

DISABILITY AND COMMUNICATION ACCESS BOARD

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March 19, 2025

TESTIMONY TO THE HOUSE COMMITTEE ON HEALTH

Senate Bill 850 SD2 – Relating to Disability Health Disparity

The Disability and Communication Access Board (DCAB) supports Senate Bill 850 SD2 – Relating to Disability Health Disparity. This bill would require 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, and appropriates funds. Effective 12/31/2050. (SD2)

Individuals with intellectual and developmental disabilities often experience significant barriers to health care, leading to preventable health conditions and deteriorating well-being. Limited access to medical professionals who understand the unique needs of individuals with disabilities, lack of appropriate accommodations, and challenges in navigating the health care system all contribute to these disparities.

Access to health care is essential for individuals with disabilities to live healthy and fulfilling lives. Identifying gaps in services and barriers to care will help determine where resources should be allocated to improve access. A comprehensive report on health disparities would provide the necessary data to guide policies and funding decisions, ensuring that individuals with intellectual or developmental disabilities receive the medical care and support they need.

Senate Bill 850 SD2 would initiate the collection of critical data that will inform efforts to improve access to health care for individuals with disabilities.

Thank you for considering our position.

Respectfully submitted,

KIRBY L. SHAW
Executive Director



UNIVERSITY OF HAWAII SYSTEM

‘ŌNAEHANA KULANUI O HAWAII

Legislative Testimony

Hō'ike Mana'o I Mua O Ka 'Aha'ōlelo

Testimony Presented Before the
House Committee on Health
Wednesday, March 19, 2025 at 9:05 a.m.

By

Jack Barile, Associate Dean for Research and Director of the
Social Science Research Institute

Denise Konan, Dean
College of Social Sciences

And

Michael Bruno, Provost
University of Hawai'i at Mānoa

SB 850 SD2 – RELATING TO DISABILITY HEALTH DISPARITY

Chair Takayama, Vice Chair Keohokapu-Lee Loy, and Members of the Committee:

The University of Hawai'i (UH) **strongly supports** SB 850 SD2. People with intellectual and developmental disabilities (IDD) are a large population group that experiences substantial health disparities. At the same time, there is very limited existing data about their health outcomes and social determinants of health, especially for Hawai'i. This leads to gaps in research, health care, and policy that result in preventable suffering and hardship for people with IDD.

We particularly support the focus of the bill on generating baseline population estimates, such as prevalence rates of IDD. From the existing, but mostly outdated national prevalence estimates, we can infer that Hawai'i's IDD population is much higher than the about 3,000 individuals that are registered with the Hawai'i State Department of Health's Developmental Disabilities Division. Realistic estimates of the true IDD population in Hawai'i could be anywhere between 20,000 and 50,000 persons or even higher. State agencies, healthcare providers, and researchers cannot serve this community if we do not even know how many people are affected. We, therefore, commend the bill's focus on collecting data about people who are not presently connected to services.

In addition, the bill contains a provision to collect data to facilitate better emergency preparedness. It is well known that the disability community is disproportionately vulnerable in disaster situations. In the context of the State's efforts to improve disaster preparedness after the devastating 2023 Maui wildfires, this is a critical component to inform policy planning and strengthen community resilience.

UH's UHealthy Hawai'i program, the College of Social Sciences Health Policy Initiative, and the University of Hawai'i Economic Research Organization (UHERO), in

collaboration with community partners, are among the many UH stakeholders that are committed to addressing health disparities in Hawai'i. We believe that the report commissioned by SB 850 SD2 is urgently necessary. Preliminary estimates from the UHERO Rapid Survey (UHERO RS) suggest that disability is an even larger risk factor for adverse health outcomes and lack of access to healthcare than other social determinants such as low income, race or rurality. Since the UHERO RS is a general population survey, it cannot provide specific data on people with IDD. But national research indicates that the IDD population is particularly vulnerable. For example, people with intellectual disabilities were eight times more likely to die from Covid than the general population. Studies have also estimated that the average life expectancy for people with autism, an IDD, is as low as 36, and they are four times more likely to die by suicide. The IDD community deserves more dedicated research to improve wellbeing and indeed save lives.

