

2025



IDAHO COUNCIL ON
DEVELOPMENTAL
DISABILITIES

ANNUAL REPORT

OCTOBER 2024 –
SEPTEMBER 2025

WHO WE ARE

The Idaho Council on Developmental Disabilities was established under the Federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act, Public Law 106-402) in 1971 and in Idaho Code §67-6703 in 1978. Council members are Governor-appointed volunteers. Most members are people with intellectual or developmental disabilities (IDD) or family members.



The Council promotes the capacity of people with developmental disabilities and their families to determine, access, and direct the services and/or supports they need to live the lives they choose, and to build the community's ability to support their choices.



COUNCIL CHAIR MESSAGE

CARLY SAXE

I have enjoyed serving as the DD Council Chair for the last six months. I have gained a better understanding of how important leadership and advocacy are to our state and local community. My experience as the chair has been positive, and the skills I have gained as a result of being part of the council have been sharpened because of being in this leadership role.



Carly Saxe pictured with Sara Stover, Governor's Deputy Chief of Staff

In July of 2025, I had the opportunity to lead the DD Council's public forum in Boise at the Hillcrest Library. Most of the participants were from Gem State Developmental Center. We went over many topics, such as the need for a strong direct care workforce and access to accessible public transportation. It was good to have community members present at this event to provide feedback on the services that are so vital to their lives.

"It is important for people with developmental disabilities to lead because leading helps you contribute to your community and state. Being in a leadership role also gives you a chance to advocate for policies that affect people with disabilities across the state of Idaho. Leading also gives you a chance to visit policymakers who are a part of making the laws that affect people with disabilities."



EXECUTIVE DIRECTOR MESSAGE

CHRISTINE PISANI

In the process of preparing our next five-year plan, we spent over seven weeks traveling throughout Idaho and meeting people with intellectual and developmental disabilities (IDD), family members, service providers, policy makers, librarians, church leaders, and community members. Our time was spent listening to people through the Council's state-wide public forums, our rural needs assessments, and one-on-one interviews with adults with IDD.



Christine Pisani pictured with Erin Barrett, Salmon Public Library

Thank you to all Idahoans who invited us into their homes, shared their lived experiences, and gave us firsthand information about what was going well and where improvements are needed to current services.

A shout-out to our state libraries! I visited each library in every community I traveled to this year. I saw great examples of children and adults with disabilities being meaningfully included in integrated library activities. Each library is actively serving people with disabilities and families through its services, loaning helpful equipment, and providing training to their communities. **Thank you!**

I also learned about the lack of access to services in communities like Preston, Salmon, Hailey, Mountain Home, Glens Ferry, and Ashton. **Rural Idaho is really hurting.** While we have a statewide shortage of direct support workers that continues to grow, it is even worse for rural Idahoans. The Idaho Council on Developmental Disabilities heard you, and we see you. We are committed to doing all we can to elevate your voices to make the changes needed to improve access to services that keep people in their homes of choice, work in the community, and lead full lives, not limited by a lack of support. We also see opportunities to develop leadership in our rural communities so that the changes needed are led by people who live in these communities.

EXECUTIVE DIRECTOR MESSAGE

The staff and members of the DD Council work to seek continuous improvement in systems that touch the lives of people with IDD and their families. The Council spends the majority of our staff working hours developing and supporting leaders with IDD and family members. Last year, the Council invested \$503,615 in the education and leadership development of people with IDD and family members. The investment we have made in this leadership is demonstrated through the leadership of people with IDD serving on state and national boards, Councils, and commissions. They are creating and leading statewide and national training, developing policies and practices, and providing public comments to state and federal policies.



From all of the staff and members of the DD Council, we thank you for the opportunity to learn from you, work with you, and create a more inclusive Idaho for all of Idaho's citizens.



OUR GOALS

System Change



During each year of the plan, individuals with intellectual and developmental disabilities and family members inform and direct changes in service systems, resulting in higher quality services that better meet the needs of individuals with intellectual and developmental disabilities by 2026.

