## 2023 Annual Report







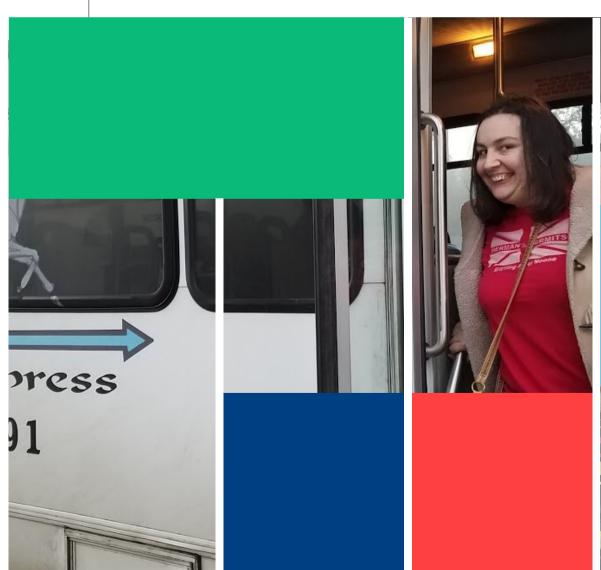
Front and Back Cover photo: Council Members at the July 2023 Meeting.

### 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 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.

The Idaho Council on Developmental Disabilities celebrates serving Idaho for the past 53 years!







## From the Executive Director

This past year has allowed the Council to collaborate with many people with disabilities, families, advocacy organizations, state agencies, service providers, and other state Developmental Disability Councils. The gift of these many collaborations has created a more unified Disability community in Idaho and has created better-informed solutions for the issues we face.

One example of this collaboration is our work with the Idaho State Independent Living Council to host a series of Lunch & Learn discussions. These discussions offered space for people with disabilities and families to learn together and help create a path forward to address the current direct care workforce crisis. My gratitude goes out to the families and people with disabilities working alongside us, guiding us in our work every step of the way.

I also want to acknowledge the many Idaho families and people with disabilities who are struggling to maintain control of their lives due to the direct care workforce shortage. The Council has made this issue one of our top priorities and will continue to do so until the workforce crisis is resolved. The Council will continue to rely on the wisdom of people with disabilities and families to create a service system where people with disabilities can thrive with highly qualified direct care workers who are paid a living wage. All of the staff at the Council thank you for the opportunity to bring people together, find common ground, and foster collaboration.

Christine Pisani Executive Director



### From the Council Chair

July 23rd, 2023 marked the start of the week that several Council Members attended the National Association of Councils on Developmental Disabilities conference in Orlando, FL. I arrived early to attend several sessions primarily for Council Chairs and Vice Chairs. It was a wonderful experience meeting people from 48 states and territories. Even today, I have over 10 connections to such states as Nevada, Washington State, and Massachusetts. As a result, each of us let the others know what conferences and events are occurring virtually and in person in their corresponding states. The others have even provided me with advice on how to respond to certain situations on Idaho's Developmental Disabilities Council.

In addition, to making my own pleasant acquaintances, I felt more in tune with Spanish speaking populations. The very last session of the conference was presented by Council Members Marilu Moreno, Maria Juarez, Edgar Zuniga, and Council Staff, Miguel Juarez. While the presentation was entirely in Spanish, there were headsets passed out to English speakers in the audience. Tears can only briefly describe how heartfelt and wonderful the presentation was. Each presenter described many challenges of trying to get services without language access. By the end, everyone was clapping ecstatically and questions were asked in both Spanish and English.

**DR Reff** Chair



### **Our Goals**

In 2022-2026, the Council plans to work on system change, capacity building, information, and education for individuals with disabilities and family members, and advocacy and leadership development.

#### **Goal 1 - 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.

#### **Goal 2 - 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.

#### **Goal 3 - 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.

#### **Goal 4 - 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.

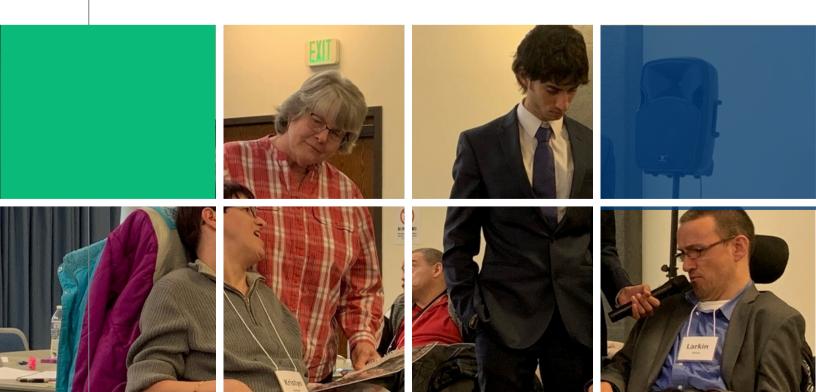


## **System Change**

#### **Community NOW!**

The Council works closely with people with intellectual and developmental disabilities and families, the Idaho Department of Health & Welfare, The Center on Disabilities & Human Development, DisAbility Rights Idaho, the American Civil Liberties Union, Developmental Disability Service Providers, and others in the Community NOW! stakeholder collaborative. Community NOW! is focused on supporting people with disabilities and families to lead in shaping the adult developmental disability service system.

