



IDAHO COUNCIL ON
DEVELOPMENTAL
DISABILITIES

2020



A Year of Meeting Challenges

Annual Report

OCTOBER 2019 – SEPTEMBER 2020

An estimated 42,000¹ Idahoans have developmental disabilities - disabilities that are life-long and often complex. Tens of thousands of Idaho families are impacted by having a family member that experiences a developmental disability; often providing care and support.

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



Who We Are

The Idaho Council on Developmental Disabilities is established and funded under the federal Developmental Disabilities (DD) Act along with our DD Network partners: Disability Rights Idaho, the state's protection and advocacy organization, and the Center on Disabilities and Human Development at the University of Idaho.

Our members are volunteers appointed by the Governor, the majority of whom must have a developmental disability or be a family member of a person with a developmental disability.

1. Prevalence rate of 2.3% based on: Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Our Purpose

DD Councils focus on creating programs based on best practice and advocating with individuals with developmental disabilities and family members for policy that empowers individuals with developmental disabilities and promotes participation as equal members of society.

We work to create an environment of self-sufficiency, self-determination, inclusion, and acceptance. We play a long standing and critical role in the leadership development of individuals and families and as innovators in the development of community-based programs as directed by individuals and families.

Funding Sources

The Council receives funding from both the federal government authorized under the Developmental Disabilities Act and the state government under the Idaho Council on Developmental Disabilities statute. In 2020 we were a sub-grantee of the Center on Disabilities and Human Development's federal Living Well Grant from the Administration on Community Living.

Our Work in 2020

The Council conducts our work based on a five-year plan. The 2017-2021 plan includes three goals, related to quality in Home and Community-Based Services (HCBS), secondary transition, and leadership development. In this report, we highlight some of our work towards each goal.



2020 Progress Towards Goals

Goal 1

Adults with intellectual/developmental disabilities experience improved quality in Home and Community Based Services.



The Council works with the Idaho Department of Health & Welfare and other partners in the **Community NOW!** (CNOW!) stakeholder collaborative. CNOW! is focused on planning for improvement of Medicaid HCBS available to adults with developmental disabilities. We spend time with individuals with disabilities and family members to assist them in fully understanding complex information, so they are able to lead systems change discussions and activities.



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

For every CNOW! meeting, a pre and a post CRAG meeting are facilitated by Council staff. The pre-meetings allow Council staff to provide in-depth education about agenda items, ensure understanding, and provide each member the time to consider the discussion topic within their own lived experience before the large CNOW! stakeholder meetings take place. Post-meetings are facilitated by Council staff to review the discussion that takes place in the CNOW! meetings and answer questions.

Two Spanish language interpreters are available and captioning is provided for CNOW! and CRAG meetings. The Council intentionally works with the same two interpreters with two goals in mind:

- 1) To build their vocabulary of the developmental disability service system, and
- 2) Help to build relationships with CRAG members.

All information to be presented in CNOW! meetings is translated into Spanish and mailed to each member two weeks before for their review.

The role of the CRAG:

At the October 2019 post CNOW! meeting, CRAG members expressed concern about the Person-Centered Planning Facilitator qualification requirement to have a Bachelor's degree. Members said there were currently not enough bilingual Targeted Service Coordinators or Support Brokers to serve the Spanish speaking community in Idaho. Degree requirements for Person-Centered Planning Facilitators would be a barrier to those from the Latino community. Some CRAG members believe what makes a good facilitator are not things that can or need to be studied in college. This input from CRAG members resulted in a waiver for the education requirement.

"More important than education is *corazón* - the desire, passion, and deep understanding of disability and accessibility. There is no training that can be a replacement for *corazón* in a professional."

In September 2020, the Council hosted a 6-part virtual **Person-Centered Thinking Training** for individuals with developmental disabilities, family members, service providers and others. Trainees learned tools and skills to really listen to individuals and support them in planning for their services and lives.



"I definitely approach any situation better equipped. After taking the training I will be aware to have an open mind on how to deal with others. I feel that I will have a better chance at understanding the people I serve by not assuming anything, but rather listen to what they have to say."

