



Idaho Council on Developmental Disabilities

2019

Annual Report

OCT 2018 – SEPT 2019

"I learned that people with disabilities have dreams and that, as a Family, I am key to help my loved one to achieve their dreams."



An estimated 31,000 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.



2019 Council Members and Staff

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.

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 critical role in the leadership development of individuals and families and as innovators in the development of community programs as directed by individuals and families.

2019 Progress Towards Goals

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

The Council worked on systems change initiatives, provided information about best practice, and supported advocacy and full participation of individuals through a variety of activities:



HCBS DD Services Quality Assurance

- Worked with the Idaho Department of Health & Welfare and other partners to continue our support of the **Community NOW!** (CNOW!) stakeholder collaborative focused on planning for improvement of home and community-based services through Medicaid available to adults with developmental disabilities. Council funds supported a contract for meeting facilitation and staff resources to support individuals and families to successfully lead.
 - We specifically focus on preparing and supporting individuals with disabilities and family members to fully participate and lead systems change discussions and activities.
- Worked with our DD Network partners as a sub-recipient of the **Idaho Living Well Grant**, funded through the Administration on Community Living, and coordinated by the Center on Disabilities and Human Development at the University of Idaho. The grant funded work for the Council with state partners to provide a statewide education campaign to educate the public about person-centered practice and develop a self-advocacy train-the-trainer model. The Council also participated in work to develop quality training and a career path for direct support professionals and improve monitoring and reporting of the abuse, neglect, and exploitation of people receiving HCBS services.
- Produced a film – **Blessings of Liberty** - to inform state legislators and the public about the importance of Medicaid in the lives of Idahoans with developmental disabilities and their families (see page 7).



Best Practice in Direct Support

- Traveled all over Idaho on a **Statewide Education Tour**. The Council recruited, trained, and supported self-advocate and family trainers to present information to local audiences about: behavior as communication; presuming competence; and knowing your rights. Two of the trainings were provided specifically for Spanish-speaking individuals and families. In all, 127 individuals with intellectual/developmental disabilities, 310 family members and 162 others participated in the 17 trainings hosted in 12 different communities. Most (94%)

"I learned that we all communicate differently and that I deserve to be heard."

"I felt like the true focus of participants directing their lives and choices was truly highlighted in a manner that hit home. The focus on individuals was fantastic."

attendees stated that they were satisfied with the training. Many attendees commented that they appreciated receiving training in their own region and learning directly from self-advocates.

- Participated in the Idaho Living Well grant **Direct Support Professionals workgroup**.

Person-Centered Planning Services

- An implementation plan for person-centered planning (PCP) services was updated. A CNOW! workgroup met throughout the year and focused on developing recommendations for a PCP facilitator and provider qualifications for the new service.
- Facilitated a meeting of Medicaid programs administrators, key staff, and contractors to share the Community NOW! **vision for person-centered planning** in Idaho.

Services for People with Dual Diagnosis (targeted disparity)

- Sponsored and coordinated training by Julie Brown, Ph.D. who provided a three-day Skills System workshop to for **73 mental health clinicians**. In the post-training survey, half of the attendees indicated that they felt more prepared to serve individuals with a dual diagnosis, and 77% of the clinicians stated that they were planning to serve more people with a dual diagnosis.
- The Council supported a day-long track of sessions in trauma-informed care at the state Human Partnerships Conference to direct support professionals and family members.
- The Council sponsored Dr. Karyn Harvey to conduct a day long training for 66 individuals, families, service providers, and key Department of Health & Welfare staff, on trauma informed care approaches for people with intellectual and developmental disabilities.

"[I learned] to assume very little and understand that trauma can be the source of great expressions of fear, striving to be safe, survive and ultimately be free from suffering."



- Council Chair, James Steed, was supported by Council staff to serve on the Advisory Board for National Mental Health and Intellectual and Developmental Disabilities Training Center

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 collaborated with partners to develop information and resources for youth with disabilities and families and built community capacity through training in innovative practices:

Strength-Based, Person-Centered Secondary Transition Planning Process

- The Council supported a workgroup of educators, Speech Language Pathologist, and communication specialists to begin development **communication strategies** to help youth and young adults who experience unique communication challenges engage in Core Gift interviews and other transition planning assessments.
- Communication strategies were piloted by Dr. Jenn Gallup at the Academy NextT transition and pre-employment summer program as part of a Council-funded research project to inform the development of learning modules for educators and other professionals to build skills in supporting communication.
- The Council partnered with DisAbility Rights Idaho to provide 3 trainings in **supported decision-making and alternatives to guardianship** to youth/young adults with disabilities, parents, and educators.
- The Council supported keynote presenter, Jonathan Martinis to present on creating a culture of collaboration and supported decision-making at the **Idaho Secondary Transition Institute** for school teams who traveled to BSU from districts all over the state for two days of learning and planning together to improve transition from high school for students in special education.
- Council staff hosted a photo booth at the annual state **Tools for Life: Secondary Transition and Technology Fair** where we surveyed students in special education, parents and educators about their experience planning for transition and to get their ideas for improving this process.