Capacity Building



By 2026, service systems have increased their capacity to provide quality services, so individuals with intellectual and developmental disabilities and family members have access to services that meet their needs and preferences.

Information & Education



By 2026, individuals with intellectual and developmental disabilities and family members have increased their knowledge and skills needed to access the services and supports they need to live meaningful lives in their communities.

Advocacy & Leadership



During each year of the plan, people with intellectual and developmental disabilities and their families are empowered to share their lived experiences and provide education and information on issues important to them, as they advocate on local, state, and/or national levels.



IDAHO PERSON-CENTERED PLANNING OUTCOMES

A priority of the Council is quality Person-Centered Planning. The Council has been working on building this skill set through the Charting the Lifecourse framework by targeting training to people with IDD, families, support brokers, targeted service coordinators, staff at Idaho Parents Unlimited, and staff at the Department of Health and Welfare.

Through our work to develop an Idaho opportunity for Spanish-speaking families and professionals, Idaho provided expertise to inform the cultural competency of the training that is now available internationally as the Charting the LifeCourse Ambassador training in Spanish.



People trained on Charting the LifeCourse

Family Members
77

Professionals
68

People with IDD
6

COMMUNITY NOW!

The KW vs. Armstrong lawsuit settlement requires the Idaho Department of Health and Welfare (IDHW) to implement specific changes in how individualized budgets are determined for Medicaid-funded developmental disability services. In 2016, the Council offered its expertise to the IDHW to focus on including individuals with intellectual and developmental disabilities (IDD) and their families in decision-making for implementing settlement.

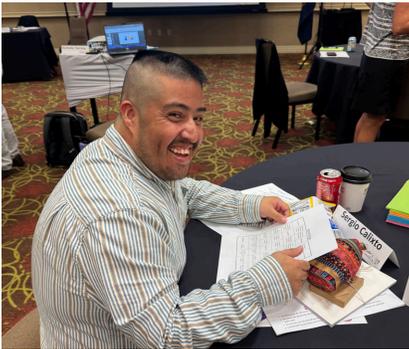
This collaboration, known as Community NOW!, emphasizes the experiences of people with IDD and family members in policy-making related to the lawsuit. It involves partnerships with IDHW, the Idaho ACLU, the Idaho Office of the Attorney General, adult developmental disability service representatives, and, **most importantly, statewide representation of people with IDD and family members** who access the range of adult developmental disability services.

Council staff supported Community NOW! by preparing members for discussions with Ruby Moore, the court-appointed Special Master for the lawsuit. Council members and Community NOW! members were able to ask questions directly to the Special Master about the KW vs Armstrong lawsuit and provide their lived experience throughout the 11-year experience with the lawsuit.



The Special Master has relied on the DD Council to meet members of the class in Idaho through the Council's statewide public forums, interviews with people with IDD, Community NOW!, and through the hundreds of people with IDD and families the Council has connections with statewide. These opportunities have given her the chance to meet people with IDD and family members and learn about how Idaho's adult developmental disability system is serving people.

The Council proudly invests in the leadership development of people with IDD and family members to lead the Community NOW! We are grateful to the exemplary leadership of our meeting leaders this year: **Larkin Seiler, Moscow; Norma Duarte, Nampa; Kevin Swearingen, Ammon; and Shiloh Blackburn, Rexburg.**



DIRECT SUPPORT WORKFORCE

Training for Home and Community Based Service (HCBS)
Direct Support Workforce

The Idaho Workforce Development Council is working with the Idaho Council on Developmental Disabilities and service providers to create an apprenticeship training program for HCBS direct support workers who work with children and adults with intellectual and developmental disabilities. The focus of the apprenticeship for the first cohort is on residential habilitation services and developmental disability agency services. The apprenticeship model is being developed by Idaho's Lewis-Clark State College with a target date of spring 2026 to launch. The web-based training, which will rely heavily on Relias training, will be hosted by the Lewis-Clark State College website.

