

## UNIVERSITY OF HAWAI'I SYSTEM 'ÕNAEHANA KULANUI O HAWAI'I

Legislative Testimony Hōʻike Manaʻo I Mua O Ka ʻAhaʻōlelo

Testimony Presented Before the House Committee on Health Wednesday, March 19, 2025 at 9:05 a.m. By Jack Barile, Associate Dean for Research and Director of the Social Science Research Institute Denise Konan, Dean College of Social Sciences And Michael Bruno, Provost University of Hawai'i at Mānoa

## SB 850 SD2 - RELATING TO DISABILITY HEALTH DISPARITY

Chair Takayama, Vice Chair Keohokapu-Lee Loy, and Members of the Committee:

The University of Hawai'i (UH) **strongly supports** SB 850 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 health outcomes 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.

We particularly support the focus of the bill on generating baseline population estimates, such as prevalence rates of IDD. From the existing, but mostly outdated national prevalence estimates, we can infer that Hawai'i's IDD population is much higher than the about 3,000 individuals that are registered with the Hawai'i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's 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. State agencies, healthcare providers, and researchers cannot serve this community if we do not even know how many people are affected. We, therefore, commend the bill's focus on collecting data about people who are not presently connected to services.

In addition, the bill contains a provision to collect data to facilitate better emergency preparedness. It is well known that the disability community is disproportionately vulnerable in disaster situations. In the context of the State's efforts to improve disaster preparedness after the devastating 2023 Maui wildfires, this is a critical component to inform policy planning and strengthen community resilience.

UH's UHealthy Hawai'i program, the College of Social Sciences Health Policy Initiative, and the University of Hawai'i Economic Research Organization (UHERO), in

collaboration with community partners, are among the many UH stakeholders that are committed to addressing health disparities in Hawai'i. We believe that the report commissioned by SB 850 SD2 is urgently necessary. Preliminary estimates from the UHERO Rapid Survey (UHERO RS) suggest that disability is an even larger risk factor for adverse health outcomes and lack of access to healthcare than other social determinants such as low income, race or rurality. Since the UHERO RS is a general population survey, it cannot provide specific data on people with IDD. But national research indicates that the IDD population is particularly vulnerable. For example, people with intellectual disabilities were eight times more likely to die from Covid than the general population. Studies have also estimated that 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 IDD community deserves more dedicated research to improve wellbeing and indeed save lives.

To be able to do 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 the 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 are required to reach the IDD community. The report commissioned by this bill can address many of these critical data gaps. The data infrastructure set up to produce the commissioned report will also serve future data collection and community needs monitoring efforts.

Thank you for the opportunity to provide testimony in support of SB 850 SD2.