



IDAHO COUNCIL ON
DEVELOPMENTAL
DISABILITIES



2021

Building Relationships

Annual Report

OCTOBER 2020 – SEPTEMBER 2021

Almost 30,000 Idahoans have intellectual or developmental disabilities - disabilities that are life-long and usually occur at birth. Tens of thousands of Idaho families are impacted by an intellectual or developmental disability; often providing essential care and support to their family members.

Idahoans with intellectual and developmental disabilities and family members must navigate a complex system; the DD Council is their connection to resources, support, peers, leadership development and advocacy.



Who We Are

The Idaho Council on Developmental Disabilities is established under the Federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402) in 1971 and in Idaho Code in 1978.

Our members are Governor appointed volunteers with the majority being individuals with intellectual or developmental disabilities or a family member of a person with a developmental disability.

Our work is guided by extensive statewide outreach and planning with people who have intellectual and developmental disabilities, their family members, and service providers. The outcomes of our outreach and strategic planning is our five year plan that is overseen by our Council members.

Our Purpose

Developmental Disability Councils focus on advocating for services based on best practice. The Council prioritizes supporting the leadership of individuals with intellectual and developmental disabilities and family members to inform policy recommendations to be person-centered and promotes the participation of individuals as equal members of society.

We work to create a culture in Idaho where the choices of individuals with intellectual and developmental disabilities are informed and supported. The Council has led in the critical role of leadership development for individuals and families and as innovators in the development of community-based programs as directed by individuals and families since 1978.

Funding Sources

The Council receives funding from the federal government authorized under the Developmental Disabilities Act and the state government under the Idaho Council on Developmental Disabilities statute.

In 2018, the Council collaborated with the Center on Disabilities and Human Development at the University of Idaho and DisAbility Rights Idaho to apply for a Living Well grant through the Administration on Community Living. The Center on Disabilities and Human Development received notice that Idaho was awarded a Living Well grant and the Council has been a subgrantee for this five-year grant since October 2018.

Our Work in 2021

The Council conducts its work based on a five-year plan. The 2017-2021 plan includes three goals, related to quality in Home and Community-Based Services (HCBS) funded through Medicaid, secondary transition, and leadership development. This is the final annual report for this five-year planning cycle. In this report we highlight some of the work completed towards each goal.

2021 Progress Towards Goals

Goal 1: Adults with intellectual/developmental disabilities experience improved quality in Home and Community Based Services

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 Council dedicates tremendous resources to spend time with individuals with disabilities and family members to assist them in fully understanding complex information so they may lead systems change discussions and activities.

In April 2021, the Council collaborated with the Department of Health and Welfare to host a series of five **webinars** for people with intellectual and developmental disabilities and family members to understand the **upcoming changes to the adult Developmental Disability Medicaid services**. The Council created four **animated videos** in English and one in Spanish to help illustrate in plain language the important points of the upcoming changes. The Council provided facilitation for each of the webinars with captioning and Spanish interpretation.



Focused webinars included content on how the service system would accommodate for complex health needs, self-direction, and certified family homes. A specific webinar for Spanish-speaking individuals and families was hosted, and a final open meeting was made available for service providers or any other person who missed the previous four webinars. Overall, 18 individuals with intellectual or developmental disabilities, 173 family members, 412 people who registered as guardians and certified family homes, and 124 others participated in the webinar series.

The **Culturally Responsive Advisory Group (CRAG)** is made up of individuals with intellectual and developmental disabilities and family members from the Latino community. The CRAG was established to ensure Community NOW! efforts include the involvement and perspective of Latino family members and individuals.



Members of the CRAG expressed a need for the Spanish speaking community to have basic information in Spanish about intellectual and developmental disabilities. With input from CRAG members, the Council created **twelve information sheets in Spanish**; these information sheets provide specific information by diagnosis and developmental milestones for many types of disabilities. CRAG members reviewed and approved the information sheets. The Council will support CRAG members to use these information

sheets to present to various faith communities that have Spanish speaking congregation members and in Latino led organizations to provide important information and education.

The Council worked with a contractor to provide online **Person-Centered Thinking training**. The training consisted of six 3-hour sessions and provided a foundational understanding of person-centered practices. This last year the Council hosted five training series, with a total of 78 attendees, including seven people with intellectual or developmental disabilities and 19 family members. Four attendees of this initial training have received training and mentoring to become Person-Centered Thinking trainers and will to continue to provide this training at the conclusion of the contract. The Council continues to identify training attendees to become trainers themselves, in an effort to establish sustainable, long-term training on person-centered practices in Idaho.

