

# 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.



## EDUCATE

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



**60%** 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:

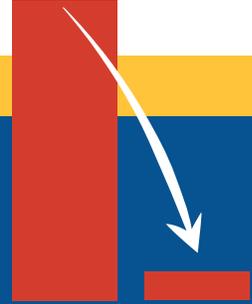
- Live — and fully participate — in the community
- Become leaders and self-advocates, creating their own paths and helping others
- Complete secondary (grades 6-12) and postsecondary (after grade 12) education
- Access health care to live longer, healthier lives
- Find and succeed in jobs that fit their 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.<sup>1</sup>



1977 2022

- DD Councils helped integrated employment **grow 17%** from 2011 to 2018, and it's still a top priority.<sup>2</sup>
- 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.<sup>3</sup>
- 1,232 policies, procedures, statutes, and regulations were created or **changed** by DD Council efforts in one year alone.<sup>3</sup>



## MEET DESI

Desi is a Wisconsin DD Council member from suburban Milwaukee. As a teen and young adult, she was told she needed the structure of working in a job specifically for people with ID/DD — jobs that pay far less than minimum wage — and living in a group home, but she felt overly controlled and disrespected in those environments.

Thanks to the Council's advocacy efforts to change expectations and expand options for employment and community living, the Department of Health Services provided the support Desi needed to find her own apartment and a job in the community. She also successfully advocated to get therapy to help her self-regulate more effectively. Desi now lives on her own, with some help managing her finances, and shops for and cooks her own healthy meals. She is taking steps to build a career in helping people find housing. She credits living independently with improving her mental and physical health.

## 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](https://www.acl.gov).

- 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