



LATE

STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
February 14, 2024

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

Dear Senator San Buenaventura and Committee Members:

SUBJECT: SB2051 RELATING TO DISABILITY HEALTH DISPARITY

The Hawaii State Council on Developmental Disabilities **STRONGLY SUPPORTS SB2051**, 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 2026. Makes an appropriation.

The collection of data and submission of a report focusing on health disparities experienced by individuals with intellectual or developmental disabilities are critical steps in addressing the systemic barriers to healthcare access and quality faced by our community members. Federal studies have shown that individuals with Intellectual/Developmental Disabilities (I/DD) disproportionately suffer disparities in healthcare, often resulting in unmet or delayed necessary care. Individuals with disabilities are four times more likely to experience unmet/delayed necessary care than people without disabilities¹. However, there is currently no local data on the possibly unmet medical needs of individuals with disabilities in Hawaii. This gap may exist because disability was previously presumed equivalent to illness, leading to misconceptions and inadequate attention to healthcare needs.¹

This study would also play a key role in helping our State Council fulfill our duties as a state agency serving all people in Hawai'i with a developmental disability. To our knowledge, there is little to no data on people with developmental disabilities in our state. While there is a three to four thousand group of people that are served under the Medicaid waiver program that we know a lot about. There are (based on federal statistics and prevalence rates) at least another 20,000 people with developmental disabilities that we know nothing about in our state. This study would begin to chip away and help us locate where and what issues this gap group of people are facing within our state.

[1] Krahn, Gloria L., et al. "Persons With Disabilities as an Unrecognized Health Disparity Population." *American Journal of Public Health* 105 (2015): S198-S206.

[2] Haverkamp, Susan M., et al. "Health Disparities among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina." *Public Health Reports* 119, no. 4 (2004): 418-26. JSTOR.]

States like North Carolina and Montana have conducted similar studies and identified significant deficiencies in their healthcare systems. For instance adults with developmental disabilities were found significantly more likely to have diabetes but were much less likely to have a diagnosis of arthritis, indicating underdiagnosis of certain conditions in this population.²

SB2051 will ensure that Hawaii has local data that can inform our state of the kinds of barriers people with intellectual or developmental disabilities face in our health systems and help identify the population we are mandated to serve. This will enable policymakers and stakeholders to develop targeted interventions and policies to address these disparities effectively.

A study of this magnitude would require \$500,000 and two years to be completed.

Thank you for the opportunity to submit testimony in **strong support of SB2051**.

Sincerely,

Daintry Bartoldus
Executive Administrator

2024 Hawaii Leadership Board

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Community Advocate

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Companies*

Caroline Witherspoon
*President
Becker Communications*

LJ R. Duenas
*Executive Director
Alzheimer's Association*

Testimony to the Senate Committee on Health and Human Services Thursday, February 14, 2024; 1:00 p.m. Hawaii State Capitol, Conference Room 225, and Videoconference

RE: SENATE BILL NO. 2051 – RELATING TO DISABILITY HEALTH DISPARITY

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

I am Ron Shimabuku, Director of Public Policy and Advocacy for the Alzheimer's Association. We testify in SUPPORT of Senate Bill No. 2051.

The Alzheimer's Association was established to assist those facing Alzheimer's disease and other dementias by providing local support groups and educational resources while advancing crucial research and public policy initiatives.

Alzheimer's disease is a public health crisis across the country. In Hawaii, approximately 29,000 individuals aged 65 and older live with Alzheimer's disease. This figure is projected to increase to over 35,000 by next year. In 2022, 60,000 family caregivers provided 91 million hours of unpaid care valued at \$1.9 billion.

The bill, as received by your Committee, would mandate the Hawaii State Council on Developmental Disabilities to submit to the legislature before the Regular Session of 2026, a report focused on the health disparities experienced by persons experiencing intellectual or developmental disabilities in Hawaii.

The Alzheimer's Association would like to point out the nexus that exists between individuals with Down syndrome and Alzheimer's disease. Recent studies have shown that of the number of adults with Down syndrome, 10-25% of individuals aged 40-49, 20-50% of individuals aged 50-59, and 60-75% of individuals older than 60 have Alzheimer's disease.

This bill is critical to ensure that the most vulnerable and minority communities in Hawaii have the proper information and resources necessary to receive care. We are hopeful and encouraged that the data collected is an impetus to address the disparities and barriers to care for individuals living with cognitive impairments as well.

We ask you to pass Senate Bill No. 2473.

Mahalo for the opportunity to testify. If you have questions, please contact Ron Shimabuku at 808.451.3410 or rkshimabuku@alz.org.