Transition to Employment

- The Council participated in a statewide coordinating committee on **Long Term Employment Supports** hosted by Vocational Rehabilitation and facilitated a quality assurance workgroup that provided policy recommendations.
- Funded contractor to update the English and Spanish versions of the **animated SSA and Work videos** for 2019 posted on the Idaho Department of Labor YouTube channel. Click on the logo below to link to IDOL videos listing on YouTube.



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.*

Leadership Development

- The Council hosted six “**Advanced Partners**” sessions around the state to continue leadership development for previous Partners in Policymaking graduates with 37 self-advocates and 43 family members participating. We partnered with DisAbility Rights Idaho to provide training in supported decision-making at the sessions. Attendees shared experiences in group discussions about the effect Partners in Policymaking has had on their lives.

“Partners, from my vantage point with the Advocacy Coalition, is an excellent grounding in Advocacy, policy and the history of disability issues. I rely on Partners grads to engage in active policy campaigns and to bring others along.”

- The Council sponsored Jonathan Martinis to present two half-day training sessions in **Supported Decision-Making** for individuals with disabilities and family

members. We partnered with the Idaho Department of Health & Welfare to livestream the sessions to 7 locations around the state. A total of 160 attendees completed a survey; 94% said that they were satisfied with the training. Related publications were printed and distributed.

- Published Idaho versions of **Supported Decision-Making** publications in English and Spanish, printed versions distributed statewide, and posted online for download.
- Established the **Self-Advocacy Training Implementation Workgroup** to develop a sustainable state model for train-the-trainer and self-advocacy training as part of the Idaho Living Well grant.

Statewide Advocacy Coalition

- Continued support of the statewide **Idaho Advocacy Coalition** (see next page)
- Funded a subgrant with community organizer, Connexus Ltd. to support Advocacy Coalition activities and development.
- The Council funded and supported a **Leadership Academy** with 43 Coalition members attending. This DD Network collaboration provided education to build leadership and advocacy skills and prepare for the upcoming legislative session. Fourteen self-advocates, 13 family members and 4 others completed surveys. All respondents were satisfied with the Leadership Academy. They enjoyed learning about policy issues, learning to (better) tell their stories, and connecting with other Coalition members.



The Council made impact by...

Developing leaders and reaching policymakers through the statewide Advocacy Coalition



The third year of the statewide Advocacy Coalition showed growth with 238 people on the list from all over Idaho including 116 family members and 57 self-advocates. 190 people are signed up to receive information text alerts about current and emerging issues. The Council is proud of the work of our Advocacy Coalition members over the past year:

“The Coalition and Council has made me a stronger advocate. I have learned it is easier to talk to legislators. We all make a difference and all our personal stories matter.”

- Advocacy Coalition members and other local advocates hosted community conversations with legislators about block granting Medicaid. Many policymakers came to the conclusion that this was not a good plan for Idaho
- Coalition members advocated against adding work requirements as part of Medicaid expansion with 60 members providing public comment to the Dept. of Health & Welfare
- Advocacy against state legislation to allow expedited evictions helped to defeat of the bill on the House floor

Blessings of Liberty ~ This film, produced by the Council, features Idahoans with disabilities and family members talking about the importance of Medicaid Home and Community-Based Services in our state. The film premiered in Boise at the Statehouse with 255 in attendance including 16 legislators, the Lieutenant Governor, Director of Health and Welfare, and other policymakers. Coalition members hosted screenings of the film in local communities including Nampa, Twin Falls, Idaho Falls and Coeur d’Alene where attendees totaled 142 people including 9 legislators. Local community conversations reached 20 legislators.



Listening and continuing to learn how to be culturally responsive.

As part of our federal mandate to address **identified targeted disparities**, the Council contracted with a **Cultural Broker**, Griselda Camacho who did outreach to the Latinx community and provided educational activities for Spanish-speaking families who have children with developmental disabilities. Ms. Camacho and Council staff worked with state agencies doing systems advocacy related to access and linguistic competency in services including work with the Division of Vocational Rehabilitation and Department of Health and Welfare.

Spanish-speaking individuals and family members were supported to be full participants in several Council projects including Community NOW!, Advocacy Coalition Leadership Academy, Blessings of Liberty events, and Advanced Partners sessions. Council publications, information releases and training materials are translated into Spanish. The Council was successful in other ways as well:

- Supported the Las Señoras group to plan and host another family conference for the Latinx community - **“Construyendo Mi Futuro – Yo Soy El Cambio!”** (Building My Future – I am the Change!) A total of 249 people attended the conference and 161 attendees completed a survey; 96% were satisfied with the conference. Attendees appreciated being able to learn in their own language and learning about the resources and information available.



"[I learned] that people with disabilities have dreams, and that as a Family I am key to help my loved one to achieve their dreams."



- Successfully advocated for the development of the required **Assistance with Medication class provided in Spanish** for Certified Family Home (CFH) providers. By providing the class in Spanish the Council was able to successfully remove the barrier to attend this class for CFH providers in the Latinx community. The first training was provided to 25 Spanish-speaking Certified Family Home providers in January.

