

OCT 2021 - SEPT 2022

ANNUAL REPORT 2022



IDAHO COUNCIL ON
DEVELOPMENTAL
DISABILITIES





Front Cover photo: Council Members Maria de la Luz Moreno and Maria Juarez in Washington, DC attending the annual National Association of Councils on Developmental Disability Conference.

Back Cover photo: Council Members Amy Cunningham and Edgar Zuniga walking during a Council 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, P.L. 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.

Mission

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.

PROMOTING LEADERSHIP

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Christine Pisani
Executive Director

As I look back on twenty-six (26) years of work at the Idaho Council on Developmental Disabilities, I feel very proud of the role the Council serves. The Council has had the opportunity to help promote individuals with intellectual and developmental disabilities and family members as the experts they are to work alongside Idaho policymakers on important issues. Since 1996, the Council has been promoting the leadership of individuals with intellectual and developmental disabilities and family members across all Council projects.

Our consistent long-term engagement with the developmental disability community has resulted in hundreds of leaders living statewide who have helped shape our services, created more inclusive communities, and changed the way state agencies include individuals with developmental disabilities to create positive change.

There is still plenty of work to do, but I want to acknowledge all the individuals with intellectual and developmental disabilities, and family members who have given so generously of their wisdom, time, and energy to create a better Idaho for all of us. The Council will continue to look to individuals and families to guide us in all the work we do. We are sincerely grateful for the many relationships that ground us and help us to prioritize the most important issues in the lives of individuals and families.

MESSAGE FROM THE CHAIR

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DR Reff
Council Chair

It has been an immense privilege to be Chair of the Council this year let alone a Council Member. Over the course of this year, we've accomplished and learned so much.

In addition to regular Council meetings, we have had a new Partners in Policymaking graduating class and a Leadership Summit. The Council has also helped coordinate and support such groups as the Culturally Responsive Advisory Group, Community NOW!, and a Quality Assurance workgroup focusing on the topic of abuse, neglect, and exploitation.

Council Members attended a Leadership Summit in September, which helped us to bond in ways I will never forget. We did three main activities. The first, a River of Life, helped us connect the negative and positive aspects of our lives, and how we wish to have improved some of our life's events. We then had conversations in pairs about leadership. Our final activity involved learning how to use our personal experiences to inform and educate legislators. These two days were mentally exhaustive but worth every second. All that attended bonded. All that attended benefited. Many hope to have another one of these sessions next year.

The list of activities and plans for more only increases. I wish to thank everyone, not just Council Members, for their participation in Council-led or supported events. You are amazing.



OUR FIVE YEAR PLAN

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The work of the Council is guided by a 5-year plan. Every five years, the Council gathers information from people with intellectual and developmental disabilities, family members of children and adults with intellectual and developmental disabilities, service providers, public agencies, and other organizations to determine what the Council's focus should be for the next five years.

Councils are required to select one or more targeted disparities: unserved or underserved groups of individuals with intellectual and developmental disabilities and family members. The Council selected individuals with developmental disabilities and their families from the Latino community as a targeted disparity for the 2022-2026 Plan.



OUR GOALS

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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 Development

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



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Community NOW!

The Council works closely with individuals 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 individuals and families to lead in shaping the adult developmental disability service system.

The Community NOW! full stakeholder group met five times virtually in 2022. All meeting materials were available in English and in Spanish and were provided in screen reader accessible formats. Community NOW! members reviewed and discussed topics such as the proposed temporary rules for the adult developmental disabilities service array, the new Home and Community Based Developmental Disability services, the direct care workforce crisis, Idaho's state systems for reporting and monitoring abuse, neglect and exploitation, and a proposal for crisis system improvement to the adult developmental disability services.



Reporting and Monitoring System

The Council contracted with the Criminal Justice Division, Boise State University for three studies on the reporting and monitoring system for abuse, neglect, and exploitation.

The results of the first study indicate that stakeholders perceive that people with disabilities are more vulnerable to victimization and less likely to speak up for themselves. Policies and procedures that need improvement, are having simple and consistent reporting procedures across service providers, a registry of those who commit abuse, neglect, or exploitation against a person with a disability, enhancing coordination and communication related to complaints and investigations, and addressing root causes of staff misconduct and/or criminal offending.

The second study will focus on assessing the knowledge of best practices when serving people with disabilities who are survivors of abuse, neglect, and exploitation.



