

Senate Committee on Ways and Means H.B. 0909, H.D. 2, S.D. 1 Relating to Infant Mortality Program

Testimony of Loretta J. Fuddy, A.C.S.W., M.P.H. Director of Health

March 28, 2013

Department's Position: The Department of Health (DOH) strongly supports this measure which would 1 2 1) establish a comprehensive infant mortality reduction program within DOH, 2) establish an infant 3 mortality reduction advisory board, 3) require providers to distribute written policies prohibiting non-4 medically indicated induction of newborn deliveries and cesarean sections prior to 37 weeks of 5 gestation, and 4) require birthing facility reporting. 6 **Fiscal Implications:** Funds would be required for two positions (planner and research analyst) and the 7 purchase of hospital discharge data. Purpose and Justification: Hawaii is widely recognized as one of the healthiest states in the nation, 8 9 but has significant disparities by race/ethnicity, geography, age, education, insurance status, and other 10 subpopulations often referred to as social determinants of health. The bill would establish a comprehensive infant mortality reduction program within DOH clarifying our role in reducing infant 11 12 mortality rates. It would establish an infant mortality reduction advisory board responsible for approving a statewide strategic plan, providing recommendations to the infant mortality reduction 13 program, and promoting collaboration among public and private stakeholders. Under the measure, DOH 14 is to develop and the board approve a statewide strategic plan to reduce infant mortality by January 1, 15

2015, with an update every three years. Notably, the bill stipulates that plan strategies address social
 determinants of health as they relate to infant mortality.

H.B. 909, S.D. 1 requires that each facility shall distribute annually, to all staff and providers

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with admitting privileges at that facility, its written policies prohibiting non-medically indicated
inductions of newborn deliveries prior to thirty-seven weeks of gestation. Providers would be required
to provide patient education material on infant mortality and pre-term birth to expectant mothers.
Providers would also be required to report to DOH information concerning pre-term birth. DOH will
produce and distribute factual and scientific educational information addressing infant mortality and preterm birth with the intention of informing policy and practice.

As amended in the Senate Health Committee, the S.D. 1 also includes language authorizing the 10 Department to convene a task force to collect data on the number of elective pre-term deliveries in 11 Hawaii and whether there is a need for a point of care newborn screening program. The task force must 12 report its findings and make policy recommendations prior to the convening of the 2014 legislative 13 session. We do not believe a task force is needed as it would mirror many responsibilities of the infant 14 mortality advisory board and for the task force role of examining data on point of care newborn 15 16 screening, it would duplicate efforts of the Critical Congenital Heart Disease (CCHD) Task Force that started in April 2012. This CCHD Task Force consists of birthing facility administrators, nursery staff, 17 pediatricians, pediatric cardiologists, third party payers, public health staff, families, and community 18 19 organizations. The consensus of the birthing facility administrators and nursery staff is that they want the state to set the state policies and procedures since this process is used for other newborn screening. 20 Any delay in screening for CCHD will put affected newborns at risk for dying suddenly due to their 21 heart condition. 22

Accordingly, we are proposing a number of amendments to the bill including addition of language from another administrative bill directly related to infant mortality (HB 905, HD 1). This

1	language would authorize the Department to implement Point of Care (PoC) newborn screening, allows
2	the newborn metabolic screening fund to be used for PoC screening services, and would allow Critical
3	Congenital Heart Defects to be added as a new disorder to the Hawaii newborn screening panel to
4	further help reduce infant mortality. Adding screening for Critical Congenital Heart Defects also allows
5	the State to address the Secretary of Health and Human Services addition of these disorders to the
6	national Recommended Uniform Screening Panel. We are proposing a S.D. 2 that:
7	(1) Adds language permitting members of the Hawaii infant mortality reduction advisory board
8	to receive reimbursement for expenses, including travel expenses, necessary for the
9	performance of their duties.
10	(2) Clarifies that birthing facilities shall both establish and distribute written policies prohibiting
11	non-medically indicated inductions of new deliveries and cesarean sections prior to thirty-
12	nine weeks of gestation.
13	(3) Adds language incorporating H.B. 905, H.D. 1.
14	To improve birth outcomes and reduce infant mortality and pre-term birth, systemic changes will
15	be needed. Through this comprehensive infant mortality reduction program, we expect an improvement
16	in statewide healthy birth outcomes and a reduction in consequential costs associated with infant
17	mortality and pre-term birth.
10	

18 Thank you for the opportunity to testify.

STATE OF HAWAII

A BILL FOR AN ACT

RELATING TO INFANT MORTALITY PROGRAM.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

