



UNIVERSITY OF HAWAII SYSTEM

‘ŌNAEHANA KULANUI O HAWAII

Legislative Testimony

Hō'ike Mana'o I Mua O Ka 'Aha'ōlelo

Testimony Presented Before the
Senate Committee on Ways and Means
Wednesday, February 19, 2025 at 10:02 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 SD1 – RELATING TO DISABILITY HEALTH DISPARITY

Chair Dela Cruz, Vice Chair Moriwaki, and Members of the Committee:

The University of Hawai'i (UH) **strongly supports** SB 850 SD1. 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 From the existing, but mostly outdated national prevalence estimates, we can infer that Hawai'i's IDD population is much higher than the about 3,000 individuals that are registered with the Hawaii 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 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 SD1.



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 SD1
RELATING TO DISABILITY HEALTH DISPARITY**

Representative Donovan Dela Cruz, Chair
Representative Sharon Moriwaki, Vice Chair
Senate Committee on Ways and Means

February 19, 2025, at 10:02 a.m., Room Number 211

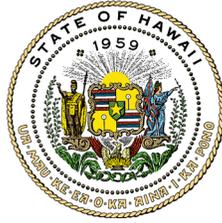
The Office of Wellness and Resilience (OWR), housed in the Office of the Governor, **SUPPORTS** S.B. 850 SD1, Relating to Disability Health Disparity. The bill provides an important opportunity to better understand the needs and challenges of individuals with intellectual or developmental disabilities (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 SD1 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
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**Testimony in SUPPORT of SB850 SD1
RELATING TO DISABILITY HEALTH DISPARITY**

COMMITTEE ON WAYS AND MEANS
SENATOR DONOVAN M. DELA CRUZ, CHAIR
SENATOR SHARON Y. MORIWAKI, VICE CHAIR

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

Hearing: Wednesday, February 19, 2025, at 10:02 A.M. in Conference Room 211

- 1 **EOA Position:** The Executive Office on Aging (EOA), an attached agency to the Department of
- 2 Health (DOH) **supports SB850.**
- 3 **Fiscal Implications:** Appropriates funds for fiscal year 2025-2026 and the same sum for fiscal
- 4 year 2026-2027 to State Council on Developmental Disabilities.
- 5 **Purpose and Justification:** This measure appropriates funds to the State Council on
- 6 Developmental Disabilities to collect data and submit a report to the Legislature on the health
- 7 disparities of individuals with intellectual or developmental disabilities. Individuals with
- 8 intellectual or developmental (ID/DD) disabilities face many health challenges as they age
- 9 including multiple chronic health conditions, vision and/or hearing sensory impairments, limited
- 10 mobility, and poor oral health. Social determinants of health, including access to healthcare,

1 family supports, and environmental conditions also effects their health. However, more data is
2 needed to better understand the needs of individuals with ID/DD as they age and to identify
3 what services would best support and improve their lives. Additionally, the report can help the
4 State develop strategies to promote preventative health care messaging specifically designed for
5 individuals with ID/DD. EOA recognizes the need for more data and information on the health
6 disparities and social determinants of health impacting individuals with ID/DD.

7 **Recommendation:** EOA supports SB850 SD1 and defers to the State Council on DD for its
8 implementation.

9 Thank you for the opportunity to testify.



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
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February 19, 2025

The Honorable Senator Donovan M. Dela Cruz, Chair
Senate Committee on Ways and Means
The Thirty-Third Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Senator Dela Cruz, and Committee Members:

SUBJECT: SB850 SD1 Relating to Disability Health Disparity

The Hawai'i State Council on Developmental Disabilities **strongly supports SB850 SD1**, which mandates the collection and reporting of data on health disparities experienced by individuals with intellectual or developmental disabilities (I/DD) in our state. This measure is a critical step toward ensuring equitable healthcare access and quality for a historically underserved population.

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 alarming trend, **Hawai'i lacks local data** to fully understand and address the scope of these disparities. The misconception that disability equates to illness has historically led to insufficient attention to the healthcare needs of this community.

