

JAN 17 2024

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# A BILL FOR AN ACT

RELATING TO DISABILITY HEALTH DISPARITY.

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

1           SECTION 1. The legislature finds that adults with  
2 intellectual or developmental disabilities experience  
3 disproportionate health disparities compared to those without  
4 disabilities. Individuals with intellectual or developmental  
5 disabilities are more likely than their peers without  
6 disabilities to have fair or poor health, be considered obese,  
7 and be diagnosed with chronic diseases, such as diabetes.  
8 Intellectual and developmental disabilities are life-long  
9 differences that typically arise before adulthood and can  
10 uniquely influence the trajectory of an individual's life,  
11 including their physical, intellectual, behavioral, and  
12 emotional development. The state council on developmental  
13 disabilities was created to advocate for and improve and protect  
14 the lives of individuals with intellectual or developmental  
15 disabilities in the State.

16           Decades of research has clearly established that people of  
17 minority groups living in the United States receive poor health



1 care and have poor health outcomes resulting from social  
2 determinants of health. On a national level, racial and ethnic  
3 disparities in access to health care and health outcomes are a  
4 persistent, pervasive public health problem. In the State,  
5 underserved populations, such as Native Hawaiian and Pacific  
6 Islanders, have been historically underrepresented in health  
7 care, as data does not accurately reflect the health disparities  
8 currently faced by this group. Additionally, individuals from  
9 the neighbor islands are also underrepresented and underserved,  
10 as access to health care resources and services are limited.  
11 However, even less is known about the extent of racial and  
12 ethnic health disparities among adults with intellectual or  
13 developmental disabilities. Accordingly, there is an urgent  
14 need to create an updated, accurate set of data that reflects  
15 the State's unique needs to assist certain agencies to better  
16 understand the needs of individuals with intellectual or  
17 developmental disabilities in their communities.

18 The legislature further finds troubling gaps in the health  
19 disparities of people with intellectual or developmental  
20 disabilities and their social determinants of health in the  
21 State. Certain recent health surveys in the state and existing



1 related initiatives do not segregate data pertaining to  
2 individuals with intellectual or developmental disabilities, nor  
3 is the data publicly available. Presently, the State relies on  
4 prevalence rate data from the federal government published in  
5 1994-1995 that does not reflect the State's population and its  
6 specific needs. Hawai'i's prevalence rate is 1.58 per cent,  
7 which equals approximately twenty-two thousand people who have  
8 an intellectual or developmental disability. Additionally, the  
9 only substantial data the state council on developmental  
10 disabilities collects on intellectual or developmental  
11 disabilities is through the medicaid waiver program, which  
12 serves approximately three thousand people. As there is a gap  
13 of approximately nineteen thousand people who may have an  
14 intellectual or developmental disability in the State, there is  
15 little information on quality of life, health care access, and  
16 health care outcomes for unaccounted individuals with  
17 intellectual or developmental disabilities.

18 Accordingly, further research is needed to understand the  
19 health disparities of people with intellectual or developmental  
20 disabilities and their social determinants of health. It is  
21 therefore imperative for the State to establish fundamental



1 baseline data for service evaluation, policy development, and  
2 research to serve the current and future needs of individuals  
3 with intellectual or developmental disabilities. Accurate,  
4 current data will also help Hawai'i provide culturally  
5 appropriate health care, address barriers to health care access,  
6 reduce health disparities, increase employment opportunities,  
7 and support individuals with developmental or intellectual  
8 disabilities to live healthy lives in the community.

9 Therefore, the purpose of this Act is to appropriate funds  
10 and require the state council on developmental disabilities to  
11 study the health disparities experienced by individuals with  
12 intellectual or developmental disabilities in the State. This  
13 project will yield much needed results to help guide the future  
14 of public health policy and practice.

15 SECTION 2. (a) The state council on developmental  
16 disabilities shall collect comprehensive data to identify gaps  
17 in social determinants of health, especially in the areas of  
18 health care access and quality and economic stability, that  
19 affect health outcomes and health disparities experienced by  
20 individuals with intellectual or development disabilities in the  
21 state that can be addressed with policy, legislative, or



1 stakeholder action, and shall submit a report to the legislature  
2 no later than twenty days prior to the convening of the regular  
3 session of 2026. The report shall include:

4 (1) A definition of the State's intellectual or  
5 developmental disability population for public health  
6 administration purposes, including the health  
7 conditions, duration, and level of severity required  
8 to qualify for disability status;

9 (2) A definition of the social determinants of health as  
10 used by the United States Department of Health and  
11 Human Services;

12 (3) Population-level differences in the State between  
13 individuals with and without intellectual or  
14 developmental disabilities on health indicators and  
15 social determinants of health, including:

16 (A) Access to necessary health care;

17 (B) Access to preventive health care, including  
18 wellness programs and emotional support services;

19 (C) Health behaviors, including the percentage of  
20 individuals who engage in physical activities or  
21 smoke cigarettes;