INTRODUCTION

SECTION 1. Infant mortality refers to the number of deaths occurring in the first year of life per 1,000 births and is a widely used proxy for the health status of an area. The national infant mortality rate was 6.4 deaths per 1,000 births in 2009; we lag well behind many other industrialized nations. Significant disparities persist between populations. A number of social, economic, and demographic characteristics of the mother are associated with infant death. Premature births and infant losses have enormous costs to our families, health care system, schools, and national prosperity; the Institute of Medicine estimates the 2005 annual societal economic cost associated with preterm birth in the U.S. was at least \$26.2 billion. The three leading causes of infant death-congenital malformations, low birth weight, and sudden infant death

syndrome- accounted for 46 percent of all infant deaths. Attention to reducing the rates of infant mortality has received significant national attention in recent years for a variety of reasons, including the fact that the rate has remained relatively constant since 2000 despite declines in prior years.

A comprehensive public policy to strengthen efforts to reduce infant mortality and eliminate disparities in infant death rates are high priority public health goals. The Department is proposing a new comprehensive infant mortality reduction program and addition of a point of care newborn screening program to the already existing metabolic and hearing newborn screening activities mandated by the state. The Secretary of Health and Human Services has added point of care screening for critical congenital heart defects to the national Recommended Uniform Screening Panel. Screening newborns for critical congenital heart defects, in addition to the metabolic disorders the existing state newborn metabolic screening program already detects, will further reduce infant mortality in Hawaii.

PART I

SECTION 2. Chapter 321, Hawaii Revised Statutes, is amended by adding three new sections to part XXV to be appropriately designated and to read as follows:

"§321-A Comprehensive infant mortality reduction

program; established. (a) The department of health shall establish, administer, and maintain a statewide, comprehensive infant mortality reduction program. The department shall convene for planning purposes and provide assistance to entities and agencies, public and private, involved in the reduction of infant mortality rates.

(b) It shall be a goal of the department of health to:

- (1) Improve statewide coordination of infant mortality reduction planning and oversight;
- (2) Oversee the implementation of evidence-based
 practices;
- (3) Adopt rules and establish policies to reduce infant mortality rates; and
- (4) Generally and comprehensively address social determinants of health and other demonstrated factors that contribute to infant mortality.

<u>§321-B</u> Hawaii infant mortality reduction advisory board,

<u>established.</u> (a) There is established within the department of health for administrative purposes the Hawaii infant mortality reduction advisory board that shall be comprised of fifteen members, thirteen of whom are to be appointed by the governor, with the advice and consent of the senate, pursuant to section 26-34. The director of health and the director of human services shall serve as ex-officio, voting members of the board. Members appointed by the governor shall serve staggered terms of two years each so that the terms of no more than five members expire each year.

(b) The membership of the board shall reflect geographic diversity and the diverse interests of stakeholders, including consumers, employers, insurers, and healthcare providers.

(c) The advisory board shall be responsible for:

- (1) Approving the statewide biannual strategic plan updated every three years to reduce infant mortality;
- (2) Advising the comprehensive infant mortality reduction program on how best to meet the goals and objectives of the infant mortality reduction strategic plan;
- (3) Providing recommendations to the comprehensive infant mortality reduction program on improving the quality, availability, and coordination of the services of the comprehensive infant mortality reduction program; and
- (4) Promoting collaboration among public agencies and private stakeholders to reduce infant mortality in the <u>State.</u>

(d) Members shall serve without compensation but shall be reimbursed for expenses, including travel expenses, necessary for the performance of their duties.

<u>§321-C</u> Infant mortality reduction strategic plan; social determinants of health focus. (a) The department shall develop and publish a statewide, comprehensive infant mortality reduction strategic plan to reduce infant mortality in the State. The department shall publish the initial strategic plan no later than January 1, 2015. The department shall review, revise, and publish an updated infant mortality reduction strategic plan three years following the date of the initial strategic plan, and every three years thereafter.

(b) The plan shall include strategies to address social determinants of health as they relate to infant mortality.

(c) The public shall have the opportunity to provide input relating to the infant mortality reduction strategic plan pursuant to chapter 91.