By conducting this study, Hawai'i can begin closing these gaps. While we have extensive data on the **3,000–4,000 individuals** served through the Medicaid waiver program, **at least 20,000 more individuals** with developmental disabilities remain largely unaccounted for in our state's healthcare landscape. Without this data, we cannot adequately identify or address their healthcare needs.

Other states, such as North Carolina and Montana, have undertaken similar studies, uncovering significant deficiencies in their healthcare systems. 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 inadequate care for certain conditions.

By passing SB850 SD1, Hawai'i will finally have the local data necessary to inform policy decisions, address systemic barriers, and fulfill our mandate to serve individuals with developmental

disabilities. The study, estimated to require \$500,000 over two years, is a vital investment in health equity and inclusive public policy.

Thank you for the opportunity to submit testimony in **STRONG SUPPORT of SB850 SD1.**

Sincerely,



Daintry Bartoldus, Executive Administrator



DISABILITY AND COMMUNICATION ACCESS BOARD

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Ph. (808) 586-8121 (V) • Fax (808) 586-8129 • (808) 204-2466 (VP)

February 19, 2025

LATE

TESTIMONY TO THE SENATE COMMITTEE ON WAYS AND MEANS

Senate Bill 850 SD1– Relating to Disability Health Disparity

The Disability and Communication Access Board (DCAB) supports Senate Bill 850 SD1 – 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.

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 SD1 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-SD-1

Submitted on: 2/14/2025 5:28:01 PM

Testimony for WAM on 2/19/2025 10:02:00 AM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	Testifying for Hawaii Disability Rights Center	Support	Written Testimony Only

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.

SB-850-SD-1

Submitted on: 2/18/2025 9:19:08 AM

Testimony for WAM on 2/19/2025 10:02:00 AM

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

Comments:

The Hawaii Self-Advocacy Advisory Council supports SB850 SD1.

SB-850-SD-1

Submitted on: 2/18/2025 7:53:34 AM

Testimony for WAM on 2/19/2025 10:02:00 AM

Submitted By	Organization	Testifier Position	Testify
Leilani Kailiawa	Individual	Support	Written Testimony Only

Comments:

Dear Senator Dela Cruz and Committee Members

As a parent of child with disabilities and a community leader, I strongly support SB 850 SD1.

By passing SB2051, Hawai'i will finally have the local data necessary to inform policy decisions, address systemic barriers, and fulfill our mandate to serve individuals with developmental disabilities. The study, estimated to require \$500,000 over two years, is a vital investment in health equity and inclusive public policy.

With gratitude,

Leilani Kailiawa

SB-850-SD-1

Submitted on: 2/16/2025 9:24:44 PM

Testimony for WAM on 2/19/2025 10:02:00 AM

Submitted By	Organization	Testifier Position	Testify
Ruth Love	Individual	Support	Written Testimony Only

Comments:

Makes sense to gather data on the disabilities including developmental, so that future needs and assistance, if any, can be addressed with factual data instead of guesstimates.

Thank you

Mrs Ruth Love

SB-850-SD-1

Submitted on: 2/18/2025 10:00:08 AM

Testimony for WAM on 2/19/2025 10:02:00 AM

Submitted By	Organization	Testifier Position	Testify
Kaili Swan	Individual	Support	Written Testimony Only

Comments:

I am in strong support of the measure because people with disability need affordable healthcare to take care of the need that affects the population of the people with developmental and intellectual disabilities. This bill is important because they deserve equal access to healthcare just like everybody else in Hawai'i. Having access to more medical data can help people in the community with making sure they have their medical needs met. Please pass this bill. Thank you.

LATE

SB-850-SD-1

Submitted on: 2/18/2025 4:02:49 PM

Testimony for WAM on 2/19/2025 10:02:00 AM

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

Comments:

Full Life Strongly supports SB850 SD1, which mandates the collection and reporting of data on health disparities experienced by individuals with intellectual and developmental disabilities in our state. This local data is needed to inform policy decisions, address systems barriers, and ensure access to important and life-saving services for people with I/DD.