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GOVERNOR  
KE KIA'ĀINA



CATHY BETTS  
DIRECTOR  
KA LUNA HO'OKELE

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DEPUTY DIRECTOR  
KA HOPE LUNA HO'OKELE

STATE OF HAWAII  
KA MOKU'ĀINA O HAWAI'I  
**DEPARTMENT OF HUMAN SERVICES**  
KA 'OIHANA MĀLAMA LAWELAWE KANAKA  
Office of the Director  
P. O. Box 339  
Honolulu, Hawaii 96809-0339

February 14, 2023

TO: The Honorable Senator Joy A. San Buenaventura, Chair  
Senate Committee on Health & Human Services

FROM: Cathy Betts, Director

SUBJECT: **SB 755 – RELATING TO HEALTH.**

Hearing: February 15, 2023, 1:00 p.m.  
Conference Room 225 & Videoconferencing, State Capitol

**DEPARTMENT'S POSITION:** The Department of Human Services (DHS) appreciates the intent, and offers comments. DHS defers to the Department of Health and the State Council on Developmental Disabilities and respectfully requests that any appropriation does not replace or reduce priorities identified in the executive budget and Governor's Messages.

**PURPOSE:** The bill 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.

The goal of the study is to provide detailed information regarding the health and well-being of the population with intellectual or developmental disabilities living in Hawaii. DHS Med-QUEST division shares the goal of improving care and reducing disparities for this population, including the social factors that impact health that extend beyond clinic walls, known broadly as the social determinants of health. This information gained can inform

policies for individuals served by Medicaid and those served by the DHS Division of Vocational Rehabilitation.

Thank you for the opportunity to provide comments on this measure.



**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 15, 2023

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

**DRAFT:** Dear Senator Buenaventura and Committee Members:

SUBJECT: SB755 RELATING TO DISABILITY HEALTH DISPARITY.

The Hawaii State Council on Developmental Disabilities **STRONGLY SUPPORTS SB755 and requests amendments**, 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.

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 I/DD 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. This indicated that in North Carolina, arthritis and chronic pain were underdiagnosed in people with limited communication skills.

The Council is happy to conduct this study and ensure we receive helpful information regarding the health disparities faced by our I/DD community in our State. After meeting with various stakeholders, the Department of Human Services, the Developmental Disabilities Division, and UH Professors with a background in this kind of work, we recommend a few edits

to the reporting outcomes of this measure. **Due to their duplicative nature, we request removals of page 3, lines 10-20, page 4, lines 1-3, and lines 12-17.**

The lines we request to be removed are because social determinants of health cover many of these topics in a more focused and achievable manner. Social determinants of health are health outcomes related to economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context.

**Under page 4 line 9 we respectfully request you add**

**(H) Prevalence of Intellectual/developmental disabilities based on Zip-code;**

**(I) Ethnicity breakdown based on Zip-code;**

**(F) Show if people with Intellectual/developmental disabilities are having worse health outcomes than their typical non-disabled peers;**

Thank you for the opportunity to provide comments in **support of SB755.**

Sincerely,

Daintry Bartoldus  
Executive Administrator



## DISABILITY AND COMMUNICATION ACCESS BOARD

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

February 15, 2023

### TESTIMONY TO THE SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

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

The Disability and Communication Access Board (DCAB) supports Senate Bill 755 – 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

**SB-755**

Submitted on: 2/10/2023 12:36:45 PM

Testimony for HHS on 2/15/2023 1:00:00 PM

| Submitted By | Organization  | Testifier Position | Testify                |
|--------------|---|--------------------|------------------------|
| Cleota Brown | Testifying for Hawaii Fetal Alcohol Spectrum Disorders FASD Actio | Support            | Written Testimony Only |

Comments:

Dear Chair San Buenaventura and Vice Chair Aquino of the Senate Committee and Members of the Health and Human Services Committee,

**The Hawai'i Fetal Alcohol Spectrum Disorders FASD Action Group a 501 c 3 with over 200 volunteer members, strongly supports SB 755.**

We respectfully ask for SB 755 to be amended to include fetal alcohol spectrum disorders be included in this bill as a developmental and/or intellectual disability to be included in this report due in 2025.

