

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

KENNETH FINK, MD, MGA, MPH
DIRECTOR OF HEALTH
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DEPARTMENT OF HEALTH
KA 'OIHANA OLAKINO
EXECUTIVE OFFICE ON AGING**
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**Testimony in SUPPORT of SB850
RELATING TO DISABILITY HEALTH DISPARITY**

COMMITTEE ON HEALTH AND HUMAN SERVICES
SENATOR JOY A. SAN BUENAVENTURA, CHAIR
SENATOR HENRY J.C. AQUINO, VICE CHAIR

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

Hearing: Wednesday, February 12, 2025, at 1:00 P.M. in Conference Room 225

- 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,

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

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

9 Thank you for the opportunity to testify.



DISABILITY AND COMMUNICATION ACCESS BOARD

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February 12, 2025

TESTIMONY TO THE SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Senate Bill 850 – Relating to Disability Health Disparity

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



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
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February 12, 2025

The Honorable Senator Joy A. San Buenaventura, Chair
Senate Committee on Health and Human Services
The Thirty-Third Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Senator Buenaventura, and Committee Members:

SUBJECT: SB850 Relating to Disability Health Disparity

The Hawai'i State Council on Developmental Disabilities **strongly supports SB850**, 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.

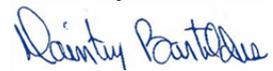
Other states, such as North Carolina and Montana, have undertaken similar studies, uncovering significant deficiencies in their healthcare systems. For example, research has shown that adults with developmental disabilities are **more likely to have diabetes** but **less likely to receive an arthritis diagnosis**, suggesting underdiagnosis and inadequate care for certain conditions.

By passing SB850, 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**.

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

Senator Joy San Buenaventura, Chair
Senator Henery Aquino, Vice Chair
Senate Committee on Health and Human Services

February 12th, 2025, at 1:00 p.m. Room Number: 225

The Office of Wellness and Resilience (OWR) in the Governor's Office **SUPPORTS** S.B. 850, 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 broken down to zip code level, can serve as an important tool to guide the 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 survey data from the I/DD individuals in our community. We understand that Hawai'i has minimal to no local data on people with I/DD, so this measure would be the first step in filling in some of those blanks. By housing the data collection and analysis and in the State Council on Developmental Disabilities, an agency that impactfully advocates for I/DD community through lived expertise, S.B. 850 provides an important opportunity to provide helpful insight into the health disparities that individuals with I/DD face.

Thank you for the opportunity to testify on this important issue.

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

SB-850

Submitted on: 2/10/2025 9:03:12 PM

Testimony for HHS on 2/12/2025 1:00:00 PM

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

Submitted on: 2/10/2025 12:28:26 PM

Testimony for HHS on 2/12/2025 1:00:00 PM

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

Comments:

Dear Chair San Buenaventura and the Senate Committee on Health and Human Services:

Full Life strongly supports SB850, which requires the collection and reporting of data on health disparities experienced by individuals with intellectual and developmental disabilities. We believe this data is necessary to ensure access to important and life-saving services for people with I/DD and their families.

Mahalo for the opportunity to testify in support of SB850

Jim Kilgore

Executive Director, Full Life

LATE

SB-850

Submitted on: 2/11/2025 1:28:38 PM

Testimony for HHS on 2/12/2025 1:00:00 PM

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 is in support of SB850 as there is no baseline data to support any health disparities for people with disabilities. People with disabilities should be able to access and have the same rights as any other citizen to healthcare.

SB-850

Submitted on: 2/11/2025 9:49:37 AM

Testimony for HHS on 2/12/2025 1:00:00 PM

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

Comments:

Aloha!

I am in strong support of SB850.

With gratitude

Leilani Kailawa

SB-850

Submitted on: 2/11/2025 12:39:10 PM

Testimony for HHS on 2/12/2025 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Ellen Awai	Individual	Support	Written Testimony Only

Comments:

I support SB850. Having been labeled 40 years this is needed to help others recognize that professionals don't know your child as well as you do and sometimes just spending more time in their infant years can make a huge difference in their lifetime!

LATE

SB850 – RELATING TO DISABILITY HEALTH DISPARITY

Aloha Chair San Buenaventura, Vice Chair Aquino and Members of the Committee:

My name is Daniela Bond-Smith. I wish to express my strong support for SB850. I am a person with a developmental disability (autism), a parent to two young children with developmental disabilities, and I am a research faculty member at the University of Hawai'i Economic Research Organization. My testimony is submitted as an individual and not as a representative of the University of Hawai'i.

Our community urgently needs this bill. As explained in the bill's preamble, we currently do not even have reliable information about how many people with intellectual and developmental disabilities (IDDs) live in Hawai'i. The currently used estimate of 22,000 people with IDD in the state is based on data from 1994/95 and according to more recent research, it is a substantial undercount. Taking into account more recent estimates for other states, we should expect at least 35,000 individuals with IDD in Hawai'i, but it could even be 50,000+. Not having reliable population estimates undermines policy development, service evaluation and health research, and this bill is vital for establishing this much-needed baseline.

Based on limited data from other states/countries and anecdotal local evidence, we know that people with IDDs are disproportionately affected by health disparities and inadequate access to care. I can personally attest to that. For example, at an appointment for a physical check-up with a new GP, I told them that I am autistic. They noted it down and offered me nothing: no checking in on the many common co-occurring conditions that autistic people have. I had to request the specific tests that I wanted to get the care that I needed. Because I happen to have a basic understanding of the relevant health literature through my work, I could successfully advocate for myself. But most people would not have such specialist knowledge. Getting adequate healthcare should not hinge on self-advocacy. In addition, there is a wide range of other barriers to healthcare access, e.g. lack of sensory accommodations, difficulties with transport to appointments, lack of information and materials in plain language, ableism and disregard of people's lived experience, etc. This is not only the fault of individuals, but it is a systemic lack of awareness and prioritization of people with IDDs in the healthcare system.

These systemic gaps are particularly serious with regard to mental healthcare. Three-quarters of autistic children have co-occurring mental health conditions and they are 28 times more likely to consider suicide. Suicide is the second largest cause of death for autistic adults. The life expectancy of people with autism has been estimated to be as low as 36. I worry about my kids as they grow up and the many other people in our community who are suffering.

We need data that documents the alarming health disparities that our community experiences and what drives them, so we have the evidence that allows us to advocate for and work towards change. This data does currently not exist, even though people with IDDs are a large population group. Especially in a political climate of great uncertainty for many marginalized populations with the new federal administration, it is important that the Hawai'i Legislature takes a stance at this time and makes it clear that the health and lives of people with IDDs matter.

Mahalo for your consideration
Dr. Daniela Bond-Smith