To be able to do research in this area, more and better data on health disparities for people with IDD is needed. Currently there is no suitable data source on IDD and health disparities in Hawai'i. Almost all existing data sources, whether they are research, government or non-governmental surveys, do not ask people about IDD, making it impossible to track health disparities for this group. In the Hawai'i context, we also lack sub-state data that would allow us to identify differences across the islands. Further, none of the existing data sources provide appropriate information on access and barriers to health care. People with IDD face barriers that are specific to this group, such as sensory and social communication challenges. Existing data does not cover these IDD-specific issues. Investment in dedicated data collection is also necessary, because specific accessibility features are required to reach the IDD community. The report commissioned by this bill can address many of these critical data gaps. The data infrastructure set up to produce the commissioned report will also serve future data collection and community needs monitoring efforts.

Thank you for the opportunity to provide testimony in support of SB 850 SD2.



**STATE OF HAWAII
KA MOKU'ĀINA O HAWAII
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES
'A'UNIKE MOKU'ĀPUNI NO KA NĀ KĀWAI KULA
PRINCESS VICTORIA KAMĀMALU BUILDING
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543**

March 19, 2025

The Honorable Representative Gregg Takayama, Chair
House Committee on Health
The Thirty-Third Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Takayama, and Committee Members:

SUBJECT: SB850 SD2 Relating to Disability Health Disparity

The Hawai'i State Council on Developmental Disabilities **strongly supports SB850 SD2**, which 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. Effective 12/31/2050. (SD2)

SB850 SD2 is an essential step in addressing the persistent healthcare disparities experienced by individuals with intellectual and developmental disabilities (I/DD) in Hawai'i. Research shows that individuals with I/DD face significant disparities in healthcare, often resulting in delayed or unmet medical needs. National data indicates that individuals with disabilities are **four times more likely** to experience these barriers compared to those without disabilities. Despite this, **Hawai'i lacks the necessary local data** to fully grasp the extent of these challenges, making it difficult to implement policies that ensure equal access to healthcare.

Currently, data is primarily available for the **3,000–4,000 individuals** enrolled in the Medicaid waiver program, leaving a much larger population—estimated at over **20,000 individuals**—with unmet or undocumented healthcare needs. Other states that have conducted similar studies, such as North Carolina and Montana, have uncovered significant gaps in care, including misdiagnoses and underdiagnosed chronic conditions. For example, research has shown that adults with developmental disabilities are **more likely to have diabetes** but **less likely to receive an arthritis diagnosis**, suggesting underdiagnosis and

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inadequate care for certain conditions. Without comprehensive data, we cannot identify or address these systemic barriers in Hawai'i.

By passing this measure, the state will take a critical step toward achieving health equity for individuals with I/DD. This study will provide the necessary information to inform policy decisions, improve healthcare outcomes, and ensure that all individuals—regardless of disability status—receive the care and support they deserve.

Thank you for the opportunity to submit testimony in **strong support of SB850 SD2.**

Sincerely,



Daintry Bartoldus
Executive Administrator



STATE OF HAWAII
OFFICE OF WELLNESS AND RESILIENCE
KE KE'ENA KŪPA'A MAULI OLA
OFFICE OF THE GOVERNOR
415 S.BERETANIA ST. #415
HONOLULU, HAWAII 96813

**Testimony in SUPPORT of S.B. 850 SD2
RELATING TO DISABILITY HEALTH DISPARITY**

Representative Gregg Takayama, Chair
Representative Sue Keohokapu-Loy, Vice Chair
House Committee on Health

March 19, 2025, at 9:05 a.m., Room Number 329

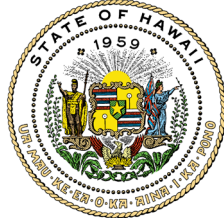
The Office of Wellness and Resilience (OWR), housed in the Office of the Governor, **SUPPORTS** S.B. 850 SD2, Relating to Disability Health Disparity. The bill provides an important opportunity to better understand the needs and challenges of individuals with intellectual or developmental disabilities (I/DD) in our communities.