Goal 2

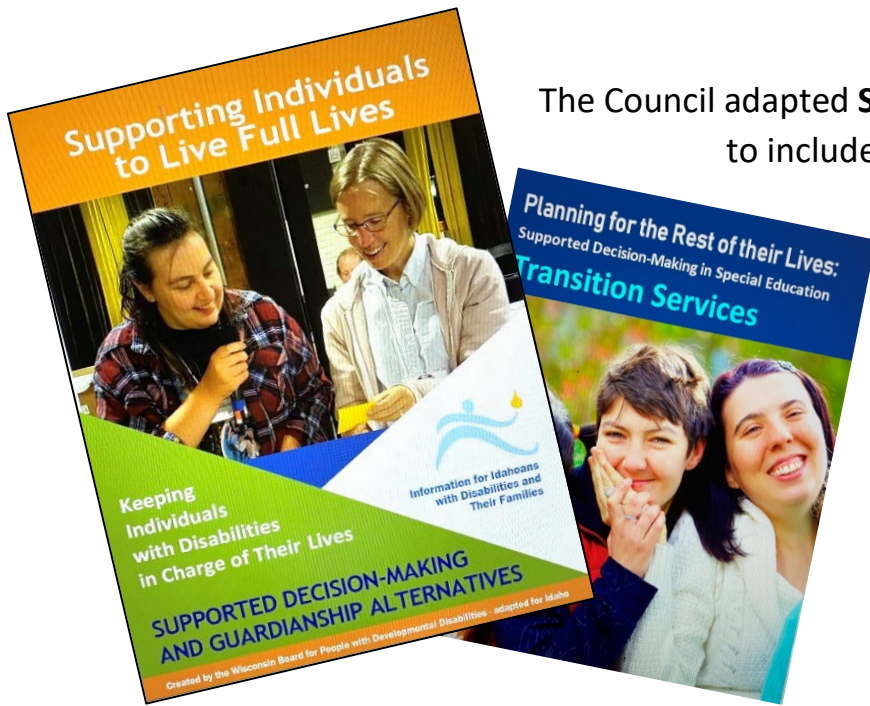
Youth and young adults with intellectual/developmental disabilities transition from school into an adult life that includes competitive integrated employment, community engagement, and full citizenship.



ICDD staff helped to plan and host a two-day 2019 **Idaho Secondary Transition Institute** at Boise State University in November 2019. The Institute is supported by a collaboration of partners from the Idaho Interagency Council on Secondary Transition which is sponsored by the Idaho Department of Education. Educators, Vocational Rehabilitation Counselors and school administrators received information about best practice in secondary transition planning for students in special education. School districts teams from across Idaho spent two days learning new strategies and developing district transition plans to improve post-secondary outcomes for students with disabilities.



As part of the Transition Institute, ICDD partnered with DisAbility Rights Idaho to provide two sessions on how to use **supported decision-making** in special education and planning for transition. Thirty-five attendees participated in these sessions.



The Council adapted **Supported Decision-Making publications** to include state-specific information. Publications were given to teachers, parents, and others who work with transition-age youth and adults. They are also available on the Council website.

As a partner in the Idaho Living Well grant, the Council is supporting a workgroup to develop content for training modules in topics related to self-advocacy. One of the topics is Supported-Decision Making and the training module will be developed from the perspective of people with intellectual and developmental disabilities.



Supported Decision-Making is getting help when you need it, from people you trust, so you can make your own decisions.

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.

Advocacy Coalition

The fourth year of the statewide Advocacy Coalition showed growth with 255 active people involved in the network from all over Idaho including 64 individuals with developmental disabilities and 123 family members. Supporting the statewide Advocacy Coalition is a collaborative effort with the Center on Disabilities and Human Development at the University of Idaho and DisAbility Rights Idaho.

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

Over the year the Coalition...

- Met with staff from Senator Crapo's Washington DC and Idaho offices to build support for targeted, federal assistance for Medicaid-funded Home and Community Based Services. COVID-19 fragmented these services, creating great challenges for individuals with I/DD, families and direct care staff.
- Developed and distributed an educational video on how to obtain an absentee ballot to vote by mail.
- Helped to provide **education on absentee voting**.



“People voted for the first time.”

Many of the seasoned advocates had voted before, but in-person at the polling booth. The Coalition contacted 37 self-advocates about voting by mail and worked directly with 16 people. This effort resulted in Coalition members voting for the first time.



