

MARCH



**Report to the Thirty Forth Legislature**

**State of Hawaii 2023**

PURSUANT TO CHAPTER 333E-3(5) PREPARE AND  
SUBMIT REPORTS TO THE GOVERNOR, THE  
LEGISLATURE, AND ALL CONCERNED DEPARTMENT  
HEADS ON THE IMPLEMENTATION OF THE STATE PLAN

**Prepared By:**

**State of Hawaii Department of Health**

**December 2023**

# HAWAII STATE DEVELOPMENTAL DISABILITIES COUNCIL 2023 ANNUAL REPORT

## Mission Statement

The mission of the Council is to empower, advocate, and support Individuals with intellectual and developmental disabilities statewide to control their own destiny and determine the quality of life they desire.

## Vision Statement

Individuals with intellectual and developmental disabilities are equal to all persons and enjoy basic human rights, among them life, freedom, and the pursuit of happiness. They have choices about where they live, work, learn, play, pursue their spiritual beliefs, are respected and receive the supports they need.

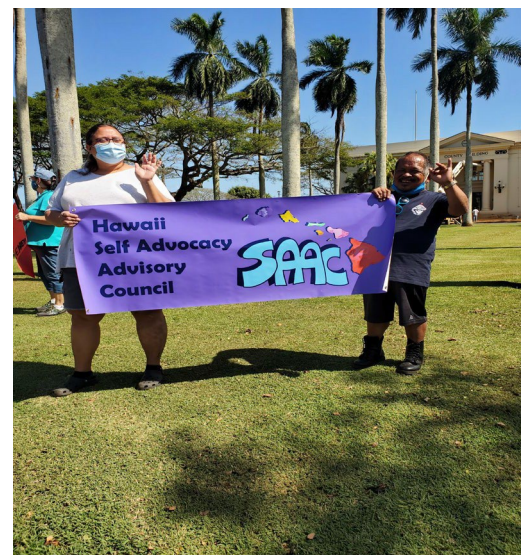
## Implementation Statement

To this end, the Council will:

- Work for self-determination
- Advocate for systems change
- Provide information education, and planning
- Serve as a Conscience/monitor of the State
- Promote best practices

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# THE COUNCIL

State Councils were established in response to the federal *Developmental Disabilities Services and Facilities Construction Act of 1970* (PL 91-517). Hawai'i's Council was established in State Law by Act 198, Session Laws of Hawai'i, in 1975.

The Council is administratively attached to the Department of Health (DoH). The department serves as the designated state agency, providing fiduciary and administrative support.

The Council engages in activities which change the system of services for people with developmental disabilities and conducts systems change, capacity building, and advocacy activities that...

- Provide training for individuals with developmental disabilities and their families including legislative advocacy, training on the legislative process, and leadership development.
- Demonstrate new approaches to services, supports, and assistance.
- Inform federal, State, and local policymakers.
- Foster interagency collaboration and coordination.
- Eliminate barriers and enhancing the design and redesign of systems.
- Develop and support coalitions.
- Educate the public
- Coordinate and support community activities that follow the Council's mission.

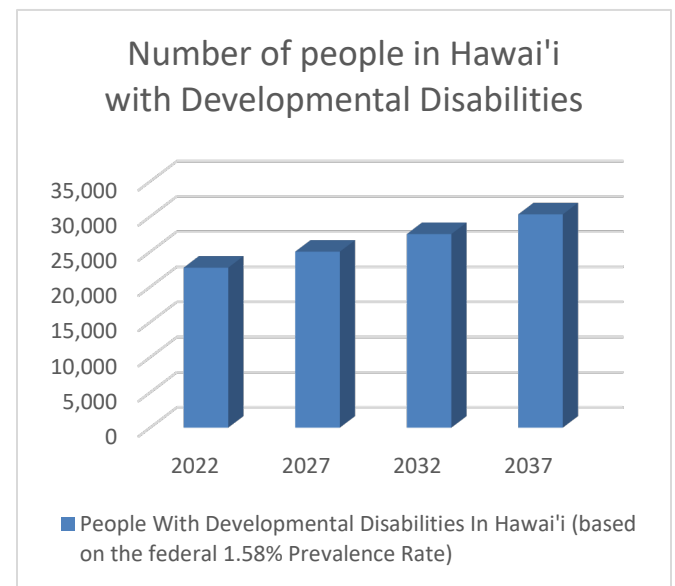
The Council, appointed by the Governor, is a group of individuals dedicated to improving the lives of Hawai'i's citizens with developmental disabilities. The philosophy of membership is that all key stakeholders are represented at the Council table: Individuals with developmental disabilities; their family members, advocates; representatives of State and private agencies who provide services; representatives of the Hawai'i Disability Rights Center (HDRC), the state's Protection and Advocacy agency; University of Hawai'i's Center on Disability Studies (CDS) and other key community interests. The beauty of this composition is in the skills and experience that each brings to the table and shares with other Council members.

