



REPORT TO THE THIRTY- FOURTH LEGISLATURE

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

**STATE OF HAWAI'I
DEPARTMENT OF
HEALTH**

DECEMBER 2024



**HAWAI'I STATE COUNCIL ON
DEVELOPMENTAL DISABILITIES**

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HAWAII STATE DEVELOPMENTAL DISABILITIES COUNCIL 2024 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



ABOUT 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.



WHAT WE DO

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.



WHO WE ARE

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 DEFINITIONS

[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

Legislative Priorities

HB1974: Introduced & Passed

- This law raises the amount of money people in certain long-term care homes get for personal needs from \$50 to \$75 each month. It states clearly that this extra money shouldn't replace or change the funds people get from the federal Supplemental Security Income Program. It also says that certain long-term care home operators must pay for basic items like toiletries, linens, meals, and snacks. It explains who can get this extra allowance.
- The monthly allowance for personal needs goes up from \$50 to \$75 for people living in adult residential care homes, domiciliary homes, adult foster homes, and similar places.
- This increase allows individuals more freedom and dignity and increases involvement in their communities.

SB2305: Passed

- This law creates a Silver Alert Program in the Department of Law Enforcement. It helps find and keep safe older adults who are missing, have trouble thinking clearly, or have developmental disabilities.
- This program helps law enforcement quickly share information with the public, respond fast, and find older adults or those with disabilities.
- This is like the Amber Alert program, but for missing older adults.

HB2359: Passed

- This law starts the Digital Equity Grant Program. It gives grants to groups who want to do projects to help people in the state have fair access to digital technology.
- The types of projects that can get grants now include paying for internet service, Wi-Fi equipment, and other things.
- This helps people with developmental disabilities, who often use telehealth services. It makes it easier for them to get the healthcare they need.



SB3094: Passed

- This law sets up a group called the Peer Support Specialist Working Group. They will make suggestions for how to use peer support specialists in the state.
- These specialists are people who have gone through similar experiences and can help others going through tough times.
- The group's suggestions will help the state decide how to use peer support specialists better, especially for people who are often left out.

Legislative Priorities Continued...

HB2556: Not Passed

- This law is about the Hawaii ABLE Savings Program. It creates an incentive program for DoE students to open ABLE accounts.
- It also creates a job in the Council to increase awareness and use of the Hawaii ABLE savings program. This program lets people with disabilities have savings accounts like others do for things like college, healthcare, and retirement.

SSB2503: Not Passed

- This law would make it so all new public places and state buildings built after July 31, 2025, must have changing rooms that anyone can use, no matter their gender. As well as a having a powered adult changing table. This helps adults that require these tables to be able to be out in the community and still have equitable bathroom access.

HB1976: Not Passed

- This measure would give money to the Statewide Elections Accessibility Needs Advisory Committee. This committee gathers information and helps people with disabilities vote.
- This law would help people with disabilities vote by removing barriers and making the whole voting process easier for them. It encourages more people with disabilities to vote.



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.

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.



AREAS OF EMPHASIS

Transition and Community Supports

- Developed and created Supported Decision-Making Training.
- Developing educational materials on alternatives to guardianship (Rep Payee, Power of Attorney, Conservatorship)
- Providing Education on Supported Decision Making
- Providing Training on how to practice and implement Supported Decision Making
- Continuing to run the Guardianship and Conservatorship Uniform Law Working Group
- Introducing measures to improve the Guardianship/Conservatorship system
- Reviewing Transition systems from the Department of Education to the Department of Health for Adults with I/DD
- Working with the Developmental Disabilities Division to ensure the eligibility criteria for Hawai'i 1915(c) waiver.

