SENATE RULES COMMITTEE AB 1129
Office of Senate Floor Analyses
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THIRD READING

Bill No: AB 1129
Author: Celeste Rodriguez (D), et al.
Amended: 7/17/25 in Senate
Vote: 27

SENATE HEALTH COMMITTEE: 11-0, 7/9/25
AYES: Menjivar, Valladares, Durazo, Gonzalez, Grove, Limón, Padilla, Richardson, Rubio, Weber Pierson, Wiener

SENATE JUDICIARY COMMITTEE: 13-0, 7/15/25
AYES: Umberg, Niello, Allen, Arreguín, Ashby, Caballero, Durazo, Laird, Stern, Valladares, Wahab, Weber Pierson, Wiener

ASSEMBLY FLOOR: 77-0, 6/5/25 - See last page for vote

SUBJECT: Birth defects monitoring

SOURCE: County of Los Angeles
March of Dimes

DIGEST: This bill permits a local health officer to maintain a system for the collection of information necessary to accomplish a local-level monitoring and reporting program similar to, and independent of, the state-level birth defects monitoring program, subject to adequate funding. Makes conforming changes in existing law to facilitate a local-level monitoring and reporting program.

ANALYSIS:

Existing law:

1) Establishes the California Department of Public Health (CDPH) to be vested with all the specified duties, powers, purposes, functions, responsibilities, and

jurisdiction as they relate to public health. [Health and Safety Code (HSC) § 131050]

2) States Legislative intent to accomplish all of the following in relation to birth defects, stillbirths, and miscarriages that represent problems of public health importance; the severe mental anguish they have on parents and relatives; associated high medical care costs; and, how more information about these conditions could result in preventive measures to decrease their incidence:

   a) Maintain an ongoing program of "birth defects" monitoring (BDMP) statewide. "Birth defect" means any medical problem of organ structure, function, or chemistry of possible genetic or prenatal origin;
   b) Provide information on the incidence, prevalence, and trends of birth defects, stillbirths, and miscarriages, and information on whether they are associated with environmental hazards, or other possible causes;
   c) Develop prevention strategies for reducing the incidence;
   d) Conduct interview studies about the causes of birth defects; and,
   e) Affirm CDPH's authority to contract with a qualified entity to operate the BDMP statewide. [HSC §103825]

3) Requires CDPH's Director to maintain a system to collect information necessary to accomplish statewide monitoring through the BDMP, including requiring specified health facilities to make available medical records of children suspected or diagnosed as having birth defects, including the medical records of their mothers; and, to make available medical records of mothers suspected or diagnosed with stillbirths or miscarriages, and other records of persons who may serve as controls for interview studies about the causes of birth defects. [HSC §103830]

4) Requires the BDMP to operate statewide. States Legislative intent to assess annually the adequacy of program resources, and that the annual assessment include a consideration of at least the numbers of births in the state; the scope of program activities; and, any urgent situation requiring extraordinary commitment of present or planned program staff or resources. [HSC §103835]

5) Requires CDPH's Director to use the information collected through the system it maintains and information available from other reporting systems and health providers to conduct studies to investigate the causes of birth defects, stillbirths, and miscarriages and to determine and evaluate measures designed to prevent their occurrence. [HSC §103840]

6) Requires CDPH's Director to appoint an advisory committee to advise on the implementation of the BDMP. Requires that representatives from epidemiology, hospital administration, biostatistics, maternal and child health, and public health be on the committee and at least one representative to be from the manufacturing industry. [HSC §103845]

7) Requires all information collected to be confidential and used solely for the BDMP. Limits access to this information to authorized program staff and persons with a valid scientific interest, who have specified qualifications; are engaged in demographic, epidemiological, or other similar studies related to health; and, agree in writing to maintain confidentiality. Requires, among other things, CDPH to maintain accurate records of all persons given access to this information; processes for when research is conducted other than by program staff; and, requirements before this information is disclosed. [HSC §103850]

8) Permits CDPH to enter into a contract for the establishment and implementation of the BDMP, with the authority to establish criteria for the contract. [HSC §103855]

9) Requires CDPH to charge a fee to all payers for any test or activity for genetic prevention services. Creates the BDMP Fund as a special fund in the State Treasury. Requires the fee revenues that are collected to be deposited into the fund to support BDMP activities. [HSC §124977]

10) Requires the BDMP to collect and store any umbilical cord blood samples received from hospitals for storage and research. Requires the BDMP, for purposes of ensuring financial stability, to ensure: fees paid by researchers be used for, and be sufficient to cover the cost of, collecting and storing blood samples; a researcher provides satisfactory evidence that adequate funding will be provided to CDPH from the fees paid by the researcher for the request; and, CDPH receives federal grant moneys to pay for initial startup costs for the collection and storage of umbilical cord blood samples. [HSC §124991(a)]

This bill:

1) Permits a local health officer to maintain a system for the collection of information within the local health jurisdiction that is necessary to accomplish a local-level monitoring and reporting program similar to, and independent of, the state-level BDMP, subject to adequate funding.