Ron Shimabuku
Director, Public Policy and Advocacy
Alzheimer's Association – Hawaii

LATE



Apoākea
INFINITE REACH
**NATIVE HAWAIIAN
INNOVATION
INSTITUTE**
EIN# 83-2973746

Senate Bill no. 2051
Wednesday, February 14, 2024 - 1:00pm
State Capitol, Conference Room 225

Aloha nō e Chair San Buenaventura, Vice Chair Aquino, and Members of the Senate Committee on Health & Human Services:

‘Apoākea (literally meaning “Infinite Reach”) Native Hawaiian Innovation Institute [ANHII] is a Native Hawaiian-led 501(c)(3) non-profit organization founded with the purpose of providing strategic and tactical solutions to issues causing & contributing to the negative consequences of disproportionality & disparity as they are suffered by socially disadvantaged & underserved communities that include, but are not limited to: Native Hawaiians and individuals with intellectual/developmental disabilities (ID/D) & their families. Our work is heavily focused on addressing gap areas in resources, services, and programs impacting individuals with intellectual/developmental disabilities & their families.

In our personal and professional experience and expertise in working with Native Hawaiians and individuals with intellectual/developmental disabilities & their families, we have determined that the lack of critical and adequate data impedes any progress made toward reducing and eliminating the disparities for individuals living with I/DD. This lack of data and understanding of the community also creates a further disconnect between culture and the way diagnosis and services are delivered. ‘Apoākea firmly believes that culturally appropriate resources, services, and programs would have a profound impact on their quality of life.

To further convey the community need, we offer this data on Autism Spectrum Disorder (ASD) from a national research study on the Department of Education: "*When compared to other children with ASD, African American children are under-identified approximately 50% of the time, whereas children from Asian, Hispanic, Native Hawaiian, and two or more ethnic backgrounds are under-identified approximately 99% of the time.*" Consider that majority of the State population is comprised of Native Hawaiians and persons with two or more ethnic backgrounds. Our current local resources, services, and programs for identifying, diagnosing, and treating Autism Spectrum Disorder (ASD) are severely inadequate. This is just one of many intellectual/developmental disabilities which require data.

Provided with critical data which portrays a more accurate picture of our communities needs, the State and other stakeholders would be positioned to make better informed decisions and appropriations for the ID/D community. ‘Apoākea appreciates the opportunity to provide testimony in **STRONG SUPPORT** of this measure and individuals with intellectual/developmental disabilities.

Me ka mahalo piha,

Brandi-Lynn Makalani Kupau Hyden
Executive Director

SB-2051

Submitted on: 2/12/2024 2:35:12 PM

Testimony for HHS on 2/14/2024 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Kaili	Individual	Support	Remotely Via Zoom

Comments:

i am in strong support of this bill beacuse health is very inportent for people with disabiliitty.

SB-2051

Submitted on: 2/13/2024 12:05:34 PM

Testimony for HHS on 2/14/2024 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Daniela Bond-Smith	Individual	Support	Written Testimony Only

Comments:

SB2051 – RELATING TO DISABILITY HEALTH DISPARITY

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

I wish to express my strong support for SB2051. I am a person with a developmental disability (Autism), a parent to two young children with developmental disabilities, and a data scientist and disability and public health researcher at the University of Hawai‘i at Mānoa. In this testimony, I am primarily speaking to you from a personal perspective.

Our community urgently needs this bill. As explained in the 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 IDDs in the state is based on data from 1994/95 and according to more recent research, it is wildly unrealistic. 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 easily 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.

There is a dearth of systematic efforts to collect data about health disparities affecting people with IDDs. I am an extremely privileged person. I have access to private health insurance and for better or worse, I can largely mask my Autistic traits to minimize discrimination that people with IDDs are routinely exposed to. As a disability and public health researcher, I also know how healthcare system works and what I am entitled to. Nonetheless, even someone as privileged as me regularly ends up with inadequate care. 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 and symptoms 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 medical literature through my job, I could successfully advocate for myself. But most people would not have such specialist knowledge. In addition, social communication, especially with an unfamiliar person, is often really hard for people with IDDs. Getting adequate healthcare should not hinge on self-advocacy, especially since that is also precisely one of the things that our disabilities often make difficult or impossible. 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 our lived experience, etc. This is not only

the fault of individuals, but it is a systemic lack of awareness and prioritization of people with IDD 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 immensely 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 IDD are a large population group. However, there is political momentum for change. In September 2023, the National Institutes of Health officially declared people with disabilities as a population with health disparities. It is important that the Hawai'i Legislature takes a stance at this time and makes it clear that our community may no longer be overlooked. As I mentioned before, I am an extremely privileged person. I worry a lot about other members of our community who do not have the same level of economic means and capacity for self-advocacy. Their lives and their health matter.

Mahalo for your consideration

Dr. Daniela Bond-Smith

LATE

SB-2051

Submitted on: 2/14/2024 9:00:25 AM

Testimony for HHS on 2/14/2024 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Chachie Abara	Individual	Support	Written Testimony Only

Comments:

I support the SB2051 bill.

LATE

SB-2051

Submitted on: 2/14/2024 10:54:52 AM

Testimony for HHS on 2/14/2024 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Zosimo A Arista	Individual	Support	Written Testimony Only

Comments:

I am in support of SB2051