The apprenticeship curriculum is based on the 2022 Direct Support Professionals Training and Retention Report Recommendations sponsored through the Administration on Community Living grant awarded to the Idaho Living Well project. The Idaho Council on Developmental Disabilities and the Center on Disabilities and Human Development collaborated with the Idaho Workforce Development Council and other stakeholders on the creation of an accredited apprenticeship model for direct support workers in HCBS for the developmental disability community.



MEDICAID STORYBOOK

The DD Council collaborated with the State Independent Living Council (SILC) to collect stories of Idaho Medicaid beneficiaries in our advocacy efforts for Home and Community Based Services, particularly in response to proposals to offset tax cuts with funding from Medicaid. The DD Council and the SILC worked collaboratively to cast a wide net to capture people's lived experience of Medicaid State Plan and Enhanced Medicaid services. Working together, the two Councils produced a comprehensive collection of stories of Idahoans that was provided to all Congressional delegates and their staff.

The Council also worked collaboratively with the SILC to coordinate meetings with the Idaho Congressional Delegation or their staff, ensuring that as many individuals with lived experience as possible participated in those meetings to share their concerns about the loss of Medicaid and the impact on their lives through House Resolution 1.



COLLECTING PUBLIC INPUT

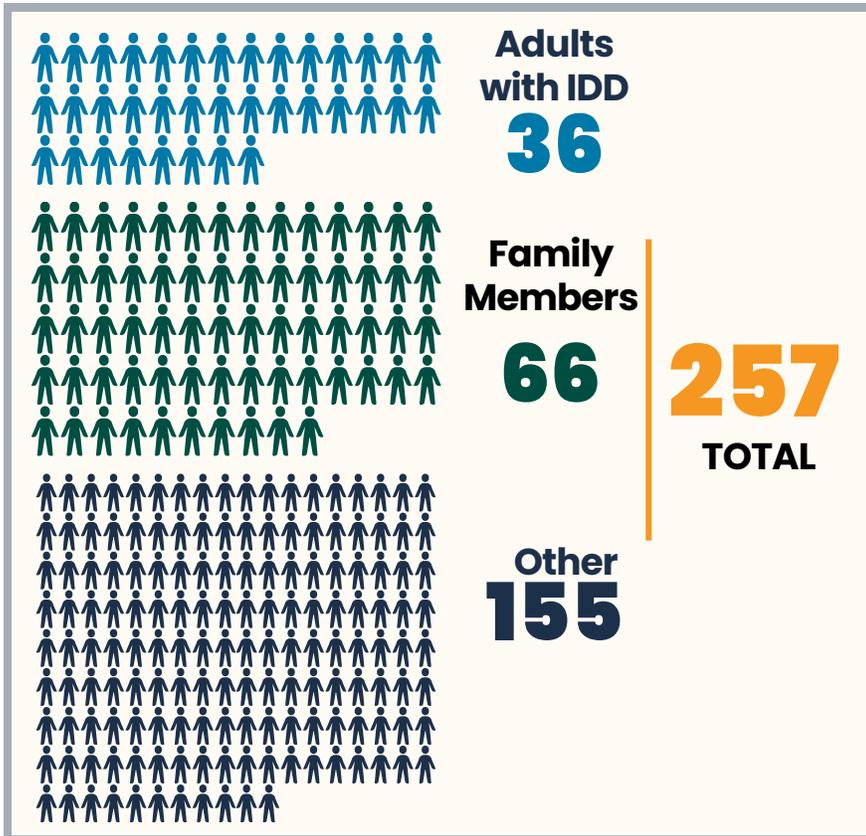
Council work is guided by a five-year plan developed by Council Members. Every five years, the Council collects public input to learn about the needs of people with IDD and their families to determine the Council's work is over the next five years.

In 2025, the Council collected public input through an online **survey** and through **12 statewide public forums** around the State. Council staff also conducted a **rural needs assessment in three rural communities** to gain deeper insight into the specific needs in Idaho's rural communities. The collected public input informs the development of the Council's 2027-2031 Plan.



