

STATE OF HAWAI'I STATE COUNCIL ON DEVELOPMENTAL DISABILITIES 1010 RICHARDS STREET, Room 122 HONOLULU, HAWAI'I 96813 TELEPHONE: (808) 586-8100 FAX: (808) 586-7543 March 17, 2023

The Honorable Representative Della Au Belatti, Chair House Committee on Health & Homelessness The Thirty-Second Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Representative Belatti and Committee Members:

SUBJECT: SB755 SD2 RELATING TO DISABILITY HEALTH DISPARITY.

The Hawaii State Council on Developmental Disabilities **STRONGLY SUPPORTS SB755 SD2**, which requires the State Council on Developmental Disabilities to submit a report focused on the health disparities experienced by persons in the State having developmental or intellectual disabilities to the Legislature prior to the convening of the Regular Session of 2025.

We respectfully request that \$500,000 be inserted as the cost of this study.

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. Thank you for the opportunity to submit testimony in **strong support of SB755 SD2**.

Sincerely, Daintry Bartoldus Executive Administrator



# **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

March 17, 2023

## TESTIMONY TO THE HOUSE COMMITTEE ON HEALTH AND HOMELESSNESS

Senate Bill 755 SD2 – Relating to Disability Health Disparity

The Disability and Communication Access Board (DCAB) supports Senate Bill 755 SD2 – Relating to Disability Health Disparity. This bill would require the State Council on Developmental Disabilities to submit a report focused on the health disparities experienced by persons in the State having developmental or intellectual disabilities to the Legislature prior to the convening of the Regular Session of 2025.

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

'ŌNAEHANA KULANUI O HAWAI'I

Legislative Testimony Hōʻike Manaʻo I Mua O Ka ʻAhaʻōlelo

> Testimony Presented Before the House Committee on Health and Homelessness Friday, March 17, 2023 at 9:00 a.m. By Denise Eby Konan, Dean College of Social Sciences And Michael Bruno, Provost University of Hawai'i at Mānoa

SB 755 SD2 – RELATING TO DISABILITY HEALTH DISPARITY

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

The College of Social Sciences (CSS) strongly supports the intent of SB 755 SD2. 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 SD2, 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 SD2.



#### SB755 SD2 RELATING TO DISABILITY HEALTH DISPARITY Senate Committee on Ways and Means

March 17, 2023	9:00 AM	Room 329

The Office of Hawaiian Affairs (OHA) **STRONGLY SUPPORTS** SB755 SD2, 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 SD2**. Mahalo nui loa.

<sup>&</sup>lt;sup>1</sup> HRS **∫**10-3.

<sup>&</sup>lt;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.

<u>SB-755-SD-2</u> Submitted on: 3/15/2023 3:56:02 PM Testimony for HLT on 3/17/2023 9:00:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Louis Erteschik	Hawaii Disability Rights Center	Support	Written Testimony Only

Comments:

In support.

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#### 2023 Hawaii Leadership Board

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Kimberly Soares Vice President Atlas Insurance

Gino Soquena Executive Director Hawaii Building and Construction Trade Council

Gordon Takaki Past President Hawaii Island Chamber of Commerce

Caroline Witherspoon President Becker Communications

LJ R. Duenas Executive Director Alzheimer's Association

# Testimony to the House Committee on Health and Homelessness Friday, March 17, 2023; 9:00 a.m. Hawaii State Capitol, Conference Room 329, and Videoconference

#### RE: Senate Bill No. 755, Senate Draft 2, RELATING TO DISABILITY HEALTH DISPARITY

Chair Della Au Belatti, Vice Chair Jenna Takenouchi, and Members of the Committee:

I am Ron Shimabuku, Director of Public Policy and Advocacy for the Alzheimer's Association. We are testifying in <u>SUPPORT of Senate Bill No. 755, Senate Draft 2</u>.

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. By 2025, this figure is projected to increase by 20.7%. In addition, many are experiencing subjective cognitive decline — one of the earliest warning signs of future dementia. In 2020, 6.7% of individuals aged 45 and over reported increased confusion or worsening memory loss, putting them at risk of later developing dementia. More than two-thirds have not talked to their healthcare professional about it.

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 2025, a report focused on the health disparities experienced by persons experiencing developmental or intellectual 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.

Given the aforementioned figures and statistics, it is important to note that there is a lack of dementia-specific data in Hawaii, particularly that of Native Hawaiians, and Pacific Islanders. As part of the Hawaii State Plan for Alzheimer's Disease and Related Dementias (ADRD) established in December 2013, Goal No. 5 seeks to improve the data collection

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process. This is critical to ensure that the most vulnerable and minority communities in Hawaii are provided with the proper information and resources necessary to receive care. We are hopeful and encouraged by this bill that the data collected is an impetus to addressing the existing disparities, and barriers to access, and improving support for individuals living with ADRD.

