



# UNIVERSITY OF HAWAII SYSTEM

## ‘ŌNAEHANA KULANUI O HAWAII

### 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

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And

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### 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.