SURVEY DATA

SURVEY RESPONSES



TOP THREE Areas respondents believe should be prioritized

- 1** Access to Home & Community-Based Services
- 2** Quality of Home & Community-Based Services
- 3** Medical Care



HIGHEST PRIORITIES

People with intellectual and developmental disabilities:

Preventing and Recognizing Abuse and Neglect

Family members of children and adults with intellectual and developmental disabilities:

Access to Home and Community Based Services

Other respondents (service providers, support staff, teachers, etc.):

Early Intervention

PUBLIC FORUMS

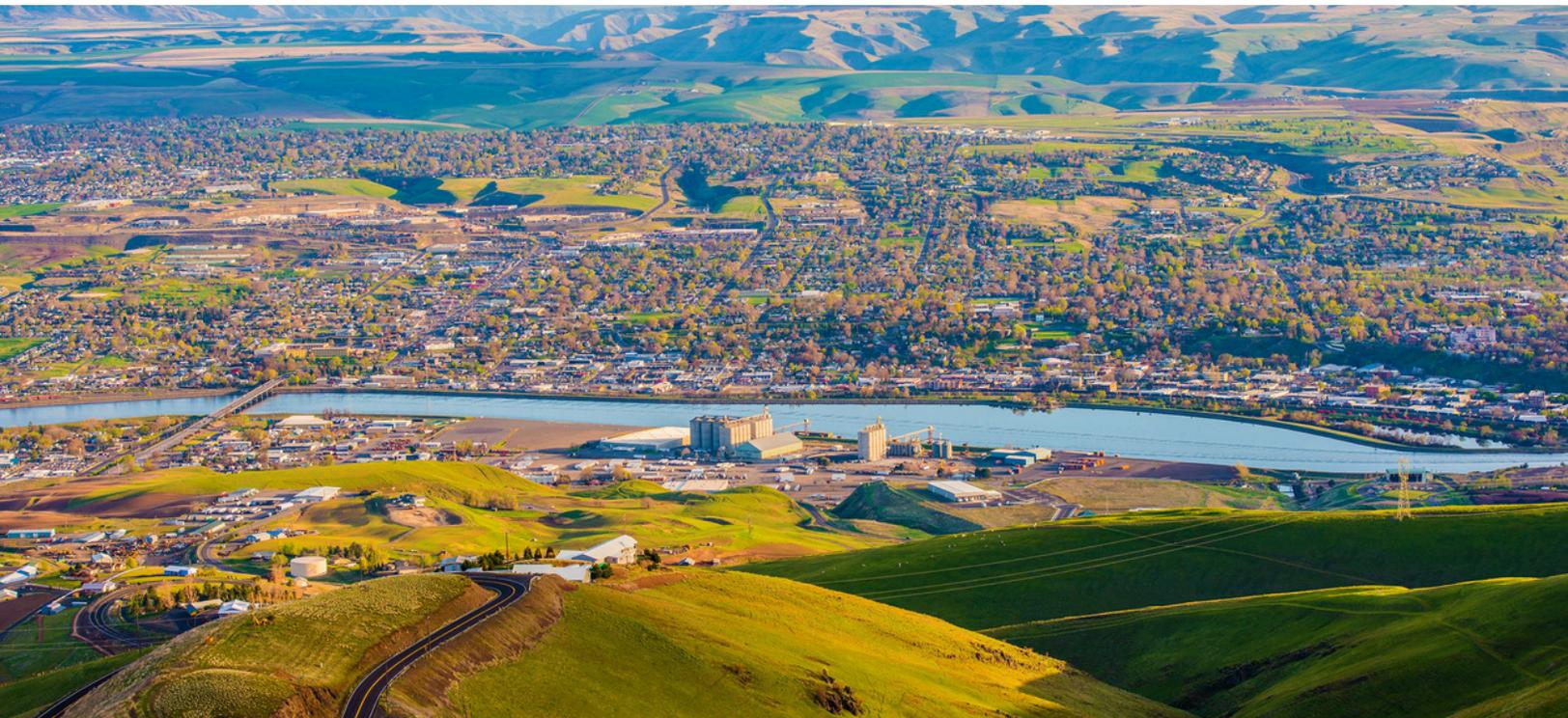
The Council held **twelve statewide public forums** gathering input from people with IDD, families, and community members. Council Members helped recruit attendees and led discussions.