Victimization Among Persons with Disabilities: Professional Stakeholder Perspectives in Idaho

Lane Kirkland Gillespie, Jessica Wells, Lisa M. Growette Bostaph, Laura L. King, Kaitie Blalock, & Makayla Butler

CAPACITY BUILDING

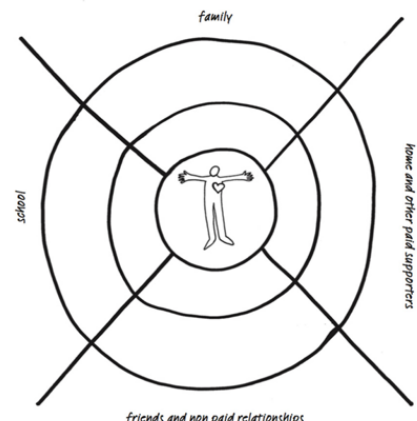
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Person-Centered Thinking

"It has changed the type of questions we train our staff to ask at the PCP meeting. It has also changed the focus of the PCP meeting from assessing needs to promoting the individual's perspective through their supports and services." Targeted Service Coordination Agency Administrator

The Council worked with a contractor to develop Idaho Person-Centered Thinking trainers. The contractor provided two separate training series in 2022. Each series included six three-hour virtual sessions. This training provided foundational understanding of person-centered practices to Department of Health & Welfare staff, service coordinators, support brokers, service providers, family members, and individuals with intellectual and developmental disabilities. Six Idaho trainers have completed the Person-Centered Thinking train-the-trainer process. These trainers received training and mentor support to become Person-Centered Thinking trainers and are expected to provide this training beyond the contract with the Council. In 2022, the Idaho Person-Centered Thinking Trainers conducted five series of trainings. A total of 77 people participated in these virtual training series.

"So many families, mine included, are intimidated to think of the future with our kid. I have used these tools to start thinking about what I DON'T want, in order to help facilitate thoughts into what we do want. This has helped families with a starting point, but also helps the process to not be so overwhelming. I also find myself using these tools in my life--my kids always comment that I'm using a trajectory!" Parent Advocate





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Culturally Responsive Advisory Group

The Culturally Responsive Advisory Group is made up of individuals with intellectual and developmental disabilities and family members from the Latino community. In June, three members met with the Director of the Department of Health and Welfare and the Medicaid Administrator to discuss the barriers non-English speaking families and individuals experience when attempting to access adult developmental disability services. The group spoke about their lack of access to Spanish language interpreters or having bilingual Department staff to assist with questions or help to navigate the service system.

The Council and members of the Culturally Responsive Advisory Group provided a formal request for the Department to consider four recommendations as priority needs for the Latino community.

The Director agreed to have quarterly meetings with the Council and members of the Culturally Responsive Advisory Group to discuss progress and additional perspectives the members of the Culturally Responsive Advisory Group would have to share.

Recommendations

1

The Department needs bilingual staff to best support the needs of the Spanish speaking community.

3

Train more translators and interpreters to understand disability and service system jargon and terminology.

2

Incentivize Spanish-speaking Home and Community Based providers.

4

Department information is available in Spanish. Training in Spanish.

INFORMATION & EDUCATION

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Community Outreach

The Culturally Responsive Advisory Group directed the Council to develop a series of information sheets in Spanish that provide information about specific intellectual and developmental disabilities to help families better identify developmental milestones in their children.

During the spring and summer of 2022, members of the Culturally Responsive Advisory Group visited churches and Latino-led events in different parts of the state. They spoke to Latino community members about the Council, the Culturally Responsive Advisory Group, and about developmental disabilities and disability services. They handed out drawstring backpacks with information materials in Spanish.



Community Outreach Events

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During the spring and summer, the Culturally Responsive Advisory Group attended a total of 8 events in Nampa, Caldwell, Boise, Jerome, and Twin Falls.

Talked to about 515 people at these events.

Over 400 backpacks with informational materials were distributed.



ADVOCACY & LEADERSHIP DEVELOPMENT

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The Council hosted a virtual class of Idaho Partners in Policymaking. The program consisted of seven monthly, online meetings, followed by an in-person graduation in June 2022. Topics covered in the program were:

- History of disability
- Parent movement
- Independent Living movement
- Self-advocacy movement
- People First language
- Identity First Language
- Individuals with Disabilities Education Act
- Healthy relationships & sexuality for individuals
- Strength-based Individual Education Plans
- Understanding behavior as communication
- Guardianship & Supported Decision-Making
- Running your own meeting
- Person-Centered Thinking
- Transition to adulthood



For the last session, the Director of the Department of Health and Welfare spoke to the class about the importance of individual and family leadership to shape quality services. The Council coordinated a panel that included Administrators and Directors from four state agencies. The class had an opportunity to learn what the panelists' individual roles are, what their work includes, how to be involved in some of the work they do, and an idea of some of the work they are trying to implement.