# DEVELOPMENTAL DISABILITY

[from PL 106-402, Sec. 102. Definitions, (8)]

**(A) IN GENERAL.** – The term "developmental disability" means a severe, chronic disability of an individual that ---

- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments
- (ii) is manifested before the individual attains age 22
- (iii) is likely to continue indefinitely
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity
  - (I) Self-care.
  - (II) Receptive and expressive language.
  - (III) Learning.
  - (IV) Mobility.
  - (V) Self-direction.
  - (VI) Capacity for independent living.
  - (VII) Economic self-sufficiency; and
  - (VIII) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.



**(B) INFANTS AND YOUNG CHILDREN** --- An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

## The Council supported the Self-Advocacy Network in becoming a non-profit organization

The State Legislature, through Act 213, Session Laws of Hawaii 2007, appropriated funds to establish and support a statewide self-advocacy network for persons with developmental disabilities (DD). The Hawaii Self-Advocacy Advisory Council (SAAC) is a group of self-advocate leaders with intellectual and developmental disabilities who are actively engaged in their community to address the concerns and needs of their peers throughout the State.

# QUICK HIGHLIGHTS

## Legislation

- **Supported SB1340**, which makes the behavior analyst licensing requirements for certain teachers easier and allows registered behavior technicians to conduct applied behavior analysis services.
  - It will help with the shortage of registered behavior technicians in Hawai'i. This is and has been a barrier for our students with developmental disabilities.
- **Supported SB318**, which makes the Department of Health establish a 5-year pilot program to create a system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders
- **Supported HB899**, which designates September as Fetal Alcohol Spectrum Disorder Awareness (FASD) Month. Our Council was given an appropriation to spread awareness of FASD.
- **Support HB1397** created a program to make a test group of cheaper housing with support systems (addiction counseling, mental health counseling, employment assistance, etc.). Specifically, it provides support to people with intellectual/developmental disabilities.
  - Historic for Hawai'i as one of the first state-led housing projects to support individuals with developmental disabilities, specifically in an integrated setting.
- **Introduced and supported SB1151**, which makes applying for the Promise Program easier and more inclusive for students. Promise Program is additional financial aid for students attending community college.
  - Now, community colleges going for a certificate are eligible for promise program funding, which creates an easier way for students who graduate with a certificate (not a diploma) to receive this funding support.
- **Supported HB278**, which creates a campaign to spread awareness and knowledge of early symptoms of Alzheimer's disease.
  - Adults with Down Syndrome and other I/DDs are at greater risk of developing Alzheimer's than others.
- **Supported HB600**, which creates a safe Route to the School Advisory Committee. This Committee will develop a statewide plan to make routes to school safer (and more accessible). As the Council, we are named as members to be on this committee in this measure.
- **Requested SB179**, which This bill changes the "Specials Needs Advisory Committee" to the "Elections Accessibility Needs Advisory Committee". The term "special" is often offensive and

negatively used against our I/DD community. One of our Self-Advocates, Ramoda worked for this name to be changed.

