



**SB755 SD1**  
RELATING TO DISABILITY HEALTH DISPARITY  
Senate Committee on Ways and Means

February 28, 2023

10:00 AM

Room 211

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The Office of Hawaiian Affairs (OHA) **STRONGLY SUPPORTS** SB755 SD1, which would require the State Council on Developmental Disabilities to study health disparities experienced by individuals with developmental or intellectual disabilities in the State in order to help in providing culturally appropriate health care, address barriers to health care access, reduce health disparities, and to support individuals with developmental or intellectual disabilities live healthy lives in the community.

**One of the greatest fears that a parent can have, will always be for the health, safety, and well-being of their children. For a parent with a child with a disability, that fear can become crushingly debilitating in the face of seemingly insurmountable barriers that they must overcome – barriers that disparately impact their financial stability, personal health, and overall quality of life. Most importantly, for our people with developmental or intellectual disabilities, our extra aloha (our love), care, and support will always be needed because of the vulnerabilities they have and the greater challenges they face. Ua ola loko i ke aloha.**

OHA wishes to emphasize that all individuals with disabilities are deserving of and require our extra care and attention. As the principal public agency in the State responsible for the performance, development, and coordination of programs and activities relating to Native Hawaiians,<sup>1</sup> OHA takes care to note that at least 11.2% of Native Hawaiian and Pacific Islander children experience at least one developmental disability, with almost one-third of these children experiencing more than one. Almost half of these families are low income with an annual household income less than 200% of the federal poverty level. Children with developmental disabilities are more likely to have a health issue.<sup>2</sup>

OHA appreciates the opportunity to voice its support on this measure and respectfully asks the Legislature to **PASS SB755 SD1**. Mahalo nui loa.

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<sup>1</sup> HRS §10-3.

<sup>2</sup> Thomas Elliott, Kortney Floyd James, Karen Coleman, *Cross-sectional Comparison of Disparities by Race Using White vs Hispanic as Reference Among Children and Youths With Developmental Disabilities Referred for Speech Therapy*, Oct. 4, 2022, available at <https://jamanetwork.com/journals/jamanetworkopen/article-abstract/2797027>.



**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 28, 2023

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

Dear Senator Dela Cruz and Committee Members:

**SUBJECT: SB755 SD1 RELATING TO DISABILITY HEALTH DISPARITY.**

The Hawaii State Council on Developmental Disabilities **STRONGLY SUPPORTS SB755 SD1**, which requires the State Council on Developmental Disabilities to submit a report focused on the health disparities experienced by individuals with developmental or intellectual disabilities in the State to the Legislature prior to the convening of the Regular Session of 2025. Appropriates funds. Takes effect 12/31/2050. (SD1)

Federal studies show that people with Intellectual/Developmental Disabilities (I/DD) disproportionately suffer disparities in healthcare, with medical needs often being met too late to be effective or not met at all. The Disability and Health Journal reports that people with disabilities were four times more likely to experience unmet/delayed necessary care than people without disabilities. However, there is no data on possibly unmet medical needs of those with disabilities here in Hawai'i. This gap may exist because, as mentioned by the Oregon study on disability health disparity, "Until recently, disability was presumed equivalent to illness, and it elicited all the associations of dependence, lack of productivity, and physical and sexual inactivity that are incumbent to the notion of illness." A people-focused approach to disability health care is relatively new, and Hawai'i must be one of the states at the forefront of this approach. Understanding the needs of those living in this state is an important step.

Other states, such as North Carolina and Montana, have conducted studies to identify I/DD health disparity and found massive deficiencies in their healthcare system. The study in North Carolina found that adults with developmental disabilities were significantly more likely to have diabetes, in accordance with federal findings, but were much less likely to have a diagnosis of arthritis. Indicating that in North Carolina arthritis and chronic pain were underdiagnosed in people with developmental disabilities.

SB755 will ensure that Hawai'i has local data that can inform our state of the kinds of barriers people with intellectual or developmental disabilities face in our health systems. Thank you for the opportunity to submit testimony in **support of SB755 SD1**.

Sincerely,

Daintry Bartoldus  
Executive Administrator



**LATE**

## DISABILITY AND COMMUNICATION ACCESS BOARD

1010 Richards Street, Room 118 • Honolulu, Hawaii 96813  
Ph. (808) 586-8121 (V) • TTY (808) 586-8162 • Fax (808) 586-8129

February 28, 2023

### TESTIMONY TO THE SENATE COMMITTEE ON WAYS AND MEANS

#### Senate Bill 755 Senate Draft 1 – Relating to Disability Health Disparity

The Disability and Communication Access Board (DCAB) supports Senate Bill 755 Senate Draft 1 – Relating to Disability Health Disparity. This bill would require the State Council on Developmental Disabilities to submit a report on health disparities experienced by individuals with intellectual or developmental disabilities in Hawaii.

There is no doubt that on average, individuals with intellectual or developmental disabilities experience health disparities. This often results in a vicious cycle, where the disparity leads to deteriorating health and additional disabilities.

A report on the health disparities experienced by individuals with intellectual or developmental disabilities will assist in identifying where resources should be directed to support and improve their quality of life.

Thank you for the opportunity to provide testimony.

Respectfully submitted,

KIRBY L. SHAW  
Executive Director



**UNIVERSITY OF HAWAII SYSTEM**  
**‘ŌNAEHANA KULANUI O HAWAII**

**LATE**

Legislative Testimony  
Hō'ike Mana'o I Mua O Ka 'Aha'ōlelo

Testimony Presented Before the  
Senate Committee on Ways and Means  
Tuesday, February 28, 2023 at 10:00 a.m.

