

STATE OF HAWAII OFFICE OF WELLNESS AND RESILIENCE KE KE'ENA KÜPA'A MAULI OLA OFFICE OF THE GOVERNOR 415 S.BERETANIA ST. #415 HONOLULU, HAWAII 98813

Testimony in SUPPORT of S.B. 850 SD2 HD1 RELATING TO DISABILITY HEALTH DISPARITY

Representative Kyle Yamashita, Chair Representative Jenna Takenouchi, Vice Chair House Committee on Finance

April 1, 2025, at 2:00 p.m., Room Number 308

The Office of Wellness and Resilience (OWR), housed in the Office of the Governor, **SUPPORTS** S.B. 850 SD2 HD1, 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 OWR 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 HD1 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



STATE OF HAWAI'I KA MOKU'ĀINA O HAWAI'I STATE COUNCIL ON DEVELOPMENTAL DISABILITIES 'A'UNIKE MOKU'ĀPUNI NO KA NĀ KĀWAI KULA

PRINCESS VICTORIA KAMĀMALU BUILDING 1010 RICHARDS STREET, Room 122 HONOLULU, HAWAI'I 96813 TELEPHONE: (808) 586-8100 FAX: (808) 586-7543

April 1, 2025

The Honorable Representative Kyle T. Yamashita, Chair House Committee on Finance
The Thirty-Third Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Yamashita, and Committee Members:

SUBJECT: SB850 SD2 HD1 Relating to Disability Health Disparity

The Hawai'i State Council on Developmental Disabilities **STRONGLY SUPPORTS SB850 SD2 HD1**, 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 7/1/3000. (HD1)

SB850 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**

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diabetes but less likely to receive an arthritis diagnosis, suggesting underdiagnosis and 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 HD1.**

Sincerely,

Daintry Bartoldus

Executive Administrator

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

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



STATE OF HAWAI'I DEPARTMENT OF HEALTH KA 'OIHANA OLAKINO EXECUTIVE OFFICE ON AGING

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Testimony in SUPPORT of SB850 SD2, HD1 RELATING TO DISABILITY HEALTH DISPARITY

COMMITTEE ON FINANCE REP. KYLE T. YAMASHITA, CHAIR REP. JENNA TAKENOUCHI, VICE CHAIR

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

Hearing: Tuesday, April 1, 2025, at 2:00 P.M. in Conference Room 308

EOA Position: The Executive Office on Aging (EOA), an attached agency to the Department of Health (DOH) **supports SB850 SD2, HD1**.

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 requires, and appropriates funds for the State Council on DD to study health disparities experienced by individuals with intellectual or developmental disabilities and collect data to inform the State's public health policies and practices.

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 affects 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.

Testimony Presented Before the House Committee on Finance Wednesday, April 1, 2025 at 2:00 p.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 HD1 - RELATING TO DISABILITY HEALTH DISPARITY

Chair Yamashita, Vice Chair Takenouchi, and Members of the Committee:

The University of Hawai'i (UH) **strongly supports** SB 850 SD 2 HD1. 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 Hawaiʻi's IDD population is much higher than the about 3,000 individuals that are registered with the Hawaiʻi State Department of Health's Developmental Disabilities Division. Realistic estimates of the true IDD population in Hawaiʻi 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 SB850 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 HD1.



DISABILITY AND COMMUNICATION ACCESS BOARD

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April 1, 2025

TESTIMONY TO THE HOUSE COMMITTEE ON FINANCE

Senate Bill 850 SD2 HD1 – Relating to Disability Health Disparity

The Disability and Communication Access Board (DCAB) supports Senate Bill 850 SD2 HD1 – 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. Appropriates funds. Effective 7/1/3000. (HD1)

Individuals with intellectual or 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 HD1 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

SB-850-HD-1

Submitted on: 3/31/2025 8:34:08 AM

Testimony for FIN on 4/1/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
James Kilgore	Full Life	Support	Written Testimony Only

Comments:

Dear Chair Yamashita, Vice Chair Takenouchi, and members of the Committee on Finance:

My name is Jim Kilgore and I am the executive director at Full Life, a nonprofit organization supporting people with disabilities on Hawai'i Island.

Full Life strongly supports SB850 SD2 HD1, which requires data to be collected and reported on health disparities for people with intellectual and Developmental Disabilities (I/DD) in the state. There are an estimated 22,000 people with I/DD in Hawai'i. Collecting this data is important to address the lack of healthcare resources and services on neighboring islands. This data is also essential to evaluate and inform public health initiatives.

Mahalo for the opportunity to testify in support of SB850 SD2 HD1.