Year after year we see our efforts to raise awareness, gain inclusion and support for FASD systems of care and diagnosis through legislation and negotiation with the State departments fall on deaf ears.

FASD affects every sector of Hawai'i's society and the costs to society are immeasurable. 94% of those affected by FASD have mental health issues; 95% cannot live independently; 80% have employment difficulties; 70% have trouble in school; 60% have trouble with the Law; 50% of adults abuse drugs and alcohol; and 45% have legal problems with sexual behaviors. These are all social determinants that can contribute and lead to homelessness and imprisonment. A major contributing factor to these statistics is many service providers and government agencies are uninformed on the complexities of FASD which lead to a missed diagnosis.

From our past experience, if FASD is not directly included in the legislation, no effort will be put towards inclusion in the future.

We support the passage of this bill with the amendment we have requested.

We appreciate the opportunity to submit legislation for SB 755.

Sincerely yours,

Cleota G. Brown, President

[Hawaii FASD Action Group](#)



**SB-755**

Submitted on: 2/13/2023 7:30:40 PM

Testimony for HHS on 2/15/2023 1:00:00 PM

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

Comments:

We are in support.

**SB-755**

Submitted on: 2/14/2023 3:41:20 PM

Testimony for HHS on 2/15/2023 1:00:00 PM

| <b>Submitted By</b> | <b>Organization</b> | <b>Testifier Position</b> | <b>Testify</b>         |
|---------------------|---------------------|---------------------------|------------------------|
| Kenichi Yabusaki    | Individual          | Support                   | Written Testimony Only |

Comments:

Dear Chairman, Vice-Chairman and Members of the Health and Human Services Committee:

I strongly support SB755 relating to Health Disparities for individuals with disabilities. All too often, the statement, "Show me the data..." is stated. Hawaii like most states have a large number of individuals with disabilities such as developmental caused by genetic parameters such as autism, spina bifida, cerebral palsy, Downs Syndrome, and the like. Disabilities caused by a teratogen, such as alcohol, namely Fetal Alcohol Spectrum Disorders ( FASD), when a fetus is exposed to the metabolites of alcohol during pregnancy is an epidemic in our societies. These conditions cause disparities (homelessness, incarceration, etc.) in access to all services. It is imperative that Hawaii address this issue by a surveillance system to bring forth data and make this a priority for Health and Human Services. People with disabilities are important members of our society and should be respected.

Sincerely,

Kenichi Yabusaki, Ph.D.

**SB-755**

Submitted on: 2/14/2023 8:50:00 AM

Testimony for HHS on 2/15/2023 1:00:00 PM

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

Comments:

i stand in support in SB755 is that people with disability can get healthcare needs their doctor and their dentest.

Date: February 15, 2023

Committee: Senate Committee on Health and Human Services

Bill #: SB 755 Relating to Disability Health Disparity

Testifier: Nancy S. Partika, RN, MPH

Aloha Chairperson San Buenaventura, Vice-Chair Aquino, and Committee Members;

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

**SB-755**

Submitted on: 2/10/2023 2:39:07 PM

Testimony for HHS on 2/15/2023 1:00:00 PM

| <b>Submitted By</b> | <b>Organization</b> | <b>Testifier Position</b> | <b>Testify</b>            |
|---------------------|---------------------|---------------------------|---------------------------|
| Kenichi Yabusaki    | Individual          | Support                   | Written Testimony<br>Only |

Comments:

Dear Members of the Health and Human Services Committee:

Please pass SB755 as it relates to health disparities for those with developmental disabilities. Please consider those affected by Fetal Alcohol Spectrum Disorders (FASD) as the number these individuals exceeds those with autism, spina bifida, cerebral palsy, and Downs Syndrome combined. If this Bill is not heard and passed, Hawaii will experience an epidemic of those in the judiciary, mental health, and homeless. We see this already, but it appears the State is in denial.

Sincerely,

Kenichi Yabusaki, Ph.D.