- Supported individuals with developmental disabilities and family members from the Latinx community with education and facilitation to serve as the Community NOW!'s **Culturally Responsive Advisory Group**. The advisory committee provides culturally and linguistically competent recommendations for the adult developmental disability program.
- Supported individuals with developmental disabilities and family members from the Latinx community to attend the Fred Riggers **Disability Awareness Day** at the Capitol and meet with their legislators.



2019 Council Members

James Steed, **Chair**, *Advocate, Blackfoot*

Ian Bott, **Vice Chair**, *Advocate, Boise*

Art Evans, *IDHW-Division of Medicaid*

Dina Flores-Brewer, *DisAbility Rights Idaho*

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

Nanna Hanchett, *Vocational Rehabilitation*

Alan Jack Hansen, *Advocate, Boise*

Jacob Head, *Advocate, Rexburg*

Deedra Hunt, *Commission on Aging*

Valerie Hurst, *Parent, Boise*

Natali Pellens, *Parent, Coeur d'Alene*

Emily Petersen, *Parent, Kimberly*

Danielle "DR" Reff, *Advocate, Boise*

Michael Sandvig, *Parent, Idaho Falls*

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

Carly Saxe, *Advocate, Eagle*

Adrienne Seamans, *Parent, Idaho Falls*

Charlie Silva, *Department of Education*

Colleen Sisk, *Syringa Family Partnership, Community Provider*

James Steed, *Person Living in an Institution, Blackfoot*

LaDonna Tuinstra, *Parent, Kuna*

Jacquie Watson, *IDHW-Maternal and Child Health*



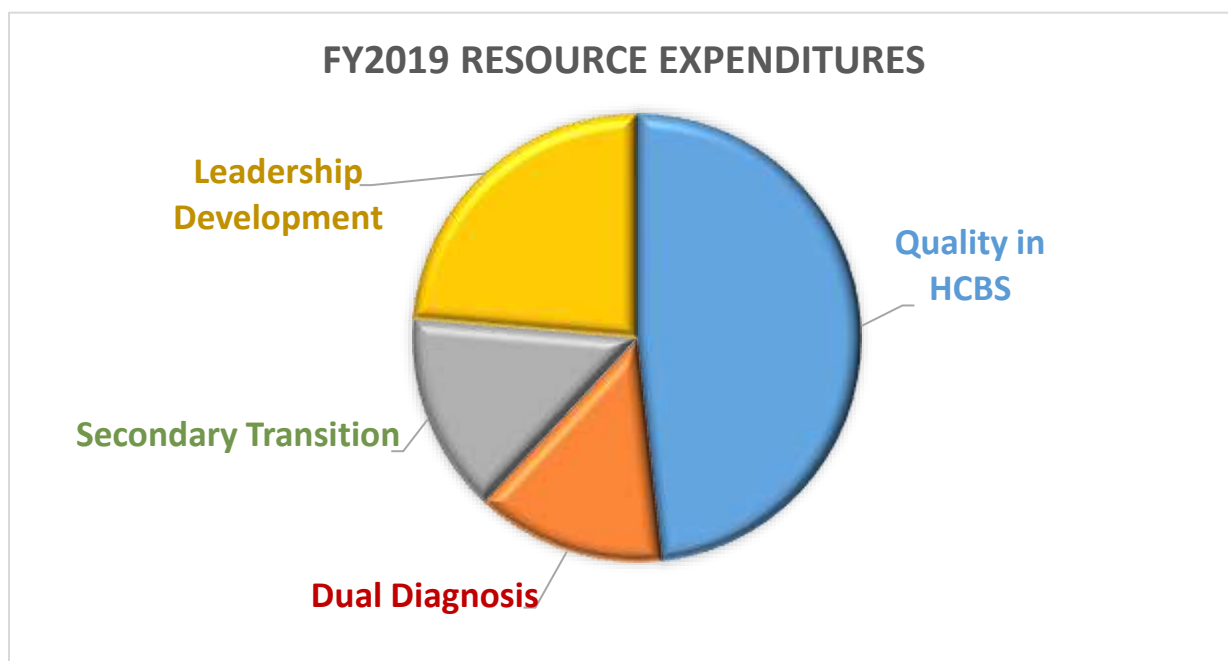
2019 Council Staff

Christine Pisani, *Executive Director*
Toni Belknap-Brinegar, *Program Specialist*
Marieke Edwards, *Research Analyst*
Trisha Hammond, *Management Assistant*
Laurie Lowe, *Office Assistant*
Melissa Morales, *Program Specialist*
Tracy Warren, *Program Specialist*



Use of Resources

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 2019 we were a sub-grantee of the Center on Disabilities and Human Development's federal Living Well Grant from the Administration on Community Living.





*The Council supported the **Community NOW!** Stakeholder Collaborative throughout the year to develop recommendations and provide input on policy and system infrastructure for improvements to Idaho developmental disability services.*

Council efforts included individualized support to ensure the full participation of individuals with developmental disabilities and family members in all systems change and policy discussions.



Contact Us

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