(d) The department shall present the strategic plan to the Hawaii infant mortality reduction advisory board for its approval. Upon approval, the strategic plan shall guide all policy development related to the reduction of infant mortality in Hawaii." SECTION 3. Chapter 321, Hawaii Revised Statutes, is amended by adding to part XXVI two new sections to be appropriately designated and to read as follows:

"§321-D Patient education; provider

responsibilities. (a) Each birthing facility shall establish written policies prohibiting non-medically indicated inductions of newborn deliveries or cesarean sections prior to thirty-nine weeks of gestation and distribute copies of the written policies at least annually to all staff and providers with admitting privileges at that facility.

(b) The department shall produce and distribute factual and scientific educational information addressing infant mortality, including pre-term birth, to all facilities.

(c) Each facility shall provide to a pregnant woman upon admission, factual and scientific educational material, including material produced and distributed by the department, regarding infant mortality and pre-term birth unless deemed by the attending physician to be unfeasible on account of the pregnant woman's medical condition or other circumstances. Each facility shall document the pregnant woman's receipt and acknowledgement of the educational material for each admission.

<u>§321-E</u> <u>Reporting requirements; health care</u> providers. (a) Beginning January 1, 2014, each licensed birthing facility in the State shall report to the department, in a manner and at intervals determined by the department by rules adopted pursuant to chapter 91, information concerning pre-term birth.

(b) The report under subsection (a) shall contain, at a minimum, the following information for each reporting period:

- (1) The number of live births at the birthing facility;
- (2) The number of incidents of pre-term birth at the birthing facility;
- (3) The medical and other causes, that may have caused a pre-term birth;
- (4) Individual, de-identified patient demographic data;
- (5) The number of patients admitted to the facility who received factual and scientific educational material regarding infant mortality and pre-term birth; and
- (6) Other information that the department specifies in rules adopted pursuant to chapter 91."

PART III

SECTION 4. Chapter 321, Hawaii Revised Statutes, is amended by adding a new part to be appropriately designated and to read as follows:

"PART . POINT OF CARE NEWBORN SCREENING

§321-A Definitions. For the purposes of this part:

"Department" means the department of health.

"Point of care newborn screening" means newborn infant screening for diseases and conditions specified by the department and administered at the institution caring for the newborn infant, followed by diagnostic testing at the institution, or at a health facility to which the infant is transferred when a positive screening result is found, to determine the cause of the positive screening result before the newborn is discharged home.

"Positive screening result" means a newborn screening result that is outside the normal range of screening results for a newborn.

§321-B Point of care newborn screening. (a) The department shall specify diseases and conditions covered by point of care newborn screening.

(b) The department shall specify policies and procedures for administration of point of care newborn screening to be administered by institutions caring for newborn infants to best prevent newborn mortality and morbidity within the State.

(c) The person in charge of each institution caring for newborn infants and the responsible physician attending the birth of a newborn or the person assisting the birth of a newborn not attended by a physician, shall ensure that every newborn infant in the person's care be tested for the diseases and conditions for point of care newborn screening specified by the department; provided that this section shall not apply if the parents, guardians, or other persons having custody or control of the child object thereto on the grounds that the tests conflict with their religious tenets and beliefs and written objection is made a part of the newborn infant's medical record.

(d) The department shall adopt rules pursuant to chapter91 necessary for the purposes of this section, including:

- Specifying diseases and conditions for point of care newborn screening;
- (2) Establishing policies and procedures for administration of point of care newborn screening tests;
- (3) Providing for quality and cost control of point of care newborn screening tests;
- (4) Providing for retention of records and related data;
- (5) Tracking completion and results of point of care newborn screening;
- (6) Formulating guidelines for care, treatment, and follow up for newborn infants with positive test results;
- (7) Providing education for parents and healthcare providers about the availability and purposes of point of care newborn screening; and

(8) Maintaining the confidentiality of newborns and families.

(e) The director of health shall submit an annual report to the legislature twenty days prior to the convening of each regular session, identifying all expenditures made from the newborn metabolic screening special fund for the department's point of care newborn screening activities."

SECTION 5. Section 321-291, Hawaii Revised Statutes, is amended by amending subsection (d) to read as follows:

"(d) There is created in the treasury of the State the newborn metabolic screening special fund. All moneys for newborn metabolic screening services <u>and point of care newborn</u> <u>screening services</u> collected under this chapter shall be deposited in the newborn metabolic screening special fund to be used for the payment of its lawful operating expenditures, including but not limited to laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs[-] <u>for newborn</u> <u>metabolic screening and for point of care newborn screening.</u>"

PART IV

SECTION 6. Section 321-323, Hawaii Revised Statutes is amended by adding two new definitions to be appropriately inserted and to read as follows: "<u>"Infant mortality</u>" means the risk of an infant dying between birth and one year of age.