2) Permits information about birth defects and conditions to be reported using either of the following systems at the discretion of the public health director or the local health officer:

   a) A system that requires reporting institutions within the local health jurisdiction to make their records available for review and information collection by designated staff of the local program to monitor birth defects and conditions; or,
   b) A system that requires reporting institutions within the local health jurisdiction, including, but not limited to, providers and laboratories, to transmit specified data manually or electronically to the local health officer.

3) Permits a local health officer to require reporting institutions within the local health jurisdiction to make their related records available to authorized local program staff; require reporting of selected information about birth defects and conditions to the local public health program; or, implement a hybrid of the two systems. Prohibits a local health officer from impeding or contradicting activities of the state-level BDMP in their jurisdiction, but may supplement the activities for local uses and purposes.

4) Requires birth defects and conditions reported in a local health jurisdiction to be at the direction of and at the discretion of the local health officer, subject to adequate funding. Permits a local health officer only to collect information if it is a unique demographic, diagnostic, or health data directly related to a birth defect or condition, and consistent with purposes of the monitoring program to facilitate access to care, unless the patient or their parent or guardian gives consent to the officer for the collection of additional data.

5) Permits a local health officer to require reporting institutions within the local health jurisdiction to report birth defects and conditions, as needed, to assess and address the needs of the local health jurisdiction; to supplement the state BDMP in jurisdictions where it is conducted, if needed; or, for reporting of birth defects and conditions in a local health jurisdiction where there is no state BDMP.

6) Makes conforming changes in existing BDMP law to facilitate local-level birth defect and conditions monitoring and reporting program implementation; authorize the use of existing local resources; permit contracting to support the local program; and, clarify that existing state-level BDMP fees deposited into

the associated program fund are prohibited from supporting the local-level programs in jurisdictions that opt to implement the provisions in this bill.

Comments

According to the author of this bill:

> Achieving healthy communities is a multifaceted approach. Medical and public health professionals play a vital role in making sure our communities are healthy, protected, and have access to care. Whenever possible, we must expand resources to support their roles in achieving healthy communities. Making improvements to our health care needs and ensuring our communities are safe from environmental hazards entail evaluating the health data we collect and making sure we identify gaps. One way CDPH is doing so is by monitoring birth defects in the state through the BDMP. However, this program is restricted to just ten counties. This bill expands on this program, specifically, by giving local health jurisdictions the ability to implement a local birth defects and conditions reporting program should they choose to do so. This allows a local health jurisdiction to collect their own data and improve services for families facing health care challenges. It builds upon the work that CDPH is doing and allows all counties to have the option to do monitoring.

Background

Birth defects. According to the Centers for Disease Control and Prevention (CDC) website, every 4.5 minutes a baby is born with a condition that affects the structure or function of their body, affecting one in every 33 babies born in the United States each year. They are also the leading cause of infant deaths, accounting for one in five (20%) of all infant deaths. Birth defects can occur during any stage of pregnancy with most occurring in the first three months of pregnancy, when the organs of the baby are forming. However, some birth defects do occur later in pregnancy as tissues and organs continue to develop. While medical advancements have greatly improved health and survival, many of these conditions are lifelong and require lifelong care. Birth defects can vary from mild to severe, and health outcomes and life expectancy depend on which body part is involved and how it is affected.

Exposures and risk factors. CDPH's website states when discussing exposures and risk factors in regards to birth defects it means anything the fetus is exposed to, as well as anything that may alter conditions within the womb, which includes everything the mother may come into contact with during pregnancy. Because most structural development of the fetus occurs during early pregnancy, CDPH

focuses on the "periconceptional" period—the month before and first three months after conception. Studies cannot always provide a definitive answer about whether a particular exposure or risk factor, or both, caused a birth defect. Instead, results are reported as changes in birth defects risk for exposed pregnancies compared to unexposed. The following are general guidelines BDMP uses:

- *Exposures* – anything that comes into direct contact with the mother or fetus;
- *Risk factors* – such as social or economic conditions, may provide clues that can help pinpoint causes;
- *Higher risks* – a doubling or more, suggests an association between the exposure and the condition in question. This may mean the studied exposure/risk factor contributes to the birth defect;
- *Decreased risks* – one-half or less, indicates a protective effect. The exposure appears to prevent the birth defect from occurring; and,
- *No change in risk* – implies that the exposure and the defect are not closely related.