Council staff led the planning committee for **Fred Riggers Disability Awareness Day** at the Idaho Statehouse organized by the Consortium for Idahoans with Disabilities. This event provides an opportunity for disability organizations and their members to participate in the legislative process, invite legislators to learn more about the organizations and resources in Idaho for people with disabilities, and award a member of the disability community for their exemplary service to the disability community. Nineteen organizations participated in the event.



During Disability Awareness Day, four individuals with developmental disabilities and five family members from the Latino community visited the Statehouse and met with their legislators to discuss issues that were important to them. Interpreters were available for individuals who needed this support.

Families advocate for people with developmental disabilities at Capitol

By **RACHEL SPACEK**
rspacek@idahopress.com

BOISE — Dozens of advocates filled the Idaho Capitol rotunda on Tuesday to celebrate Fred Riggers Disability Awareness Day and to meet with legislators about issues that will impact people with disabilities this session.

Junior Lazaro, 17, woke up bright and early Tuesday to make the commute from his family's home in Caldwell to the Capitol. He had a 10:30 a.m. meeting with his local senator, Republican Patti Anne Lodge.

Lazaro, accompanied by his Spanish-speaking mother and an interpreter, told Lodge that if an expedited eviction bill comes up again this session and passes, it would have negative impacts on his family.

"It would be very detrimental for me and my mom and especially my little brother," Lazaro said.

Lazaro said both he and his little brother are autistic, but since he is more high-functioning, he feels like he is his little brother's voice.

"There has not been any bill proposed this year to speed up evictions, but in previous sessions, the Idaho Apartment Association has introduced a bill that would require evictions be completed within an expedited time frame. The time frame called for a court trial to be held no more than 12 days from the filing of a complaint for the eviction."

"The ACLU of Idaho recently told the Idaho Press they expect to see the expedited eviction bill come up this session."

"It concerns us because it provides a burden on due process," said Ruby Mendez-Mota, advocacy fellow with the ACLU.

She said the bill would "disproportionately harm" vulnerable communities.

Last session the bill narrowly failed to pass the House.

Melissa Morales, program specialist for the Idaho Council on Developmental Disabilities, said she wanted to highlight the work of Latino advocates at the Capitol on Tuesday. (Morales is also a member of the Idaho Press editorial board.)

"I am very proud of them," Morales said about the Lazaros and other Latino families who met with their legislators Tuesday. "It takes a tremendous amount of courage to step into the Statehouse and fight for a community that doesn't always include you. I am so proud that they are willing to take that on and fight for all of us, when we don't always return the favor."

Morales said many of the advocates used an interpreter to speak to their legislators, something she said many legislators were not used to.

"When you have some-



Junior Lazaro and his mother stand with Sen. Patti Anne Lodge in the Idaho State Capitol on Tuesday.

one that has a language-access barrier, but also a disability like autism, we need to know that when we talk about accessibility, that we include all of that," Morales said.

FRED RIGGERS DISABILITY AWARENESS DAY

Along with meeting with their legislators,

the group of disability advocates met in the Capitol rotunda for a small ceremony to remember Fred Riggers, who died in 2016 at 73 years old and who fought many years for equal rights of people with disabilities.

Attendees were clad in bow ties, Riggers' signature accessory every time he went to the Capitol.

"The Consortium of Idahoans (with Disabilities) come together every year and spend time looking into what policies to ensure (legislators) are working for people with disabilities," said Jennifer Zielinski, board chair of the Consortium of Idahoans. "We look at things that would hinder and create setbacks and at what needs a stronger voice to say 'no' and people stand up to it."

The Consortium for Idahoans with Disabilities, a coalition of Idaho agencies and organizations concerned with issues affecting people with disabilities, comes together every year in the rotunda to advocate for themselves to legislators and meet and collaborate.

Rachel Spacek is the Latino Affairs and Canyon County reporter for the Idaho Press. You can reach her at rspacek@idahopress.com. Follow her on Twitter @RachelSpacek.

COVID-19 Pandemic Response

The Council, Coalition members, and Developmental Disabilities Network staff conducted a **survey to check in** with 24 individuals with developmental disabilities and 90 family members. People reported they were anxious, and said that they were concerned about their health, their services and supports. Parents of young children with disabilities were struggling to manage everything.

“Remote learning is a joke. I am now having to choose between working to support the family, or being the educator, caregiver, school aide, and therapist, or being the mom. Can’t do it all and we have very little support right now.”