"Social determinants of health" means the conditions in which people are born, grow, live, work and age, including the health system, provided that these conditions are attributable, in large part, to health inequities and avoidable differences in health status among demographic groups."

PART V

SECTION 7. There is appropriated out of the general revenues of the State of Hawaii the sum of \$ or so much thereof as may be necessary for fiscal year 2013-2014 to:

- (1) Fund epidemiological and planning activities related to infant mortality reduction;
- (2) Collect and analyze Hawaii-specific infant mortality data; and
- (3) Identify social determinants of health as they relate to infant mortality.

The sum appropriated shall be expended by the department of health for the purposes of this Act.

PART VI

SECTION 8. In codifying the new sections added by sections 2 and 3 of this Act, and the new part III of this act, the revisor of statutes shall substitute appropriate section numbers for the letters used in designating the new sections in this Act.

SECTION 9. New statutory material is underscored.

SECTION 10. This Act, upon its approval, shall take effect on July 1, 2050.



EXECUTIVE OFFICE ON EARLY LEARNING HONOLULU

TERRY LOCK DIRECTOR

> Testimony in **Support** of H.B. 909 S.D. 1, Relating to Infant Mortality Program By Terry Lock, Director

> > Senate Committee on Ways and Means March 28, 2013 9:05 a.m., Room 211

Chair Ige, Vice-Chair Kidani, and Members of the Committee:

Aloha, I am Terry Lock, Director of the Executive Office on Early Learning (EOEL). EOEL is in support of House Bill 909 Senate Draft 1.

EOEL is charged with coordinating efforts on behalf of young children by creating partnerships and alignment of policies and programs to achieve improved outcomes in health, safety, and school readiness and success. Over the past year, EOEL has engaged partners across the state to define the desired outcomes for children and families, as well as the critical strategies to achieve those outcomes, which should be prioritized over the next three to five years. This work – the Hawaii Early Childhood Action Strategy – is described in *Taking Action for Hawaii's Children*, which can be found at earlylearning.hawaii.gov.

One of these priority strategies is to improve birth outcomes for our keiki. H.B. 909 S.D. 1 aligns with this strategy. It would, among other things, establish a comprehensive infant mortality reduction program under the Department of Health and require licensed birthing facilities to report information on pre-term births.

We defer to the Department of Health on matters contained in this bill that are under their jurisdiction.

Thank you for the opportunity to submit testimony.

` 1319 Punahou Street Honolulu, Hawai'i 96826-1001



808-983-6000 www.kapiolani.org

Thursday, March 28, 2013; 9:05 am Conference Room 211

The Senate Committee on Ways and Means

- To: Senator David Ige, Chair Senator Michelle Kidani, Vice Chair
- From: Laura Bonilla, RN Executive Director – Pediatric Service Line

Re: HB 909, HD2, SD1 Relating To Infant Mortality Program Comments Supporting the Intent but with Amended Language

My name is Laura Bonilla, Executive Director for the Pediatric Service Line at Kapi'olani Medical Center for Women & Children (Kapi'olani). Kapiolani is Hawaii's leader in the care of women, infants and children. With 207 beds and 66 bassinets, it is Hawaii's only maternity, newborn and pediatric specialty hospital. Kapi'olani is also a tertiary care, medical teaching and research facility. Specialty services for patients throughout Hawai'i and the Pacific Region include intensive care for infants and children, 24-hour emergency pediatric care, air transport, maternal fetal medicine, and high-risk perinatal care. The hospital offers numerous community programs and services, such as the Kapi'olani Child Protection Center and Sex Abuse Treatment Center. Kapi'olani Medical Center is an affiliate of Hawai'i Pacific Health, the state's largest health care provider

HPH supports the intent of HB 909, HD2, SD1 which establishes a comprehensive infant mortality reduction program, advisory board, and reporting requirement for birthing facilities.

We certainly appreciate the effort this bill makes in elevating the importance of studying infant mortality in the state of Hawai'i. The creation of the proposed Infant Mortality Board is a helpful first step toward this effort.

We respectfully offer the following amendments:

1. On Page 2, Section 321-B:

We recommend specifying that the thirteen (13) members appointed by the governor include a general pediatrician and a neonatologist in collaboration with the Hawai'i Chapter of the American Academy of Pediatrics; and a general obstetrician and maternal fetal medicine specialist in collaboration with the American Congress of Obstetricians and Gynecologists (ACOG), Hawai'i Section; as well as a member of the Hawai'i Medical Association.