- **HB794** establishes October as "Disability Awareness Month: Employment, Enrichment, and Inclusion". This is something the Council has already celebrated every year in October. This month is a time to spread awareness about disability inclusion, employment supports and outcomes for our population, and what other supports our population needs to thrive in our community. It is a good opportunity to highlight our past accomplishments in these areas.\
- **HB1440**
  - This measure regarding the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act. While this measure did not make it through the session, we, as the Council were asked to convene an informal working group to address the concerns of our community as it relates to this uniform law. The working group established by Rep. Tarnas has met four times with over 30 different agencies and community stakeholders represented.
  - The judiciary has been actively participating in the group in working towards implementing the Guardianship Uniform Law.

## Legislative Forums

- Held three legislative forums covering Kauai and Hawai'i counties in October. These forums are for the public to hear from their legislatures regarding issues that face our intellectual/developmental disability community members. We did not have a forum on Maui this year due to focusing efforts on support and recovery from the Maui Wildfires. We have added a special section in this report detailing our efforts on Maui this year.

## Legislative Briefing

- Held an informal informational briefing at the capitol. In partnership with the Alzheimer's Association, Aging and Disability Resource Center, and the Fetal Alcohol Spectrum Disorder Task force we shared our legislative priorities for the coming legislative session. We had over 50 individuals with developmental disabilities attend as well to share their legislative asks for the coming session.



## Day at the Capitol

- In March, we held our annual Day at the Capitol Event, in which our stakeholders and community members come to the capitol and participate in the legislative process. We had over 400 participants from across the State. Participants got to meet with their legislators, testify on measures, participate in a mock hearing, learn from PAR about the legislative process, and celebrate and spread awareness surrounding developmental disabilities awareness month.



## Maui Wildfires

- Designated the Unit Head for Access and Functional Needs response for the State of Hawai'i
- Created and Hosted the Disability Hui Meetings which started on 8/15/23. These weekly meetings brought together disability-related stakeholders with the Red-Cross and FEMA to coordinate for the coming week to help with the relief/recovery efforts.
- Flew two staff to Maui on 8/16/23 to assess and help with disability-related issues.
  - They connected with front-line providers.
  - Initiated Maui Disability Task Force daily meetings.
  - Assisted Red-Cross in identifying people with disabilities.
  - Coordinated a shipment of durable medical equipment.

# THE COUNCIL AREAS OF EMPHASIS

## Community Supports

- Enhancing residential placements within communities by avoiding the placement of individuals with developmental disabilities into institutions.
- Promoted collaboration with parent groups to identify residential needs throughout the State.
- Continue to work with County transportation coordinators statewide to assure bus routes are meeting the needs of individuals with developmental disabilities so they can utilize generic services to access their community.
- Educated Legislators, City and County Council members, and Mayors about transportation and housing needs of individuals with disabilities.
- Worked with Rural Health Association to assist in getting individuals intellectual and or developmental disabilities psychiatry services
- Continued to participate in the Hawai'i Housing Affordability Coalition (HiHAC)
- Developing supportive decision-making trainings
- Developing educational materials on alternative to guardianship.

## Public Awareness, Education, and Training

- Created public awareness campaign to promote Developmental Disabilities and Disability Employment Awareness month.
- Created promotional tools and spread public awareness surrounding Developmental Disabilities Month in March. We held a campaign with our self-advocates to create a theme. They came up with several themes and then voted on their top choice, the winning theme this year was "Respect others and all people with disabilities".
- Healthy Relationships. We provide trainings on sexuality and how to have healthy relationships for people with intellectual and developmental disabilities. We have six certified trainers.
  - Provided three parent trainings, two trainings to the Developmental Disabilities Division case managers, and one training to Medicaid Waiver Agencies.
  - Presented at the Leadership in Disabilities & Achievement of Hawai'i Conference
- Hosted a three-day training and certification for the National Task Group on Intellectual Disabilities and Dementia Practices



- This training better equips family members and direct service professionals on how to care for people with dementia and developmental disabilities.
- Joined the Hawai'i Islands Mayor's Committee on People with Disabilities