By

Denise Eby Konan, Dean  
College of Social Sciences

And

Michael Bruno, Provost  
University of Hawai'i at Mānoa

**SB 755 SD1 – RELATING TO DISABILITY HEALTH DISPARITY**

Chair Dela Cruz, Vice Chair Keith-Agaran, and Members of the Committee:

The College of Social Sciences (CSS) strongly supports the intent of SB 755 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 detailed health indicators 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.

The University of Hawai'i's UHealthy Hawai'i program, the CSS Health Policy Initiative and the UHERO health research group, in collaboration with community partners, are committed to addressing health disparities in Hawai'i. In response to the critical gap for ongoing, real-time data about health outcomes, healthcare access and socioeconomic outcomes, UHERO launched its "Rapid Data Architecture for Evidence-Driven Health Policy in Hawaii" project last year. It is designed to deploy quickly and efficiently, collecting data on health outcomes, healthcare access, and socioeconomic impacts for the general population. The project also includes extensive work on developing innovative, community-centered data collection strategies that are required for reaching the most vulnerable population groups.

In addition to such existing efforts dedicated to identifying health disparities among vulnerable population groups in general, investment into a targeted effort focusing on people with IDD, as commissioned by SB 755 SD1, is urgently needed. For example, people with intellectual disabilities were 8 times more likely to die from Covid than the general population. 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 existing fragmented data indicates that this population is particularly vulnerable and deserves more dedicated research to improve wellbeing and indeed save lives.

To enable 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 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, such as plain language and Easy Read versions of survey questionnaires, are required to reach a representative cross-section of the IDD community. The report commissioned by this bill can address many of these critical data gaps.

We particularly support the focus of the bill on measuring population-level differences between individuals with and without IDD to quantify disparities. Because of the extensive data gaps in this area, we also want to highlight the importance of generating fundamental estimates, such as prevalence rates of IDD by zip code as mentioned in the bill. From national prevalence estimates we know 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, 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. It is therefore important that the bill includes collecting data on people who are not presently connected to services. Finally, we hope that the data infrastructure set up to produce the report will serve future data collection and community needs monitoring efforts.

Thank you for the opportunity to provide testimony in support of SB 755 SD1.

**SB-755-SD-1**

Submitted on: 2/26/2023 8:23:49 PM

Testimony for WAM on 2/28/2023 10:00:00 AM

<b>Submitted By</b>	<b>Organization</b>	<b>Testifier Position</b>	<b>Testify</b>
Daniela Bond-Smith	Individual	Support	Written Testimony Only

Comments:

Aloha Chair Dela Cruz, Vice Chair Keith-Agaran and Members of the Committee:

I wish to express my strong support for SB755 SD1. 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 speaking to you from a personal perspective.

Our community urgently needs this bill. There is a dearth of systematic efforts to collect data about health disparities affecting people with intellectual and developmental disabilities (IDD). 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 IDD 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 proceeded to tell them that I have severe gut microbiome dysbiosis that drastically limits the range of foods that I can eat without incurring very debilitating symptoms. Again nothing. I told them that I had not been able to eat a single piece of fruit or vegetable in more than a year; and they still did not offer me any laboratory testing to check on how my body functions with such prolonged nutritional gaps. 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 IDD. Getting adequate healthcare should not depend on self-advocacy, especially since that is also precisely one of the things that our disabilities often make difficult or impossible.

This anecdote does not describe an anomaly. I saw a pediatric psychologist specialized in Autism with my son to get some advice on calming strategies that might work for him. They suggested using the Calm app, a mental health app for adults that is completely inaccessible for a 5-year old Autistic kid. Many healthcare providers, even those that are (supposedly) specialized in IDD, lack an understanding of our disabilities. 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.

This is 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 celebrated my 37th birthday last December and I got there with the help of my family and to a large extent, sheer luck. But I worry immensely about my kids as they grow up and the many other people in our community who are suffering.

Finally, people with IDD are also a large population group. We do not have reliable numbers about the size of the IDD population because robust, up-to-date data does not exist. But extrapolating from recent prevalence estimates among Autistic children, there may be as many people with Autism in Hawai'i as people living in Hilo. And that is only Autism, not even counting the other IDDs.

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. 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-755-SD-1**

Submitted on: 2/27/2023 9:54:13 AM

Testimony for WAM on 2/28/2023 10:00:00 AM

<b>Submitted By</b>	<b>Organization</b>	<b>Testifier Position</b>	<b>Testify</b>
Linda Elento	Individual	Comments	Written Testimony Only

Comments:

Aloha Chair Dela Cruz, Vice Chair Keith-Agaran, and Memers of the Senate Committee on Ways and Means,

Disparities in health and educational services begin at birth or prenatally. For instance, speech and language therapy have been limited due to a misbelief that an individual with Down syndrome has intellectual disabilities and cannot benefit from speech therapy. An individual who is not able to speak due to a disability may not be able to express pain or need, or may be judged as not being able to understand.

Our state needs to access the latest research and treatments being developed internationally.

This bill may be more effective by--

1. specifying all ages of individuals with developmental disabilities,
2. addressing undiagnosed individuals,
3. including legal requirements such as the ADA Title II effective communication and Child Find of the IDEA,
4. require the Department of Education, State Public Charter School Commission, and Department of Health Early Intervention Services to collect or provide data compliant with privacy laws,
5. involve parents and caregivers.

Thank you for the opportunity to provide comments.