#### With this, we respectfully urge your favorable consideration of this bill.

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

himabuku

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



# Testimony to the House Committee on Health and Homelessness Friday, March 17, 2023; 9:00 a.m. State Capitol, Conference Room 329 Via Videoconference

### RE: SENATE BILL NO. 0755, SENATE DRAFT 2, RELATING TO DISABILITY HEALTH DISPARITY.

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

The Hawaii Primary Care Association (HPCA) is a 501(c)(3) organization established to advocate for, expand access to, and sustain high quality care through the statewide network of Community Health Centers throughout the State of Hawaii. The HPCA <u>SUPPORTS</u> Senate Bill No. 0755, Senate Draft 2, RELATING TO DISABILITY HEALTH DISPARITY.

By way of background, the HPCA represents Hawaii's Federally Qualified Health Centers (FQHCs). FQHCs provide desperately needed medical services at the frontlines to over 150,000 patients each year who live in rural and underserved communities. Long considered champions for creating a more sustainable, integrated, and wellness-oriented system of health, FQHCs provide a more efficient, more effective and more comprehensive system of healthcare.

The bill, as received by your Committee, would appropriate an unspecified amount of general funds for fiscal years 2023-2024, and 2024-2025, for the State Council on Developmental Disabilities (Council) to compile and submit a report focused on the health disparities experienced by persons in the state having developmental or intellectual disabilities. This bill would require the Council to report its findings and recommendations to the 2025 Legislature, and would take effect on December 31, 2050.

The HPCA agrees wholeheartedly with the findings issued by the Senate Committee on Ways and Means in Standing Committee Report No. 0921, to wit:

", , , Your Committee finds that the report required by this measure will help the State better understand the health disparities experienced by, and social determinants of health for, persons in the State having developmental or intellectual disabilities. This data will allow the State to identify the optional allocation of resources to support persons having developmental or intellectual [disabilities] and to improve their access to care..." Testimony on Senate Bill No. 0755, Senate Draft 2 Friday, March 17, 2023; 9:00 a.m. Page 2

### For this reason, the HPCA urges your favorable consideration of this measure.

Thank you for the opportunity to testify. Should you have any questions, please do not hesitate to contact Public Affairs and Policy Director Erik K. Abe at 536-8442, or eabe@hawaiipca.net.



March 15, 2023

House Representative Della Au Belatti, Chair House Representative Jenna Takenouchi, Vice Chair Testimony to the House Committee on Health & Homelessness Friday, March 17, 2023; 9:00 am. State Capitol, Conf. Room 329 & Videoconference

RE: Senate Bill 755 Senate Draft 2 – RELATING TO DISABILITY HEALTH DISPARITY

Aloha Chair Belatti, Vice Chair Takenouchi, and Members of the Committee:

On behalf of the Epilepsy Foundation of Hawaii (EFH), we urge your **SUPPORT of Senate Bill 755 SD2**, RELATING TO DISABILITY HEALTH DISPARITY. This bill would require the State Council on Developmental Disabilities to submit a report to the Legislature focused on the health disparities experienced by people living with developmental or intellectual disabilities in Hawaii prior to the convening of the Regular Session of 2025.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 million Americans with epilepsy and seizures. Epilepsy Foundation of Hawaii, advocates and provides services for the almost 14,000 individuals living with epilepsy throughout Hawaii. Collectively, we foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition characterized by seizures, which are sudden surges of electrical activity in the brain, that affects a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy, and approximately 1 in 10 people will experience a seizure, at some point in their lifetime.

Epilepsy is a chronic medical problem that for many people can be successfully treated. Unfortunately, treatment doesn't work for everyone. AT LEAST 1 million people in the United States have uncontrolled epilepsy, which is considered a disability by the Social Security Administration (SSA). Epilepsy is common in people with intellectual and developmental disabilities (IDD).

Adults with IDD and epilepsy (IDD-E) have neurologic, psychiatric, medical, and social challenges compounded by fragmented and limited care. Current services are often unable to adequately address the needs of this population, who face disparities in health care.

On behalf of the Epilepsy Foundation of Hawaii and our Board of Directors, we are eager to support SB755 SD 2 as it would impact and influence minimum care standards for individuals living with epilepsy and intellectual and developmental disabilities.

We humbly thank you for the opportunity to testify and urge your **SUPPORT of Senate Bill 755 SD2**.

Mahalo nui loa,

Our mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. **Please learn more about our advocacy work at epilepsy.com/advocacy.** 



Nurm Manuel

Naomi Manuel Executive Director Epilepsy Foundation of Hawaii

Our mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. Please learn more about our advocacy work at epilepsy.com/advocacy.

<u>SB-755-SD-2</u> Submitted on: 3/15/2023 4:41:14 PM Testimony for HLT on 3/17/2023 9:00:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Kaili Swan	Individual	Support	Remotely Via Zoom

Comments:

I stand in support of this SB755 SD2 because health is almost important with people with disabilities please pass this bill thank you.

Date: March 17, 2023 Committee: House Committee on Health and Homelessness Bill #: SB 755, SD2 Relating to Disability Health Disparity Testifier: Nancy S. Partika, RN, MPH

Aloha Chairperson Au Belatti, Vice-Chair Takenouchi, and Committee Members;

My name is Nancy Partika, and, as a lifelong public health professional, I wish to indicate strong support for SB 755, SD2, 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, and appropriates funds for this purpose.