The Council has been a lead agency in the work of creating a **reporting and monitoring system for people with disabilities to report abuse, neglect and exploitation**. The Council approved funding to conduct three separate studies to be carried out by Boise State University's Criminal Justice Division. These studies are intended to highlight the gaps in services to monitoring and reporting abuse, neglect, and financial/sexual exploitation in the adult service systems in Idaho.



The Council also serves on the leadership team for a Violence Against Women with Developmental Disabilities grant through the Department of Justice. This grant was awarded to the Coalition Against Sexual and Domestic Violence. The Council provided intentional leadership on the recruitment of individuals with intellectual and developmental disabilities who live in rural areas to provide critical lived experience on grant activities. **See Us Now!**, or SUN!, is an Idaho collaboration working at the intersection of developmental disability and violence.

Goal 2: Youth and young adults with intellectual/developmental disabilities transition from school into an adult life that includes competitive integrated employment, community engagement, and full citizenship

The Council participated in meetings of the Idaho Interagency Council on Secondary Transition to plan the fall **Secondary Transition Institute** at Boise State University on November 3-4, 2021. The Institute is an event where educators and other school district team members receive information and participate in team planning to improve transition activities in their schools.

The Council worked with the Center on Disabilities and Human Development and DisAbility Rights Idaho to host a **Fred Riggers Event webinar on Supported Decision Making**.

This one-hour introduction to Supported Decision Making and alternatives to guardianship was presented by DisAbility Rights Idaho staff; 26 people attended, including 4 people with disabilities and 11 family members.



Supported Decision Making

Goal 3: Leaders with intellectual/developmental disabilities are engaged with other people with disabilities and family in a statewide coalition that has a strong, collective voice on policy issues and systems change

The Council prepared for a 10th class of **Idaho Partners in Policymaking**, with a first session taking place in September 2021. Due to the pandemic the class met virtually. Partners in Policymaking is an innovative leadership development program for adults with developmental disabilities and parents of children with disabilities. The Idaho Council has hosted this life-changing leadership development program since 1997. Partners receive information, training, resources, and skill building so they may have the best possible life experiences for themselves and for their children. The program was developed specifically to teach people with intellectual and developmental disabilities and family members of young children with disabilities to:



- Work on long-term change;
- Become active partners with policymakers at all levels to shape services and policies that impact people with disabilities and families;
- Create a vision for what are possibilities and work to create them.

The 2021-2022 class of Partners in Policymaking has ten individuals with an intellectual or developmental disability and eight parents of children with a disability.



Supporting the **statewide Advocacy Coalition** is a collaborative effort with the Center on Disabilities and Human Development at the University of Idaho, DisAbility Rights Idaho, and LINC, an independent living center.

The Coalition supported three **Fellows**. Fellows are individuals with intellectual or developmental disabilities or family members who participate in a program focused on advocacy and community organizing. They conduct outreach to members in their community, spend time deeply understanding policy issues, and support others to take needed action.

The Council contracted with Living Independence Network Corporation (LINC) to **develop leadership, advocacy, and technology skills** for people with intellectual and developmental disabilities and parents of children and youth with intellectual and developmental disabilities.

Through the Self-Advocacy and Leadership Training, a collaboration between the Council and LINC, five individuals with disabilities from across Idaho learned more about advocacy and received technical support when needed. The group met online weekly for ten weeks, and graduates were connected with ongoing advocacy efforts.