“As a family we are struggling with the twins and trying to bring consistency into their lives when there is little to no services and service hours are constantly changing.”

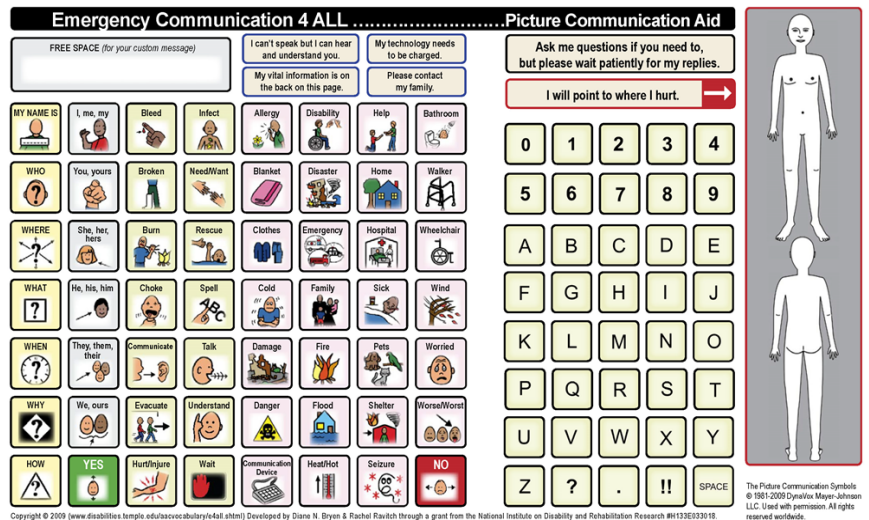
The Council responded to the COVID-19 pandemic in many other ways:

- Provided ongoing COVID-19 information updates in plain language and in Spanish to help people stay informed with fact-based information;
- Provided technical assistance to the Department of Health & Welfare and Governor’s Office for plain language in their Fact Sheets;
- Successfully advocated for a specific phone number for Spanish speaking families and individuals to call the Department of Health & Welfare;
- Distributed 1,000 handmade facemasks to the farmworker community coordinated with the Idaho Community Council and Living Independent Network, Inc.



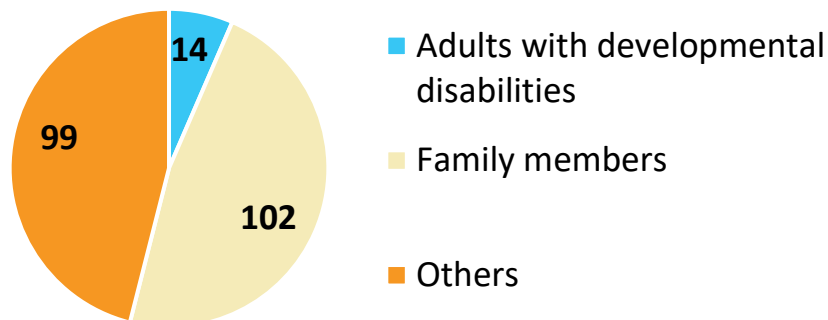
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EMERGENCY
COMMUNICATION TOOLS
MAILED TO INDIVIDUALS,
FAMILIES, AND OTHERS



As a result of concerns and needs that were raised by individuals with developmental disabilities and family members, the Council hosted **webinars**. Topics included changes in services through the Adult and Children's DD programs, how to get the services you need in education, laughter yoga, managing COVID-19 stress, and coping strategies.

215 people attended one or more webinars:



"These webinars for coping during this COVID-19 pandemic time have been very helpful for me as both a family member and care provider for an individual with developmental disabilities. I appreciate all the individuals that have taken the time to plan, prepare, and present ideas that are helpful for coping with the added stress, anxiety, and strain at this time in the world. There have been ideas for activities to do, self-care ideas, meditation, breathing exercises, and much more. Thank you."