In early 2024, in partnership with the Health Policy Initiative at the University of Hawai'i, OWR conducted the Hawai'i Quality of Life and Workplace Wellness Survey. More than 10,000 residents statewide responded, providing the State with an in-depth look at pressing social, economic and health issues affecting our communities. The survey data, which can be disaggregated down to specific zip codes using the Hawai'i Well-Being and Quality of Life Dashboard, now serves as an important tool to guide funding and decision-making for community organizations, policymakers, State agencies, and many others to help improve our local quality of life.

One of the challenges that the Office faced with the Hawai'i Quality of Life and Workplace Wellness Survey was collecting enough survey data from the I/DD individuals in our communities to be meaningful in the data analysis phase. We understand that Hawai'i has minimal to no local data on people with I/DD, so this measure would be an important first step to changing this reality. Further, by housing the data collection and analysis in the State Council on Developmental Disabilities, an agency that impactfully advocates for I/DD community through lived experience and expertise, S.B. 850 SD2 provides a critical opportunity to provide helpful insights into the I/DD community's strengths, as well as the health disparities that individuals living with I/DD face.

Mahalo nui loa for the opportunity to testify on this important issue.

Tia L. R. Hartsock, MSW, MSCJA
Director, Office of Wellness and Resilience
Office of the Governor



JOSH GREEN, M.D.
GOVERNOR OF HAWAII
KE KIA'ĀINA O KA MOKU'ĀINA 'O HAWAII

KENNETH FINK, MD, MGA, MPH
DIRECTOR OF HEALTH
KA LUNA HO'OKELE

**STATE OF HAWAII
DEPARTMENT OF HEALTH
KA 'OIHANA OLAKINO
EXECUTIVE OFFICE ON AGING**
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**Testimony in SUPPORT of SB850 SD2
RELATING TO DISABILITY HEALTH DISPARITY**

COMMITTEE ON HEALTH
REPRESENTATIVE GREGG TAKAYAMA, CHAIR
REPRESENTATIVE SUE KEOHOKAPU-LEE LOY, VICE CHAIR

Testimony of Caroline Cadirao
Director, Executive Office on Aging
Attached Agency to the Department of Health

Hearing: Wednesday, March 19, 2025, at 9:05 A.M. in Conference Room 329

EOA Position: The Executive Office on Aging (EOA), an attached agency to the Department of Health (DOH) **supports SB850 SD2.**

Fiscal Implications: Appropriates funds for fiscal year 2025-2026 and the same sum for fiscal year 2026-2027 to State Council on Developmental Disabilities (DD).

Purpose and Justification: This measure appropriates funds to and requires the State Council on DD to collect data on the health disparities of individuals with intellectual or developmental disabilities and submit a report to the Legislature with recommendations and proposals for State legislation and policies that would reduce these health disparities.

Individuals with intellectual or developmental (ID/DD) disabilities face many health challenges as they age including multiple chronic health conditions, vision and/or hearing

sensory impairments, limited mobility, and poor oral health. Social determinants of health, including access to healthcare, family supports, and environmental conditions also effects their health. However, more data is needed to better understand the needs of individuals with ID/DD as they age and to identify what services would best support and improve their lives. This report can provide EOA with valuable insight and help to identify areas of improvement.

Recommendation: EOA supports this measure and defers to the State Council on DD for its implementation.

Thank you for the opportunity to testify.

SB-850-SD-2

Submitted on: 3/14/2025 3:31:46 PM

Testimony for HLT on 3/19/2025 9:05:00 AM

Submitted By	Organization	Testifier Position	Testify
Hawaii Self Advocacy Advisory Council	Hawaii Self-Advocacy Advisory Council	Support	Written Testimony Only

Comments:

The Hawaii Self-Advocacy Advisory council supports SB850 SD2.