A total of **41 people with disabilities** and **57 family members** participated, with 86 from rural areas and 52 from urban areas. **Attendees shared experiences regarding local recreational opportunities and resources, noting that while some rural areas have accessible transportation, others do not.**



Concerns include:

- lack of developmental disability services, especially in rural areas
- difficulty accessing specialized medical care in rural areas
- direct support staff shortage and lack of training of direct support staff
- difficulty finding jobs and getting job coaching



RURAL NEEDS ASSESSMENT

To gain a deeper understanding of the specific challenges in rural Idaho, Council staff spent a week in **Kamiah, Ashton, and Glens Ferry** to conduct a rural needs assessment.

During these three weeks, staff met with adults with IDD, family members, service providers, and community members to learn about their experiences in these three rural communities.

A report of this rural needs assessment will be available on the Council website in February 2026.



ADVOCACY & LEADERSHIP

Council Member Recognition

Council member Maria Juarez was asked to serve on the National Association of Council on Developmental Disabilities (NACDD) Ad-Hoc Conference Committee established in September 2024. The committee was responsible for guiding the future of NACDD conferences.



Maria was actively committed to the development of all committee recommendations; however, with her expertise, recommendations were adopted that set a high standard for translation of conference materials and interpretation services for people who have limited English proficiency and for people who need ASL services.

Thank you for your leadership, Maria!

Idaho Council Members Take Action in Idaho and at the Federal Level



Advocates pictured with Congressman Russ Fulcher

This year, our Council Members have provided exemplary leadership, weighing in on state and federal issues that impact children and adults with IDD.

Council members had over 100 visits with state legislators and congressional delegates or their staff. Thank you for your leadership and for contributing your important voice to help inform our policymakers.

2025 Legislative Session

Monitored and tracked over **35** bills

- Testified in support of **one** bill
 - Idaho ABLE Accounts
- Testified in opposition to **two** bills
 - Medicaid Expansion Conditions
 - Medicaid Reform & Cost Containment Act



**MEETINGS
WITH
LEGISLATORS**

21 STAFF
COUNCIL MEMBERS **30**

Our Care Can't Wait Coalition

Our Care Can't Wait is a coalition of people with disabilities, families, disability advocacy organizations, and HCBS provider agencies working to ensure people with disabilities and families have a well-qualified, reliable workforce that meets their needs to live the life they choose.

Through the Coalition, the Council created the *Our Care Can't Wait Advocacy Toolkit*, a cross-disability toolkit for people with disabilities and families to use to inform their policymakers about the dire situations people are experiencing due to the workforce crisis. These toolkits were distributed statewide through service providers and advocacy organizations, and are available on our website. The Center on Disabilities and Human Development, Independent Living Centers, and service providers hosted letter-writing campaigns using the toolkit, resulting in nearly 1,000 letters sent to state legislators addressing this critical workforce issue.