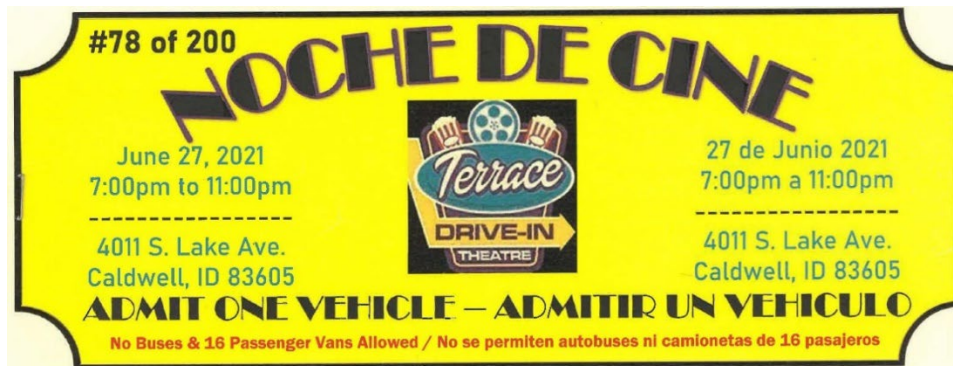
COVID-19 Response

The Council supported and staffed four **pop-up COVID-19 vaccination clinics**. The Council did this work in collaboration with the Idaho State Independent Living Council and the Community Council of Idaho, a well-established and respected community resource to farm workers in Idaho. The DD Council invested significantly in this important intersectional work. All messaging was done in English and Spanish with Spanish interpreters available at each pop-up clinic. This work established trusted relationships that has served the disability community and the Spanish speaking community well in pursuing other meaningful policy work that benefits people who lack access to services and supports. Coordination of food boxes and emergency go bags were provided at each pop-up clinic as well as information available in English and Spanish about disability and community resources.



COVID-19 vaccination clinics supported

- Sunday, April 25, 2021, in **Weiser**. This clinic was held at El Venadito, a Head Start Center through the Community Council of Idaho. Vaccinations were provided by St. Alphonsus with a total of 29 people vaccinated.
- Saturday, June 19, 2021, in **Shoshone**. This clinic was hosted by The Golden Years Senior Center with five people vaccinated.
- Sunday, June 27, 2021, in **Aberdeen**. At this clinic, 4 people were vaccinated.
- Sunday, June 27, 2021, in **Caldwell**. This clinic took place during the Noche de Cine event with 15 people vaccinated. During Noche de Cine, Council Member Marilu Moreno attended to support with distributing information to families about the Council.



Developing the next five-year plan

During 2021, the Council spent a significant time developing the 2022-2026 plan. The five-year plan is based on needs identified through extensive data collection. A general survey received 296 responses, including 34 people with intellectual or developmental disabilities and 200 family members of children or adults with intellectual or developmental disabilities. Respondents identified priority areas for the Council. The Council then followed up with a rural survey to identify needs and barriers specific to Idaho's rural population. This survey received 203 responses. Additionally, the Council hosted four online focus group discussions, where individuals with intellectual or developmental disabilities, family members, and others shared their ideas and experiences around abuse, neglect, financial exploitation, and direct support staff. Council members reviewed and discussed the data collected in several planning sessions. In the spring of 2021, the draft five-year plan was made available for public comment. The final plan was approved by the Council in April 2021. This plan guides the Council's work beginning October 1, 2021. The plan is available on the Council's website.

2021 Council Members

New members joined the Council in July 2021 and are noted as *(new)*.

Emily Petersen, **Chair**, *Parent, Kimberly*
Danielle “DR” Reff, **Vice-Chair**, *Advocate, Boise*

Silvia Arnold *(new)*, *Parent, Rigby*

Ian Bott, *Advocate, Boise*

Amy Cunningham, *DisAbility Rights Idaho*

Art Evans / Michael Case *(new)*, *IDHW-Division of Medicaid*

Julie Fodor / Janice Carson *(new)*, *Center on Disabilities and Human Development, U of I*

Jenna Garrett, *Parent, Moscow*

Nanna Hanchett / Michael MacGuffie *(new)*, *Vocational Rehabilitation*

Deedra Hunt, *Commission on Aging*

Valerie Hurst, *Parent, Boise*

Jennifer Johnson *(new)*, *The Sensory Playce, Community Service Provider*

Sarah Lopez / Stephanie Walters *(new)*, *IDHW-Maternal and Child Health*

Maria De La Luz Moreno, *Parent, Boise*

Natali Pellens, *Parent, Coeur d’Alene*

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*

LaDonna Tuinstra, *Parent, Kuna*

Nick Wyatt *(new)*, *Advocate, Boise*

Edgar Zuniga, *Advocate, Caldwell*



2021 Council Staff

Christine Pisani, *Executive Director*

Marieke Edwards, *Research Analyst*

Miguel Juarez, *Program Specialist*

Trisha Hammond, *Management Assistant*

Richelle Tierney, *Policy Analyst*

Tracy Warren, *Program Specialist*

Our Developmental Disabilities Network Partners:





IDAHO COUNCIL ON
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Department of Health and Welfare, DD Council, in accordance with 60-202, Idaho Code; 21800C20