The Council staff spent a significant amount of time during 2023 reflecting on the leadership of people with intellectual and developmental disabilities and family members in Community NOW! The Council invited previous and current Community NOW! members to share their experiences in Community NOW!, and learn how the Council can better support them in the future to lead Community NOW! This was done through focused interviews and a focus group discussion. A total of 23 past and current Community NOW! members were interviewed. On April 5, 2023, the Council hosted an in-person focus group for people with intellectual and developmental disabilities and family members.



Thirteen people with disabilities and five family members attended this focus group. Through small group activities and full group discussions, the Council learned how to better support people with disabilities and family members to lead Community NOW! All discussions were facilitated by people with disabilities and family members. Spanish interpretation was provided. These discussions gave us the chance to explore opportunities to increase the leadership of people with intellectual and developmental disabilities and family members in Community NOW! The Council contracted with a skilled meeting facilitator, who will support the learning and skill development of three people with developmental disabilities and two family members over the next year to learn the skills of leading the Community NOW! meetings.

#### **Reporting and Monitoring System**

The Council, through an Idaho Living Well grant, has been a lead agency in the work of creating a reporting and monitoring system for people with disabilities to report abuse, neglect, and (financial and sexual) exploitation. Throughout 2023, the Quality Assurance Workgroup worked towards developing recommendations intended to create an accountable reporting and monitoring system for people with disabilities who experience abuse, neglect, and exploitation. Draft recommendations from the workgroup are:

**Recommendation 1: Single Agency.** 

**Recommendation 2: Single Number to Call.** 

**Recommendation 3: Caregiver Misconduct Registry.** 

**Recommendation 4: Alternative Pathways to Resolution.** 

Final recommendations will be presented in 2024.

The Council also invested in two additional studies on abuse and people with disabilities in Idaho. These studies were conducted through a contract with Boise State University Criminal Justice Program.

## **Capacity Building**

#### **Person-Centered Community of Practice**

The Council continues its work with the University of Missouri, Kansas City, with expert guidance from the Charting the LifeCourse Nexus Training and Technical Assistance Center, to develop a Community of Practice on Person-Centered Planning. In March of 2023, the Council hosted a summit for Charting the LifeCourse Ambassadors, Person-Centered Thinking trainers, professional planners, agency partners, and other advocates to develop an action plan to help make improved planning a reality. From this work, our Community of Practice partners recommended having greater access to information and training on best planning practices and identified the need for stronger infrastructure to support this work.





Throughout 2023, Community of Practice partners continued to meet monthly at virtual Roundtables where planners shared innovative techniques, tools, and challenges. In 2024, this work will include expanding the group of Idaho Ambassadors and developing a Spanish-speaking focused Ambassador training.

#### **Language Access**

In the past three years, Latino Council Members and Council Staff have met several times with the Director of the Department of Health and Welfare and other Department staff to discuss the challenges the Latino community experiences in accessing services. In October 2023, the position of Language Assistance / Limited-English Proficiency Program Manager was established within the Department of Health and Welfare. This was a direct result of a June 2022 Latino Council member presentation on specific recommendations to improve access to services for the Latino developmental disability community to the Director of the Department of Health and Welfare. The program manager position is tasked with collaborating with community partners, customers, and leadership within the Department of Health and Welfare to improve the service delivery and customer experience by eliminating language and cultural barriers, establishing and implementing expanded agency-wide standards and policies, and obtaining customer feedback.

## Information & Education

#### **Unidos Hacemos El Cambio**

The Council worked with three Latino Council Members to plan and organize a conference in Burley on June 3, 2023. The theme of the conference was: Unidos Hacemos el Cambio / United We Make Change. The conference was presented entirely in Spanish and all conference materials were provided in Spanish.

The Latino Council Members and Council staff met monthly to plan the conference. They developed the agenda for the conference, met with potential conference sponsors to secure sponsorships, and invited organizations to be present at the conference with their Spanish-speaking staff. The Latino Council Members and Council staff traveled to the Burley area three times in the months leading up to the conference to conduct outreach for the conference and provide radio interviews.



















Yolanda Cruz and Sofia Cervantes from the California Council on Developmental Disabilities were invited to provide a two-part workshop at the conference on acknowledging the stigma associated with disability in the Latino community, the benefits of early intervention, and developmental milestones typically observed in children at specific given ages.

Five people with intellectual and developmental disabilities and 67 family members attended the conference. Childcare was provided on-site at the conference and overseen by the Community Council of Idaho's Head Start teachers. Attendees shared they appreciated the information provided at the conference, and being able to connect with all the different organizations that were present. Many attendees asked the Council to not forget about them and to continue to bring information and education to their area. The Council was also approached by three other rural communities to provide the same education in their communities.