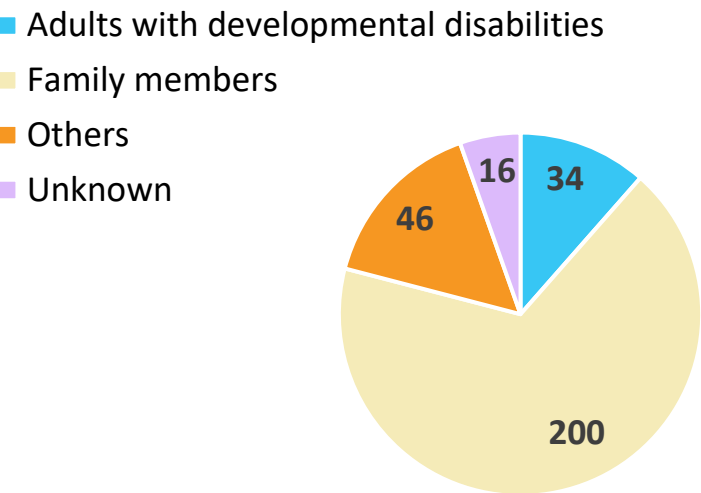
Collecting Public Input

The Council work is based on a five-year plan. Every five years, the Council collects public input to learn the needs of people with developmental disabilities and their families and determine what the Council should work on over the next five years. In 2020, the Council collected public input through two surveys: a general survey that 296 people responded to, and a survey targeting Idaho’s rural counties that received 203 responses. The Council also conducted four focus groups around specific topics. The collected public input informs the development of the Council’s 2022-2026 Plan.

General Survey

Most responses to the General Survey came from people in Ada County (126) and Canyon County (49).

296 people responded to the General Survey



Top 3 areas selected by respondents:

- 1. Access to Home and Community Based Services
- 2. Preventing and Recognizing Abuse and Neglect
- 3. Education

“Me being different and having to use supports doesn’t make me any less of a person. I still want to live life to the fullest and want to be able to do that.”