This will enhance the effectiveness of the advisory board and allow for a wider range of input. Given the importance of reducing infant mortality, the specialties recommended above will lead to the creation of a panel that can most effectively assess and address patient outcomes for optimal benefits.

2. Allow the advisory board, rather than the Department of Health (DOH) to determine and make recommendations as to the scope of medical practice and strategies to reduce infant mortality.

As the advisory board will be comprised of a wide range of interest, including medical specialists, it would be best suited to formulate plans and strategies on this matter. For example, sections of this bill are duplicative to national guidelines and practices already instituted at birthing centers related to national induction of labor guidelines and already specify that elective induction should not occur prior to 39 weeks of gestation. Thus, the advisory board would be in the best position to review practice options and render recommendations.

3. Delete Part II on pages 4-6.

Statutorily mandating the distribution of patient educational materials is unnecessary and duplicative as this is a function which is already in place. This also runs the risk of being out of sync with evolving practices through the natural evolution of best practices in medicine. Instead we would prefer that the Infant Mortality Board be the source of dissemination of this information rather than by statute.

Imposing a reporting requirement on birthing facilities will be burdensome for such facilities. The type of information required is not maintained by the birthing facilities. For example, information as to the medical cause of a pre-term birth is not readily identifiable, nor is it recorded and maintained.

We ask for your favorable consideration of our recommendations above.

Thank you for the opportunity to provide these comments.

Date: March 26, 2013

- To: Honorable David Ige Honorable Michelle Kidani
- From: Lin Joseph Director of Program Services March of Dimes Hawaii Chapter
- Re: In support of HB909 HD2 SD1

Committee on Ways and Means
March 28, 2013
Conference Room 211, State Capitol

Chair Ige, Vice Chair Kidani, Members of the Committee:

I am writing to express strong support for HB909 HD2 SD1: Relating to Infant Mortality Program.

For over 70 years, the March of Dimes has been a leader in maternal and child health. Our mission is to *improve the health babies by preventing birth defects, premature birth, and infant mortality*.

In 2009, 18,887 babies were born in the state of Hawaii. According to the National Center for Health Statistics, 12.6% of them were born preterm or less than 37 weeks gestation, and more than 5 of every thousand born died in infancy. That means in an average week, 363 babies are born, 46 babies are born preterm, and 2 babies die before their first birthday. Prematurity is the leading cause of neonatal death in the first 30 days of life and a major contributor to infant mortality. In 2003, the March of Dimes launched a national campaign to raise awareness of the problem of prematurity and to reduce the rate of preterm birth in the United States.

In 2009, pursuant to HCR 215 SD1, March of Dimes partnered with the Department of Health and Healthy Mothers Healthy Babies to survey Hawaii hospitals regarding implementation of policies and procedures to reduce elective cesarean sections and labor inductions, and found that only 55% of Hawaii hospitals performing deliveries had policies in place that are consistent with American Congress of Obstetricians and Gynecologists (ACOG) guidelines of no elective labor inductions or cesarean sections before 39 weeks gestation. In its report of HCR215 to the legislature, DOH recommended the formation of a task force to further pursue the reduction in elective procedures before 39 weeks through development of quality initiatives, training, and collection of data relating to elective deliveries, review of regulations governing state licensure of hospitals, and a public awareness campaign on the risks of delivery prior to 39 weeks gestation. In 2012, March of Dimes again partnered with the Department of Health to take up the challenge to reduce Hawaii's prematurity rate by eight percent by 2014. We are working together on increasing public awareness to reduce Hawaii's preterm birth through our "Healthy Babies



March of Dimes Foundation

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marchofdimes.com/hawaii

March 26, 2013 Honorable David Ige Honorable Michelle Kidani Page 2

are Worth the Wait" campaign that encourages women to wait for labor to begin on its own if their pregnancy is healthy.

In addition, we are in support of Part V, Section 5, for the task force convened by the Department of Health to determine the need for point of care newborn screening, to include screening for Critical Congenital Heart Disease (CCHD). Congenital heart disease is a problem with the heart's structure and/or function which is present at birth. "Critical" means that the heart defect causes severe life threatening symptoms and requires intervention within the first hours, days or months of life. These conditions are sometimes difficult to detect by physical exam and observation in the first few days of life, but point of care newborn screening for CCHD can provide early detection of a congenital heart defect and lead to early treatment.

Therefore, March of Dimes asks the Senate Committee on Ways and Means to support the passage of HB909 HD2 SD1.

Mahalo for the opportunity to present testimony in support of HB909.