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. The State'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 little information on quality of life, health care access, and 15 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. 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 the State 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 to yield
- 13 much needed results to help guide the future of public health
- 14 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

Ţ	stakeholder action, and shall submit a report to the legislature		
2	no later	than tw	wenty days prior to the convening of the regular
3	session o	f 2027.	The report shall include:
4	(1)	A defi	nition of the State's intellectual or
5		develo	opmental disability population for public health
6		admini	stration purposes, including the health
7		condit	tions, duration, and level of severity required
8		to qua	alify for disability status;
9	(2)	A defi	nition of the social determinants of health as
10		used b	y the United States Department of Health and
11		Human	Services;
12	(3)	Popula	tion-level differences in the State between
13		indivi	duals with and without intellectual or
14		develo	pmental disabilities on health indicators and
15		social	determinants of health, including:
16		(A) A	access to necessary health care;
17		(B) A	access to preventive health care, including
18		М	vellness programs and emotional support services;
19		(C) H	lealth behaviors, including the percentage of
20		i	ndividuals who engage in physical activities or
21		S	moke cigarettes;

1		(D)	mealth 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)	Fact	ors contributing to the population-level
21		diff	erences, 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	developme	ntal 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 the purposes of this Act:
12	"Hea	lth disparities" means population-level differences in
13	health ou	tcomes that are related to a history of social,
14	economic,	or environmental disadvantages that are avoidable and
15	not prima:	rily caused by underlying health conditions that led to
16	the disab	ility.
17	"Inte	ellectual 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	intellect	ual, behavioral, and emotional development and impacts
21	how indiv	iduals experience the world around them.

1	SECTION 3. There is appropriated out of the general
2	revenues of the State of Hawaii the sum of \$ or so
3	much thereof as may be necessary for fiscal year 2025-2026 and
4	the same sum or so much thereof as may be necessary for fiscal
5	year 2026-2027 for the state council on developmental
6	disabilities to collect comprehensive data and compile and
7	submit to the legislature a report focused on the health
8	disparities experienced by individuals with developmental or
9	intellectual disabilities in the State prior to the convening of
10	the regular session of 2027.
11	The sums appropriated shall be expended by the department
12	of health for the purposes of this Act.
13	SECTION 4. This Act shall take effect on July 1, 2025.
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	JAN 2 1 2025

Report Title:

SCDD; Developmental Disabilities; Intellectual Disabilities; Health Disparities; Health Equity; Report; Appropriations

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 2027. Appropriates funds.

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