Studies that are conducted in order to discover the role of exposures and risk factors on birth defects must validate biologically plausible pathways of exposure—meaning ways the mother could have been exposed. Proximity is not enough. If a pregnant woman lives near a source of environmental concern, for example, things like whether she could have inhaled, ingested or otherwise been exposed to harmful conditions must also be considered. The following exposures and risk factors may have some impact on a fetus if the mother was exposed during pregnancy: air pollution; alcohol; chemicals, pesticides, and solvents; diet and nutrition; drinking water; drugs; folic acid/vitamins; and, medications.

BDMP. According to CDPH's website, the California BDMP is a population-based registry that has been an active ascertainment registry since 1982 when the California State Legislature authorized it to collect data on birth defects, stillbirths, and miscarriages. BDMP currently monitors over 150,000 births in 10 counties (Fresno, Kern, Kings, Madera, Merced, Orange, San Diego, San Joaquin, Stanislaus, and Tulare)—approximately 30% of the births in California, representative of the state's population. BDMP registry data provide ongoing tracking (also called surveillance) to monitor rates and trends of select birth defects. The data also provides pregnancy outcome data for the pregnancy blood samples included in the California Biobank Program. BDMP's objectives are to: increase the quality and quantity of California-based birth defect data available for

purposes of public health monitoring and investigator-led research; increase communication of birth defects information; and, monitor public health and safety concerns relating to birth defects.

Information is collected on specific congenital and inherited disorders to provide the public, researchers, and the medical community with accurate data on birth defects. BDMP sets procedures for identifying children with birth defects, reviews medical records, and links cases with state and national agencies. Data collection focuses on structural malformations including major heart defects, oral clefts, neural tube defects, hypospadias, abdominal wall defects, Down syndrome and other chromosomal defects. BDMP monitors the rates of birth defects by geographic and demographic attributes, and focuses on common birth defects with substantial public health impact. BDMP responds to inquiries from the public, and research and medical communities. It provides data for public health reports, needs assessments, and program evaluation, and also works to communicate relevant information and identify appropriate resources specifically for California families concerned about birth defects.

The author's office provided information stating that current law does not authorize local health jurisdictions to implement birth defects reporting in their respective jurisdictions, and limits their reporting programs to infectious/communicable diseases and/or food- or vector-borne conditions. Likewise, some of the largest and most diverse counties (Alameda, Los Angeles, Sacramento, San Francisco, and San Jose) are not represented in the statewide BDMP.

FISCAL EFFECT: Appropriation: No Fiscal Com.: No Local: No

SUPPORT: (Verified 8/14/25)

County of Los Angeles (co-source)
March of Dimes (co-source)
American Academy of Pediatrics, California
Children Now
First 5 Association of California
Health Officers Association of California

OPPOSITION: (Verified 8/14/25)

None received

ARGUMENTS IN SUPPORT: Los Angeles County (LAC) and the March of Dimes, as cosponsors, and other supporters of this bill state that monitoring birth

anomalies can be an indispensable tool for local health programs to identify newborns and infants with select health conditions and connect them with necessary care (case finding); determine the best prevention strategies and allocate resources more effectively; highlight areas for further research, address care gaps or quality issues, and evaluate underperforming practices or products; and, respond to environmental or public health emergencies that may pose risks. For instance, if this authority were currently available in LAC, it could be utilized to monitor the effects of the recent fires on births in the coming years to identify possible impacts of exposure to after-fire toxicity in air, water, or soil. Likewise, LAC states it could track birth-related incidents of cerebral palsy, an area of particular concern to their Board of Supervisors. Finally, they could monitor the incidence of Sickle Cell Disease (SCD) to ensure that families of infants diagnosed with SCD are enrolling in appropriate specialty care.

ASSEMBLY FLOOR: 77-0, 6/5/25
AYES: Addis, Aguiar-Curry, Ahrens, Alanis, Alvarez, Arambula, Ávila Farías, Bains, Bauer-Kahan, Bennett, Berman, Boerner, Bonta, Bryan, Calderon, Caloza, Carrillo, Castillo, Chen, Connolly, Davies, DeMaio, Dixon, Elhawary, Ellis, Flora, Fong, Gabriel, Gallagher, Garcia, Gipson, Jeff Gonzalez, Mark González, Hadwick, Haney, Harabedian, Hart, Hoover, Irwin, Jackson, Kalra, Krell, Lee, Lowenthal, Macedo, McKinnor, Muratsuchi, Nguyen, Pacheco, Papan, Patel, Patterson, Pellerin, Petrie-Norris, Quirk-Silva, Ramos, Ransom, Celeste Rodriguez, Michelle Rodriguez, Rogers, Blanca Rubio, Sanchez, Schiavo, Schultz, Sharp-Collins, Solache, Soria, Stefani, Ta, Tangipa, Valencia, Wallis, Ward, Wicks, Wilson, Zbur, Rivas
NO VOTE RECORDED: Lackey, Ortega

Prepared by: Reyes Diaz / HEALTH / (916) 651-4111
8/20/25 23:28:49

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