2025 COUNCIL MEMBERS

Carly Saxe, Chair, Advocate, Eagle

Kevin Swearingen, Vice-Chair, Advocate, Ammon

Sara Bennett, Parent, Lewiston

Eric Brown, Idaho Department of Health & Welfare, DD Bureau

Janice Carson, Center on Disabilities and Human Development, U of I

Randi Cole, Department of Education, Office of Special Education

Amy Cunningham, Disability Rights Idaho

Jenna Garrett, Parent, Moscow

Deedra Hunt, Commission on Aging, Adult Protection

Jennifer Johnson, The Sensory Playce, Community Service Provider

Maria Juarez, Parent, Nampa

Rochelle Larsen, Parent, Rigby

Angela Lindig, Idaho Parents Unlimited, Non-Profit

Michael MacGuffie, Idaho Division of Vocational Rehabilitation

Ann Martindale, Parent, Ashton

Julie McConnel, Parent, Nampa

Maria Moreno, Parent, Boise

Danielle "DR" Reff, Advocate, Boise

Melissa Roa, Idaho Department of Health and Welfare, Public Health

Michael Sandvig, Family Member of Person Living in an Institution, Idaho Falls

Edgar Zuniga, Advocate, Caldwell

COUNCIL STAFF

Christine Pisani – Executive Director

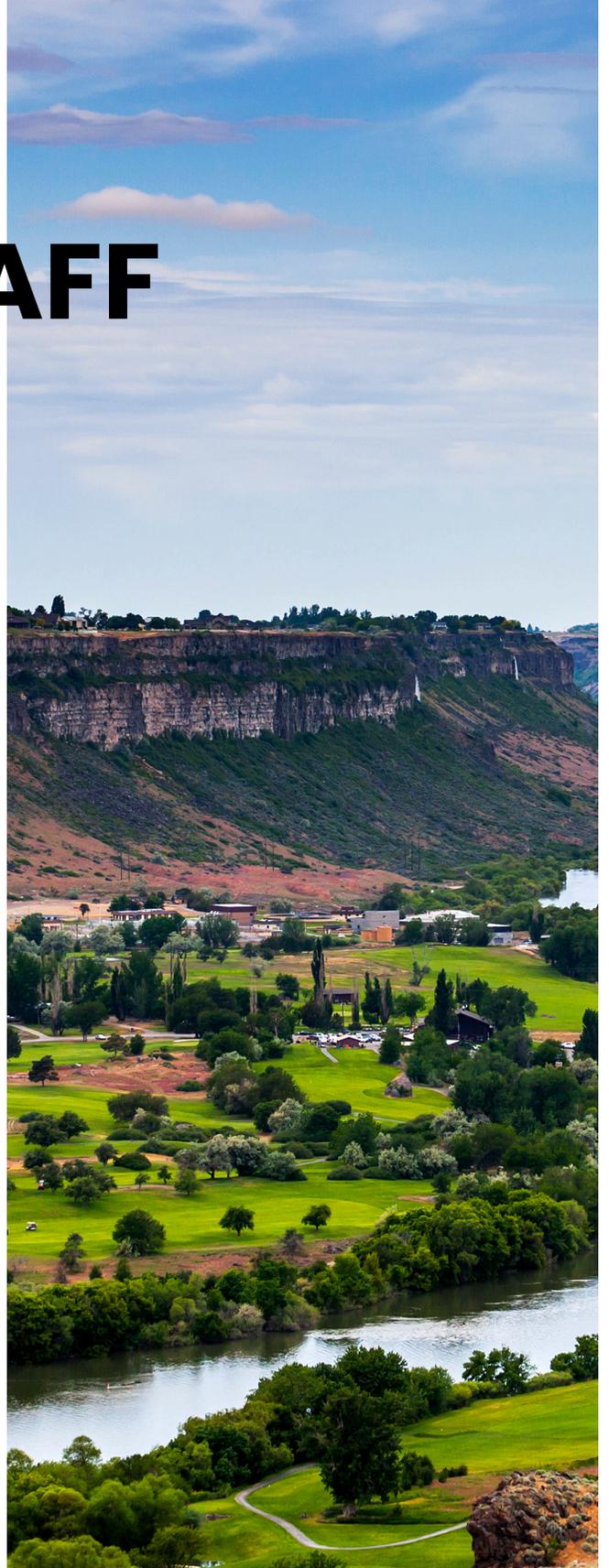
Marieke Edwards – Research Analyst

Mona Engelbrecht – Financial Specialist

Miguel Juarez – Program Specialist

Jill Smith – Program Specialist

Richelle Tierney – Policy Analyst



This work is supported by a grant from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201 with 100% federal funding award totaling \$526,312 (Federal Fiscal Year 2025 Grant No.: 2501IDSCDD). Council efforts are those of the grantee and do not necessarily represent the official views of nor are endorsed by ACL, HHS, or the U.S. government.





THANK YOU



700 W. State, Ste. 119
Boise, ID. 83702



(208) 334-2178



icdd.idaho.gov