SB-850-SD-2

Submitted on: 3/14/2025 6:34:12 PM

Testimony for HLT on 3/19/2025 9:05:00 AM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	Hawaii Disability Rights Center	Support	Remotely Via Zoom

Comments:

We support this bill. We certainly know anecdotally that individuals with intellectual or developmental disabilities have worse health conditions and worse outcomes than the general population. What is particularly concerning is the finding on page three that there is a huge gap between the numbers of such individuals and those that are served by the Medicaid waiver. We believe that reflects many systemic shortcomings in the implementation of the waiver by both the Department of Health and the Department of Human Services. While we hope that the results of this study will provide useful information in a variety of contexts, we would also urge the Legislature to work with the Departments to make the necessary changes to the Waiver sooner than later.



March 17, 2025

HAWAII HOUSE COMMITTEE ON HEALTH

Representative Gregg Takayama, Chair

Representative Sue L. Keohokapu-Lee Loy, Vice Chair

Representatives Terez Amato, Jenna Takenouchi, Cory M. Chun, David Alcos III, Lisa Marten, Diamond Garcia, and Ikaika Olds, Committee Members

RE: SB 850 RELATING TO DISABILITY HEALTH DISPARITY – SUPPORT

Dear Chair Takayama, Vice Chair Keohokapu-Lee Loy, and Committee Members,

I am submitting this letter in support of SB 850 on behalf of Easterseals Hawaii. Easterseals Hawaii served 2,025 Hawaii community members with intellectual and developmental disabilities (I/DD) in 2024. Our purpose is to create a more equitable world where people with I/DD can choose their own path.

SB 850 aims to address the health disparities experienced by individuals with I/DD as compared to the rest of the population. Research shows that individuals with I/DD experience significantly higher rates of poor overall health, chronic conditions, poor oral health, preventable deaths, and more.¹ Such alarming disparities warrant further research into the causes and contributors of these health disparities with the goal of identifying solutions.

Easterseals Hawaii supports SB 850 and respectfully requests your “aye” vote.

Mahalo for the opportunity to submit this letter.

A handwritten signature in black ink, appearing to read "Rachel Liebert Lewis".

Rachel Liebert Lewis

Director, Public Policy and Advocacy

Easterseals Hawaii

PublicPolicyAndAdvocacy@eshawaii.org

¹ <https://jamanetwork.com/journals/jama-health-forum/fullarticle/2821686>

SB-850-SD-2

Submitted on: 3/14/2025 3:20:16 PM

Testimony for HLT on 3/19/2025 9:05:00 AM

Submitted By	Organization	Testifier Position	Testify
Jessie L Gonsalves	Individual	Support	Written Testimony Only

Comments:

SB850 SD2 is a bill that gives money to the DD council to do a study for people with disabilities to have equal access to health care.

SB-850-SD-2

Submitted on: 3/17/2025 2:27:18 PM

Testimony for HLT on 3/19/2025 9:05:00 AM

Submitted By	Organization	Testifier Position	Testify
Annette Mente	Individual	Support	Written Testimony Only

Comments:

Thank you Chair Takayama and Committee members for hearing this critically needed bill to collect data on the diverse I/DD population in the state. It will help target limited resources to priority groups . Please vote in support for its passage.

SB-850-SD-2

Submitted on: 3/17/2025 3:55:32 PM

Testimony for HLT on 3/19/2025 9:05:00 AM

Submitted By	Organization	Testifier Position	Testify
James Labrie	Individual	Support	In Person

Comments:

I am in strong support of SB850 SD2 to help collect data for people with disabilities to access health care services in order for them to stay healthy.

SB-850-SD-2

Submitted on: 3/17/2025 6:47:52 PM

Testimony for HLT on 3/19/2025 9:05:00 AM

Submitted By	Organization	Testifier Position	Testify
Jonathan Niau	Individual	Support	Written Testimony Only

Comments:

Thank you for this opportunity to provide testimony in support of SB850.

I am from Kekaha, Kauai and I recently graduated from Waimea High School. Last year I had to go to Oahu, because I needed healthcare that I couldn't get on Kaua'i. SB850 provides money to study health disparities across Hawai'i. Once we find these disparities, we can work on making sure everyone has access to the healthcare that they need. Maybe in the future, with the help of SB850, kids from Kaua'i will be able to get all the healthcare they need at home.

I support SB850. Thank you