## Transition and Employment

- We created a pilot high school internship program through our Bridging and Aging I/DD Grant. High school students would intern at an Adult Day Health Program. We had four pilot interns across Maui and Kauai. All interns reported a desire to incorporate or work in the disability field because of the internship. Next year, this program will be statewide with more internship opportunities.
- Supported Work Now Hawaii by adding Registered Behavioral Technicians (RBT) training to their list of offered high school-to-work programs.
- Part of the National Expansion of Employment Opportunities (NEON) grant. This grant will increase employment opportunities in Hawai'i for people with disabilities and developmental disabilities.
- A part of the Association for Persons Supporting Employment First (APSE) Chapter
  - Hosted a two day training on every island to increase the skill level of direct support professionals.
  - Held the APSE Summit to discuss employment and employment training regarding people with developmental disabilities.
- Collaborated with many agencies to create activities to support students and young adults with disabilities with getting a job and earning competitive wages; such as supporting job fairs, informational venues such as Footsteps to Transition Fair, neighbor island employer outreach programs for over 200 individuals.
- Continued to share information about the creation of the Hawaii ABLE (Achieving a Better Life Experience) account program collaboration with the State of Oregon.
  - Continue to help individuals sign up for a have Hawaii ABLE savings accounts.
- Promoted Employment Awareness Month. Each county declared October to be Developmental Disabilities Employment Awareness Month and on Kauai, we honored our Employee of the Year who got to meet with Mayor Kawakami.

## Health & Children & Youth

- Continued to work on promoting universal standardized developmental screening.
- We are a part of the Fetal Alcohol Spectrum Disorder Task-Group
- Co-Chair the Kauai Community Children's Council
- We are a part of the Keiki Oral Health Coalition
- Received and implemented the Bridging and Aging Grant
  - Created the Health Sexuality trainings
  - Updated Kauai's and Hawai'i Island's Kupuna Resource Book to include people with I/DD
  - Added disability resources to the Aging and Disability Resource Center
  - Advocated to reinstate medically fragile children into the Medicaid Waiver program

## Self-Advocacy & Self-Determination

- The Council supports the Hawaii Self Advocate Advisory Council (SAAC) in maintaining over 200 members statewide.
- Supporting self-advocates to join community groups and boards
- Supported 4 self-advocates to be self-employed by being Feeling Safe Being Safe (FSBD) trainers teaching public and private agencies, offices, schools on the importance of emergency preparedness.
- Empowered Advocates to provide testimony during the legislative session
- Continue to host train the trainer events to continue our Feeling Safe Being Safe Program
- Engage 50+ self-advocates with legislators in our informal legislative briefing.
- Empowered self-advocates to co-host our legislative forums that took place in October
- Supported a self-advocate who is now on the Hawai'i County Voter Accessibility Advisory Committee

# THE COUNCIL OFFICES & CONTACT INFORMATION

## Legal Authority

State Councils were established in response to the Federal *Developmental Disabilities Services and Facilities Construction Act of 1970 (PL 91-517)*. Hawaii's Council was established in State Law by Act 198, Session Laws of Hawaii in 1975. The Council is administratively attached to the Department of Health. The Department serves as the Designated State Agency, providing fiduciary and administrative support. Although the Council operates in the state government, their federal law stipulates a non-interference law that allows the Council to maintain its autonomy, distinct independent role and responsibility

**Hawaii State Council on Developmental Disabilities Office Address:**

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**Current Council Members**

Chair: James Labrie

Vice Chair: Victoria Murry

Secretary: Michelle Muralt

Ho'opi'ookalani Balaz

Kevin Bardsley-Marcial

Bathey Fong

Cynthia D. Fowler

Melissa Gibo

Howard Greenberg

Melissa Gibo

Josh Ige

Debbie Kobayakawa

Anne M. Chipchase

Mary Brogan

Shana Metsch

Darwin Nagamine

Alana Souza

Kirko Takahashi

Reinalyn Terrado

Santo Triolo

Mark Vierra

R. Jackson Whitaker