Eight individuals and seven family members graduated from Idaho Partners in Policymaking.



"I found I was able to ask the right questions as it related to each subject. I felt I could speak my mind, contributing to the discussion, helping each Partner. I felt I could be a more informed citizen with each of the trainings. I found myself more able to be informed about my legal rights. I got to the point where I can advocate for myself and others." Self-advocate

Legislative Activity

"I am grateful for the leadership of many individuals with disabilities and families involved in this year's legislative session. The voice of the Disability community is important and necessary to create an Idaho that is inclusive, accessible, and provides opportunities for all of its' citizens to thrive!" - Christine Pisani, Executive Director

MEETINGS WITH LEGISLATORS

 **47**
STAFF

 **25**
COUNCIL
MEMBERS

 **80+**
TRACKED BILLS

- Monitored and tracked over 80 bills
- Testified in support of ten bills and opposed two
- Worked with the Idaho Down Syndrome Council to pass the Down Syndrome Diagnosis Information Act
- Drafted study proposal for the Direct Care Workforce Crisis in Home and Community Based Services
- Partnered with the Alzheimer's Association to draft the Endangered and Missing Persons Act

1 
STUDY PROPOSAL

10   **2**
PROVIDED TESTIMONY

1 
SIGN ON
LETTER



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REMEMBERING ERICK YEARY

A Tribute by: Christine Pisani

In 2003, I was privileged to travel to eastern Idaho to meet with leaders from the developmental disability community. At that time, the Council was looking for adults who used developmental disability services to help create a new type of service: the My Voice My Choice self-direction option under the developmental disability waiver. Erick Yearly, a resident of Ammon, came highly recommended for an interview by his targeted service coordinator. I met Erick and his parents in their home for an unforgettable three hours. Erick's passion and desire to be part of a movement led by people with developmental disabilities to create positive change for people with developmental disabilities were strong. His energy was contagious.





ADVOCATE & FRIEND

Erick took part in a six-month training with two other teammates from eastern Idaho. In those six months, the team learned about what it means to share leadership and help other people with developmental disabilities find their voice. In 2004, Erick and his teammates presented to the Idaho Legislature in what was then the “Gold Room” about what self-determination meant to them. This day in January held historical importance because these were the first individuals with intellectual and developmental disabilities to provide leadership in the state legislature about their desire to have choice and control over their services. As regional self-advocacy teams were created, this statewide group of leaders decided to move self-advocacy to the next level for Idaho. Erick was a founding member of the Idaho Self-Advocate Leadership Network. The state self-advocacy organization was led by and for people with developmental disabilities. Erick provided vision and total commitment to this movement. He led countless presentations throughout the state and nationally.

In 2005, the Council hosted the Self-Determination Bus Tour. Erick was on the bus for every eastern Idaho town to lend his leadership to the disability community. When the Council coordinated Determined to Vote with a grant from the Office of the Secretary of State, Erick was a state trainer for three national election cycles. He helped train hundreds of people with disabilities about why their vote mattered, registering to vote, and using the accessible voting machines. He was an instrumental teacher to many individuals with disabilities, Council staff, Department of Health & Welfare staff, and the service provider community.

Erick was a powerful, passionate, and charismatic leader. Sadly, Erick passed in November of 2022. We miss him and the character he provided at all our gatherings.

Rest in Power, Erick!



2022 COUNCIL MEMBERS

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New members joined the Council in July 2022 and are noted as (new).

Danielle “DR” Reff, Chair, Advocate, Boise

Natali Pellens, Vice-Chair, Parent, Coeur d’Alene

- Ian Bott, Advocate, Boise
- Janice Carson, Center on Disabilities and Human Development, U of I
- Michael Case, IDHW-Division of Medicaid
- Amy Cunningham, DisAbility Rights Idaho
- Jenna Garrett, Parent, Moscow
- Deedra Hunt, Commission on Aging
- Jennifer Johnson, The Sensory Playce, Community Service Provider
- Maria Juarez (new), Parent, Nampa
- Rochelle Larsen (new), Parent, Rigby
- Michael MacGuffie, Vocational Rehabilitation
- Maria de la Luz Moreno, Parent, Boise
- Emily Petersen, LINC, Local Non-Profit Agency
- Michael Sandvig, Family Member of Person Living in an Institution, Idaho Falls
- Carly Saxe, Advocate, Eagle
- Adrienne Seamans, Parent, Idaho Falls
- Karren Streagle, Special Education - Department of Education
- 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
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Richelle Tierney
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