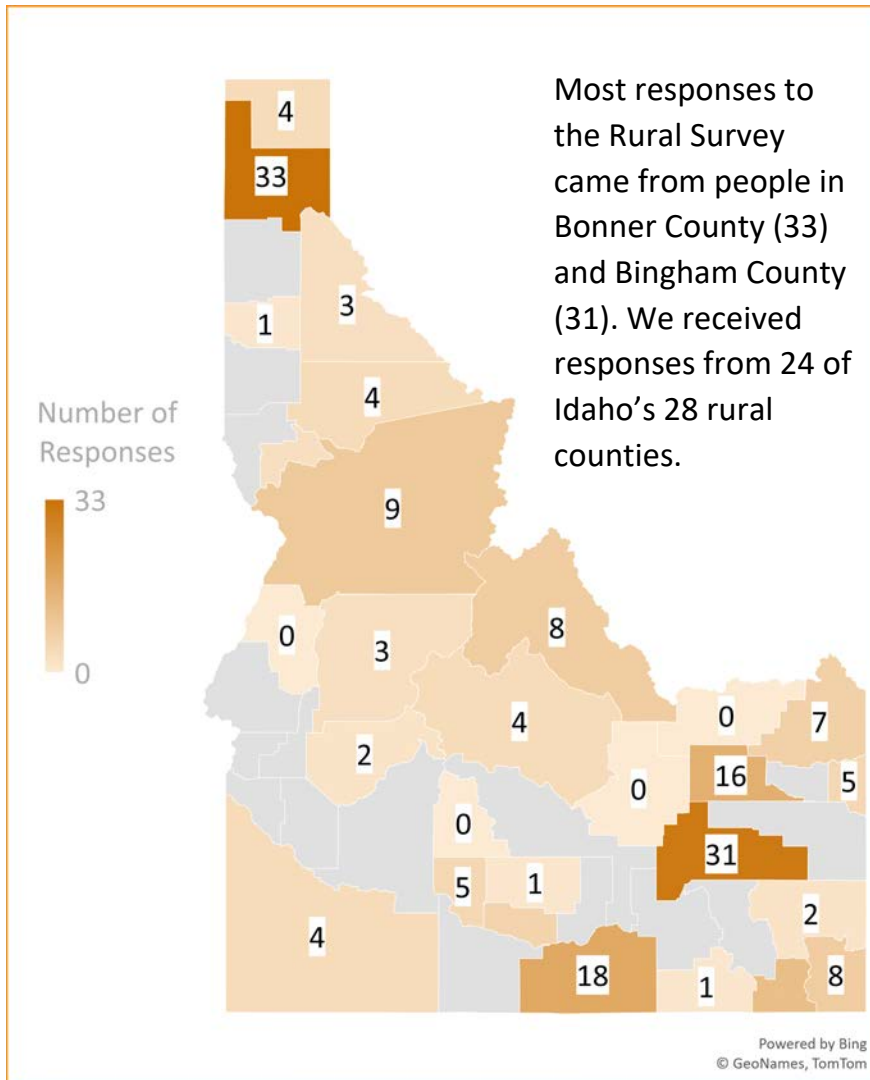
Focus Groups

The Council hosted online focus group discussions around four topics. Individuals with developmental disabilities, family members and others shared their experiences and ideas about:

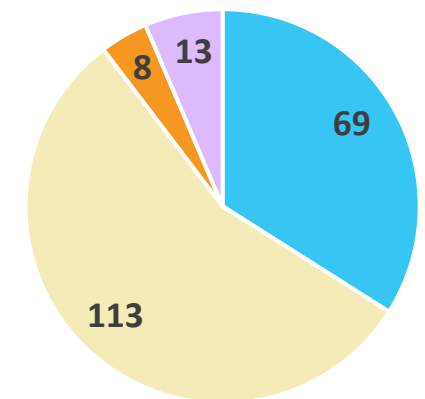
- Direct Support Professionals
- Abuse
- Neglect
- Financial Exploitation

Rural Survey

Because the number of responses from Idaho's rural counties to the General Survey was low (24), the Council followed up with a survey that specifically targeted Idaho's 28 rural counties. In this survey, individuals with developmental disabilities, family members and others were asked to identify issues in rural Idaho that prevent people with disabilities from living the lives they want in their communities.



203 people responded to the Rural Survey



- Adults with developmental disabilities
- Family members
- Others
- Unknown

The biggest issues in rural Idaho according to survey respondents:

1. There are not enough recreational opportunities and activities in my area that are accessible.
2. There is not enough accessible public transportation in my area.
3. There are not enough Developmental Disability service providers in my area.
4. There are not enough employment opportunities in my area.
5. There are not enough Direct Support Professionals in my area.

2020 Council Members

New members joined the Council in July 2020 and are noted as *(new)*.

James Steed, **Chair** (to April 2020), *Advocate, Blackfoot*

Emily Petersen, **Chair** (Appointed April 2020), *Parent, Kimberly*

Danielle Reff “DR”, **Vice-Chair**, *Advocate, Boise*

Ian Bott, *Advocate, Boise*

Amy Cunningham, *DisAbility Rights Idaho*

Lydia Dawson *(new)*, *Idaho Association of Community Providers, Community Non-Profit*

Art Evans, *IDHW-Division of Medicaid*

Julie Fodor, *Center on Disabilities and Human Development, University of Idaho*

Jenna Garrett *(new)*, *Parent, Moscow*

Nanna Hanchett, *Vocational Rehabilitation*

Alan Jack Hansen, *Advocate, Boise*

Jacob Head, *Advocate, Rexburg*

Deedra Hunt, *Commission on Aging*

Valerie Hurst, *Parent, Boise*

Gina Johnson *(new)*, *Advocate, Meridian*

Maria De La Luz Moreno *(new)*, *Parent, Boise*

Natali Pellens, *Parent, Coeur d’Alene*

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

Claudia Saustegui, *Nampa YMCA, Community Non-Profit*

Carly Saxe, *Advocate, Eagle*

Adrienne Seamans, *Parent, Idaho Falls*

Charlie Silva/ Karren Streagle *(new)*, *Special Education -Department of Education*

Colleen Sisk/ Anthony Gassman *(new)*, *Syringa Family Partnership, Community Provider*

LaDonna Tuinstra, *Parent, Kuna*

Jacquie Watson/ Sarah Lopez *(new)*, *IDHW-Maternal and Child Health*

Edgar Zuniga *(new)*, *Advocate, Caldwell*

2020 Council Staff

Christine Pisani, *Executive Director*

Marieke Edwards, *Research Analyst*

Trisha Hammond, *Management Assistant*

Richelle Tierney, *Policy Analyst*

Tracy Warren, *Program Specialist*

Our Developmental Disabilities Network Partners:





**IDAHO COUNCIL ON
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DISABILITIES**

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