



# STATE COUNCILS ON DEVELOPMENTAL DISABILITIES (DD COUNCILS)

A guiding force for positive, life-altering change for people with intellectual and developmental disabilities (ID/DD)

To achieve the vision of the DD Act, state DD Councils use federal funding to:



# **CREATE**

partnerships, collaborations, innovative programs, and equal opportunities to improve the daily lives of people with ID/DD.



## SPARK

community change by bringing together people and partners to create equity in education, health, employment, and life.



# **EMPOWER**

self-advocates and family leaders, influence law and policy, and educate and protect people with ID/DD.



## **FDUCATE**

decision-makers using research and lived experiences to improve the lives of people with ID/DD.



or more of the members of each DD Council must be people with ID/DD or close family members. Councils are founded on the principle that those with lived experience should always be included in conversations to find and foster solutions.

#### PROUD TO BE A CATALYST FOR POSITIVE CHANGE

DD Councils' work removes barriers and increases opportunities for people with ID/DD so they can:

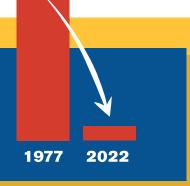
- Live and fully participate in the community
- Become leaders and self-advocates, creating their own paths and helping others
- Complete secondary (grades 6-12) and postsecondary (after grade 12) education
- Access health care to live longer, healthier lives
- Find and succeed in jobs that fit their individual interests and goals
- Stay connected and safe during emergencies
- Enjoy recreational and social activities

Their work also involves educating the public on how including people with ID/DD has a positive social and economic impact on communities.

56 STRONG

56 DD Councils across the United States and its territories are part of the DD Network — a collaborative group of organizations and advocates working to serve and empower people with ID/DD.

In 1977, **84%** of people with ID/DD lived in institutional settings. Now, it's less than **8%** — thanks in part to the work of the DD Councils and their partners. In 1999 Hawaii was one of the first state's to close their large institution.



- ➤ DD Councils helped integrated employment **grow 17%** from 2011 to 2018, and it's still a top priority. Hawaii ranks in the bottom 3 in the Nation of employing individuals with DD.²
- 2.8 million people with lived experience with ID/DD participate in DD Council activities today. 53,570 of those are participating in advocacy to create change. In Hawaii we have 22,000 individuals with I/DD.3
- 1,232 policies, procedures, statutes, and regulations were created or **changed** by DD Council efforts in one year alone, in Hawaii we created or changed 14.3



#### **MEET KAILI**

Kaili Swan is a member of the Hawaii Self-Advocacy Advisory Council and is currently a volunteer with the Hawaii State Council on Developmental Disabilities office. Thanks to the Council, he has learned how to write and speak testimony during the Hawaii State Day at the Capitol event for people with disabilities this past March 2022 legislative session.

He also provides support to the Ewa Neighborhood board, where he lives, on issues concerning disabilities. Kaili is an emergency preparedness trainer in the "Feeling Safe, Being Safe" emergency preparedness program. He teaches people with disabilities how to prepare for natural disasters by training them to document their doctors numbers, medications, and how to prepare emergency kits, meeting their neighbors to help each other during disasters, and practicing an evacuation plan to local shelters. He was invited by the Honolulu City and County emergency communication center and to the HI civil defense center in Diamond Head Crater to discuss emergency preparedness. When he isn't volunteering his time to advocate for others, he is at his part time job at the DOE.

#### **STAYING SAFE THROUGH COVID-19**

DD Councils quickly pivoted and continue to work with public and private partners to:

- Create and share accurate information in plain language and multiple languages, so people with ID/DD can make informed decisions
- Advocate to prioritize vaccines and protective equipment for people with ID/DD and those who support them
- ➤ **Uphold civil rights** guaranteed under law, such as visits by people who provide necessary support during hospitalizations and equal access to health care and education
- Ensure access to home and community-based services and technology to stay connected and informed
- ➤ Train first responders to work with people with ID/DD successfully and respectfully

We have begun to think of advocacy as more than just 'speaking up for yourself' but more of a problem-solving process to identify what you want to change in your life, the resources needed for this change, and creating the plan to make the necessary change.

A self-advocate graduate of Maine's Speaking Up For Us (SUFU) program



#### August 2022

ACL is an operating division of the U.S. Department of Health and Human Services. Learn more at ACL.gov.

Hawaii State Council is an attached agency to the DOH with a federal noninterference clause in order to keep their autonomy.

- 1 The National Residential Information System (RISP)
- 2 The National Data Collection on Day and Employment Services for People with Developmental Disabilities
- 3 DD Councils FY2020 Performance Measures, Individual and Family Advocacy (IFA) Measures