## Advocacy & Leadership Development

#### **Our Care Can't Wait Coalition**

The 2023 Office of Performance Evaluation (OPE) report released in March of 2023 found that Idaho's direct care workforce shortage is significantly greater than the national average, with a need for 3,000 additional workers to meet national staffing shortage levels. This gap is only expected to grow. As a result of the findings and recommendations the Council initiated the Our Care Can't Wait Coalition in May of 2023 to work on the implementation of the recommendations from the OPE report. The statewide Coalition includes people with disabilities, family members, DisAbility Rights Idaho, the Center on Disabilities and Human Development, the Parent Training Center, the Idaho Caregiver Alliance, AARP, the three Independent Living Centers, the Idaho State Independent Living Council (SILC), Idaho Association of Community Based Service providers, and the Idaho Association of Home Care Agencies. The Coalition meets twice a month and has four separate workgroups which include media outreach, advocacy events, data research, and Medicaid budget.

The Council coordinated a meeting in July with the Governor's Office to discuss the direct care workforce, the need for increased Medicaid staffing, and rate increases for HCBS service providers. This meeting included the SILC, a family advocate, and the DD Council. The person we were working with who could share his lived experience as an HCBS participant who has experienced a long-term lack of direct care support was unable to attend due to an unreliable support staff.

## **OUR CARE CAN'T WAIT**

The Council created a series of fact sheets in English and Spanish to highlight the OPE recommendations, inform policymakers on the role of a direct care worker, and a fact sheet that highlights what the direct care workforce shortage means to people with disabilities and families. The Council led a subgroup to present as the Our Care Can't Wait Coalition to a Medicaid Managed Care Legislative Task Force meeting this past summer. The partners involved in the presentation were LIFE, an independent living center, the Idaho Association of Community Providers, the Idaho Parent Training Center, and the DD Council.

Through the advocacy events workgroup, the Council led outreach and collaboration to present to the Joint Legislative Oversight Committee on the direct care workforce shortage. This hearing presented an opportunity for many people with disabilities and family members to be present for this critical hearing. The Council supported a person with a developmental disability to prepare and present his testimony related to his lived experience with the lack of direct care workers for the past three years. His story was so compelling that several media outlets covered his story statewide.









The DD Council and the Idaho State Independent Living Council began hosting lunch and learn events in May of this year. The participants from around the state met virtually twice a month for any HCBS participant on the Aged and Disabled Waiver or the Adult DD Waiver. The Lunch and Learn events were hosted every other week and provided education in plain language on the Home and Community Based Service system, the Office of Performance Evaluation presentation of the report and recommendations on the sustainability of the direct care workforce in HCBS, and advocacy strategies for people to use in their hometowns to attend monthly Capital for a Day events hosted by the Governor. The education and discussions with people with disabilities and families in the Lunch and Learn events helped to build an informed statewide advocacy group that would later be invited to attend a two-day legislative advocacy event.



# 2023 Idaho Legislative Session by the Numbers



88
DAYS IN SESSION



**595** 

BILLS INTRODUCED







26
RESOLUTIONS ADOPTED

"With the release of the Office of Performance Evaluations report on the Sustainability of Idaho's Direct Care Workforce in Home and Community Based Services, people with disabilities and family members are needed more than ever to help implement the important recommendations highlighted in this critical report."

Christine Pisani, Executive Director

#### **DD Council Activity**

- Monitored and tracked over 47 bills
- Testified in support of two bills and opposed two
- Signed on to a joint letter for the release of OPE's Sustainability of Idaho's Direct Care Workforce Report
- Provided Comments on the Direct Care Workforce Crisis Report
- Presented to the Senate H&W Committee on improving systems for reporting and monitoring abuse, neglect, and exploitation of people with disabilities



**MEETINGS WITH LEGISLATORS** 

22 COUNCIL MEMBERS

STAFF
46

### **2023 Council Members**

New members joined the Council in July 2023 and are noted as (new).

Danielle "DR" Reff, Chair, Advocate, Boise Maria de la Luz Moreno, Vice-Chair, Parent, Boise

Sara Bennett (new), Parent, Lewiston

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

Michael Case, IDHW-Division of Medicaid

Randi Cole (new), Department of Education, Office of Special Education

Amy Cunningham, DisAbility Rights Idaho

Jenna Garrett, Parent, Moscow

Deedra Hunt, Commission on Aging

Jennifer Johnson, The Sensory Playce, Community Service Provider

Maria Juarez, Parent, Nampa

Rochelle Larsen, Parent, Rigby

Michael MacGuffie, Vocational Rehabilitation

Andrew Mills (new), Advocate, Caldwell

Natali Pellens, Parent, Coeur d'Alene

Emily Petersen, LINC, Non-Profit

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

Carly Saxe, Advocate, Eagle

Adrienne Seamans, Parent, Idaho Falls

Stephanie Walters, IDHW-Maternal and Child Health

Nick Wyatt, Advocate, Boise

Edgar Zuniga, Advocate, Caldwell



## **Council Staff**



**Christine Pisani**Executive Director



**Jill Smith**Program Specialist



**Marieke Edwards** Research Analyst



**Miguel Juarez**Program Specialist



**Richelle Tierney** Policy Analyst



**Will Wallace**Customer Service





## **Thank You!**

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