In Hawaii, the intellectually/developmentally disabled (I/DD) population is diverse, less visible, and problematic to summarize. It is estimated that there are around 22,000 people who have an I/DD living on all islands and counties statewide. This estimate is based on the national prevalence of developmental disability per 100,000 residents. Persons who have an I/DD are all ages 0-90+, the range of conditions/diagnoses considered to be within the I/DD designation is wide-ranging. It includes, but is not limited to: Autism Spectrum Disorder (ASD); CHARGE syndrome; Cerebral Palsy; Epilepsy; Fetal Alcohol Spectrum Disorder (FASD); Fragile X; Down Syndrome/Trisomy 21; Intellectual Disability; Prader-Willi Syndrome; Spina Bifida; Williams Syndrome, and more.

In 2022, the HSCDD issued a community-wide online 54 question survey geared towards determining more about the health, educational and employment-related needs of Hawaii's estimated 22,000 individuals with an intellectual/developmental disability in Hawaii.

Following 11 weeks of survey-information gathering, a total of 200 survey responses were received and analyzed. Responses were received from all islands, except Lanai, and from a wide age-range. The most commonly listed diagnoses of those who responded to the survey were: Autism Spectrum Disorder/ASD (50%), Intellectual disability (46%), Cerebral palsy (13%) and Epilepsy (13%), with a number of less common diagnoses also listed.

Families were identified as being integral to care and housing, as well as case management for services. Lack of qualified and available providers is an issue statewide. Mental/emotional health appears to be a clear unmet need, particularly for those individuals with communication issues.

In response to the question "What Is your top health care need now?", the need for more/better medical management came out as the highest need (31%), followed by prevention/self-care support (23%), mental health management/support (23%), caregiving support services (20%), and dental health (8%).

Because the number of 2022 survey responses was low and represented a small percentage of the estimated population, more in-depth and accessible assessment of health care needs and disparities is warranted in order to plan for, develop and implement appropriate services for this underserved population. The study and report described in this bill will greatly assist HSCDD and other providers in the health services and support community to better serve individuals with an I/DD.

Mahalo for your thoughtful consideration of SB 755, SD2,.

#### <u>SB-755-SD-2</u>

Submitted on: 3/16/2023 9:36:59 AM Testimony for HLT on 3/17/2023 9:00:00 AM

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

Comments:

#### SB 755 SD2 – RELATING TO DISABILITY HEALTH DISPARITY

Aloha Chair Della Au Belatti, Vice Chair Takenouchi and Members of the Committee:

I wish to express my strong support for SB 755. 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. 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 selfadvocacy, 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



UNIVERSITY of HAWAI'I° Mānoa

Department of Economics and UHERO Ruben Juarez HMSA Distinguished Endowed Professor rubenj@hawaii.edu Phone: 808-956-7143

The Senate 32<sup>nd</sup> Legislature State of Hawaii

RE: Strongest Support of SB 755 SD2 -- RELATING TO DISABILITY HEALTH DISPARITY

Hearing: Wednesday, March 17, 2023

Aloha Senators,

I am Dr. Ruben Juarez, the HMSA Distinguished Endowed Professor in Health Economics at the University of Hawaii Economic Research Organization (UHERO) and Economics Department, University of Hawaii.

I am writing to provide my strongest support for SB 755 SD2.

As you know, health disparities is one of the most pressing issues facing Hawaii's populations, and these are significantly exacerbated among people with disabilities. These disparities were made even more obvious during the pandemic, where nationally, people with intellectual disability were 800% more likely to die from COVID-19 than the general population.

To enable prevention and treatment, more research is needed to understand any gaps faced by individuals with disabilities. At present, there is no reliable source for this data in the state, and we are forced to rely on national data sources, which are often not applicable to local population. Although some of our public health efforts at UHERO have been in collecting valuable data for decision makers to make informed decisions, we currently do not have the infrastructure to collect this information from people with disabilities, and we hope that SB 755 SD2 will enable this collection.

Urgent solutions are needed to better understand and address health disparities in people with disabilities and I personally believe that SB 755 SD2 is an investment to start building this infrastructure and will translate in cost-saving for the state.

I urge you to show Hawaii's commitment to addressing health disparities in people with disabilities. I ask that you vote in support of and pass SB 755 SD2.

Sincerely,

Ruben Juarez, PhD HMSA Distinguished Endowed Professor in Health Economics University of Hawaii at Manoa (Honolulu resident of Zip Code 96826)

## <u>SB-755-SD-2</u>

Submitted on: 3/16/2023 3:46:22 PM Testimony for HLT on 3/17/2023 9:00:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Susan Oka	Individual	Support	Written Testimony Only

Comments:

Dear Representative Della Au Belatti, Chair and Representative Jeanna Takenouchi, Vice Chair,

I am asking that FASD (Fetal Alchohol Spectrum Disorder) be included in this report on diparities.

Thank you,

Susan Oka