- 1 (D) Health status and outcomes, including the  
2 percentage of individuals who are considered  
3 obese or diagnosed with chronic diseases,  
4 including diabetes, hypertension, and  
5 cardiovascular diseases;
- 6 (E) Drivers of health outcomes, including the impetus  
7 to seek health care and how individuals seek  
8 health care;
- 9 (F) Emergency preparedness, including evacuation  
10 planning and ability;
- 11 (G) Health insurance coverage;
- 12 (H) Social determinants of health and health  
13 outcomes, including household income, employment  
14 status, education level, access to health  
15 information technology tools and systems, access  
16 to transportation, and the social and community  
17 environment; and
- 18 (I) Other indicators and determinants that contribute  
19 to an individual's physical and mental health;
- 20 (4) Factors contributing to the population-level  
21 differences, including race, ethnicity, gender, age,



1 county of residence, and economic and social  
2 disadvantages and discrimination;

3 (5) A determination of the population-level differences  
4 and contributing factors that are preventable or  
5 avoidable;

6 (6) Any other information that would assist the State in  
7 determining safe, equitable, and culturally  
8 appropriate public health actions that would improve  
9 health care and address the health disparities  
10 experienced by individuals in the State with  
11 developmental or intellectual disabilities; and

12 (7) Proposed legislation, including best practices, for  
13 the State to reduce the health disparities experienced  
14 by individuals in the State with developmental or  
15 intellectual disabilities.

16 (b) In preparing the report, the state council on  
17 developmental disabilities may consult with community  
18 stakeholders on the following:

19 (1) Improvements to provider training about intellectual  
20 or developmental disabilities;



- 1           (2) Life experiences of individuals with intellectual or
- 2           developmental disabilities;
- 3           (3) Accessibility mandates for health infrastructure that
- 4           include the needs of individuals with intellectual or
- 5           developmental disabilities;
- 6           (4) Communication guidelines and standards for health care
- 7           providers to communicate with individuals with
- 8           intellectual or developmental disabilities; and
- 9           (5) Other topics as deemed relevant by the state council
- 10          on developmental disabilities.

11          (c) For purposes of this Act:

12          "Health disparities" means population-level differences in

13 health outcomes that are related to a history of social,

14 economic, or environmental disadvantages that are avoidable and

15 not primarily caused by underlying health conditions that led to

16 the disability.

17          "Intellectual or developmental disabilities" means a

18 lifelong difference that typically arises before adulthood that

19 uniquely influences the trajectory of the individual's physical,

20 intellectual, behavioral, and emotional development and impacts

21 how individuals experience the world around them.



1 SECTION 3. In accordance with section 9 of article VII of  
 2 the Hawaii State Constitution and sections 37-91 and 37-93,  
 3 Hawaii Revised Statutes, the legislature has determined that the  
 4 appropriations contained in Act 164, Regular Session of 2023,  
 5 and this Act will cause the state general fund expenditure  
 6 ceiling for fiscal year 2024-2025 to be exceeded by  
 7 \$ or per cent. This current declaration takes  
 8 into account general fund appropriations authorized for fiscal  
 9 year 2024-2025 in Act 164, Regular Session of 2023, and this Act  
 10 only. The reasons for exceeding the general fund expenditure  
 11 ceiling are that:

- 12 (1) The appropriation made in this Act is necessary to
- 13 serve the public interest; and
- 14 (2) The appropriation made in this Act meets the needs
- 15 addressed by this Act.

16 SECTION 4. There is appropriated out of the general  
 17 revenues of the State of Hawaii the sum of \$ or so  
 18 much thereof as may be necessary for fiscal year 2024-2025 for  
 19 the state council on developmental disabilities to collect  
 20 comprehensive data and compile and submit to the legislature a  
 21 report focused on the health disparities experienced by



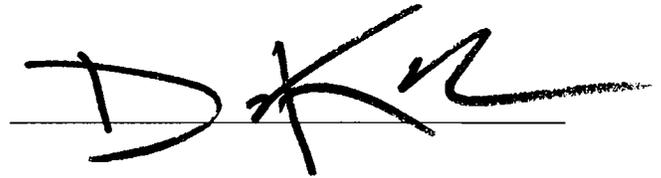
1 individuals with developmental or intellectual disabilities in  
2 the State prior to the convening of the regular session of 2026.

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

5 SECTION 5. This Act shall take effect on July 1, 2024.

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INTRODUCED BY:



# S.B. NO. 2051

**Report Title:**

State Council on Developmental Disabilities; Developmental Disabilities; Intellectual Disabilities; Health Disparities; Health Equity; Report; Appropriation; Expenditure Ceiling

**Description:**

Requires the State Council on Developmental Disabilities to collect data and submit to the Legislature a report focused on the health disparities experienced by individuals with intellectual or developmental disabilities in the State prior to the convening of the Regular Session of 2026. Makes an appropriation.

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