Public Awareness, Education, & 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

Transportation Housing 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.
- Lead Agency for the National Expansion of Employment Opportunities (NEON) grant through ODEP, which is under the U.S. Department of Labor. This grant will increase employment opportunities in Hawai'i for people with disabilities and developmental disabilities. The NEON task force is currently conducting a Demonstration Project on Hawaii Island to identify barriers to services for adult job seekers with IDD.
- Attended National NEON
- Facilitated monthly meetings of DOE, DVR, CAMHD, DDD, DLIR, and CDS to continue to address employment barriers for people with disabilities and to bring policies and practices into alignment across agencies.
- Supported MOU between DDD and DVR to bring services into alignment and to facilitate increased cooperation supporting job seekers.
- Co-hosted the 2nd annual Employment First Summit for the State of Hawaii. (this may overlap the 2nd bullet under the APSE thing.) The Summit provided 3 tracks – 1. Training in Competitive Integrated Employment for professionals working with I/DD 2. Individual Placement and Support training for mental health professionals 3. Direct training for job seekers with I/DD.
- Co-wrote the grant proposal for Disability Innovation Fund (DIF)—Creating a 21st Century Workforce of Youth and Adults with Disabilities Through the Transformation of Education, Career, and Competitive Integrated Employment Model Demonstration Project, requesting \$10 mil funding to support DOE and DVR to provide additional employment supports to disconnected and justice involved youth with disabilities.
- A part of the Association for Persons Supporting Employment First (APSE) Chapter
 - Co-hosted a two day training on every island (except Maui due to the fires) to increase the skill level of direct support professionals.
 - Participated in APSE regional meetings - quarterly
- 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 with I/DD and family members.
- 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. Hawaii County Mayor's office presented the Proclamation declaring October as Disability Employment Awareness month in West Hawaii on October 19, 2023 at a ceremony honoring individuals with I/DD who are employed as well as the DSPs who support them.

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 Aging and IDD Grant.
 - 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
 - We created a mental health survey to identify the un-met needs of individuals with IDD and or dual diagnosis living in urban and rural areas of Hawaii. The survey will be sent out in the fall 2024.
 - We created a dementia care resource guide for individuals with IDD and their family members. It is currently available on our website.
 - We created an emergency form that can be downloaded from the DD Council website. It has a functional needs list on the backside, so if there is an emergency, emergency responders would be able to easily see/identify their needs. Particularly if they need to evacuate to a shelter, this will help shelter staff understand their needs.
 - We also held a Dementia Care Training put on by the National Task Group on Intellectual Disabilities and Dementia Care. It was hosted across 2 days, with a third train the trainer.
 - We continued to have the high school workforce development internship program. We had 5 interns this summer including a University of Hawai'i at Mānoa student. We are now looking at expanding the internship program to college/university programs as practicum placements.

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

DD COUNCIL OF EMPHASIS COMMITTEES

Community Supports & Transition Committee

- Holly Manaseri, Chair
- Mary Brogan (sends proxy)
- Cindy Fowler
- Josh Ige
- Alysha Kim
- James Labrie
- Raymond Mamea
- Mark Vierra

Transportation, Housing & Employment Committee

- Hoopiokalani Balaz, Chair
- Mary Brogan (sends proxy)
- Lea Dias
- Cindy Fowler
- Melissa Gibo
- Alysha Kim
- Cristina Valenzuela

Nominating Committee

Melissa Gibo, Chair

Raymond Mamea, Vice Chair

Josh Goetz

Deborah Kobayakawa

Public Awareness, Education & Training Committee

- Anne Chipchase, Chair
- Mary Brogan (sends a proxy)
- Howard Greenberg
- Brandi-Lynn Hyden
- Debbie Kobayakawa
- Alysha Kim
- James Labrie
- Alana Souza

Health & Children & Youth Committee

- Alana Souza, Chair
- Shana Metsch, Co-Chair
- Anne Chipchase
- Kevin Bardsley-Marcial
- Brandi-Lynn Hyden
- Alysha Kim
- Reinalyn Terrado
- Kiriko Takahashi
- Eden Watabayashi

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.

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