

# Getting to What Matters



Idaho Council on Developmental Disabilities

2015 Annual Report





## Our 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.*



## Who We Are

The Idaho Council on Developmental Disabilities is established and funded under the federal Developmental Disabilities 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. DD Councils focus on creating programs and advocating policy that empowers individuals with developmental disabilities and allows them to participate as equal members of society. We work to create an environment of self-sufficiency, self-determination, inclusion, and acceptance. Councils also play a critical role in quality assurance and as innovators in the development of community programs and solutions.



# Access to Health Care Matters

*Debra Parsons, Council Chair*

2015 was a year of information gathering and learning for me. It is always fun to gain knowledge and experience, but I will admit that some of the "stuff" I faced this past year was far more challenging than fun. Last winter my husband, Russell, was diagnosed with cancer and unfortunately, we were among the 78,000 Idahoans who fell into the **Medicaid Gap**. What does falling into the Medicaid Gap mean?

In 2014, thousands of uninsured Idahoans became eligible for assistance to help them purchase coverage through the state's health insurance exchange. This helped families with middle-income become healthier and more financially secure. However, thousands of Idahoans have been left out because they earn too little to qualify and don't have health care coverage through their work. Idaho has not yet taken action to make coverage available for this group of hardworking Idahoans who fall into the 'coverage gap.'



Because Idaho has not passed legislation that would allow for Medicaid coverage for 78,000 Idahoans, I spent whole days at the legislature last year sharing my story with as many legislators as I was able. The experience brought into sharp focus the need for affordable health care coverage for all Idahoans. The legislative session passed with no movement on this important issue, so the work needs to continue to educate and advocate.

As we continue to gather information, tell stories of people in the Medicaid Gap, and continue the dialogue with our elected officials, I have to believe we can make many positive changes in our great state.

I am grateful for the opportunity to serve the Council and work alongside other state Councils. We are not alone in this work. We can accomplish great things if we continue to work together.

***Working together, ordinary people can perform extraordinary feats.  
They can push things that come into their hands a little higher up,  
a little further on towards the heights of excellence.***







# The Individual Story Matters

*Christine Pisani, Executive Director*

As staff of the Council we often talk about the many and varied projects the Council undertakes and the meaning they bring to our work. Staff wholeheartedly agree that what is most meaningful in the work we do are the opportunities to learn from, and work directly with, adults with developmental disabilities and families.

While I hold great enthusiasm for so much of the work we do, we were presented an opportunity this year that has been a long time coming. The Council has been heavily involved in the successful implementation of the new Federal Home and Community Based Services (HCBS) Rules\*. The Council has hosted focus groups, written public comment on both transition plans, provided user friendly information to individuals and families to help interpret the rules, and participated in numerous meetings with the Dept. of Health & Welfare.

However, our largest investment in this specific work has been with our sister organization, the Center on Disabilities and Human Development (CDHD) at the University of Idaho. Over the past year we have created a statewide study, reflective of the wide and diverse range of support needs of all participants, including those with the most significant disabilities. This study is unique in that people on the developmental disability waiver are being interviewed in person. The family is included when the participant's disability presents a barrier to communication with researchers or if the participant asks for family to be included. The study will establish a baseline of what the service system looks like now through the eyes of adults with developmental disabilities. Researchers are asking adults about integration, choice, control, and privacy they experience with their HCBS services.

Our first interviews happened in north Idaho and we will continue to work our way across the state. There is no replacement for being invited into someone's home and hearing from them and their family about the details of their lives, how they make it work, or not. This is the first time the Council has participated in a study that intentionally seeks the opinions of everyone represented in the developmental disability waiver, and for me that is very exciting.

The results of this initial study will be provided to the Division of Medicaid for use in evaluating service provider compliance within the first year of implementation of the HCBS rules. A follow-up study is planned to include the same participants in 2019 to provide a comparison between pre and post implementation of the HCBS rules.

There is power in a personal statement. Stories help to paint a picture for policymakers. Stories present the real consequences, good or bad, of the rules and the laws they approve. Thank you to all of the individuals and families who have invited us into their homes. Thank you for the gift of "your story".

\* If you would like information about the Centers for Medicaid and Medicare (CMS) Home and Community Based Services (HCBS) Rules please visit: <http://hcsadvocacy.org/>.

***Your life begins  
to end the day you  
start being silent  
about the  
things that matter.  
Martin Luther King, Jr.***



# FY2015 Goals & Objectives

## Service System Improvement:

- Inclusive Education
- Employment First Initiative
- Disability Mentoring Day
- Quality Support Staff
- Developmental Disabilities Services Systems Change
- Community Development

## Leadership Development:

- Statewide Self Advocacy Organization
- Self Advocacy Leadership Training
- Leadership Development for Families
- Council Member Leadership

## Information, Outreach, Inclusion:

- Inclusion and Awareness
- Access to Information

## Policy Involvement:

- Participation with Coalitions
- Legislative Advocacy Training
- Council Policy Agenda and Member Advocacy

## Council Staff

Christine Pisani  
*Executive Director*

Toni Belknap-Brinegar  
*Program Specialist*

Suzie Hanks  
*Member Support*

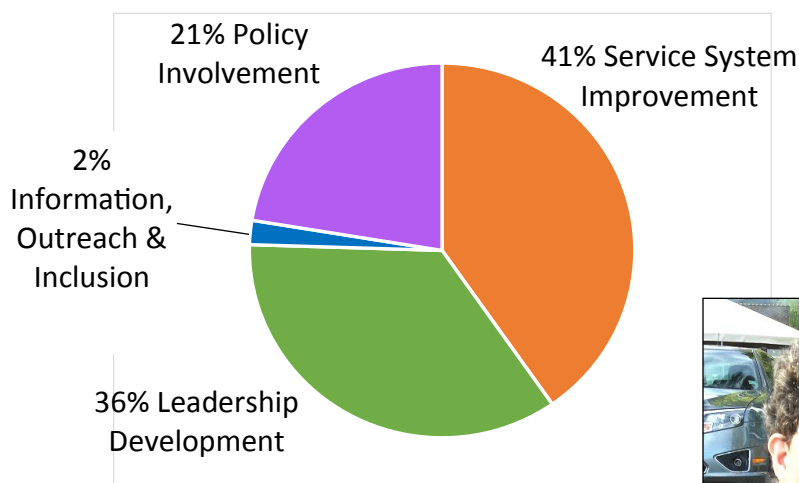
Laurie Lowe  
*Office Specialist*

Bonnie Markham  
*Partners in Policymaking  
Program Coordinator*

Tracy Warren  
*Program Specialist/Planner*

Jean Weber  
*Management Assistant*

## Fiscal Year Resource Distribution by Goal Area





# Inclusive Education



## Inclusive Education Summit

The Inclusive Education Task Force hosted an **Inclusive Education Summit** in November 2014 to provide information about a merged 4-year degree in general and special education and present the possible benefits of such a degree for students and teachers. Dr. Debi Gartland of Towson University, Maryland presented an overview of the merged education degree she developed at that university. The summit was attended by 41 people including: representatives of education departments from each of the 7 institutions of higher education; several school districts; general and special education teachers; school administrators and one school superintendent. Parents of children with disabilities from Moscow and Boise participated as well as representatives from the State Department of Education, Idaho Parents Unlimited, and the Council. A panel of self-advocates talked about their experiences while attending school in an effort to highlight the benefits of an inclusive education model. Summit attendees provided suggestions for 'next steps' in Task Force work to move Idaho towards an "All means **ALL**" model of education.



Kristin Beaver, Crystal Kepner-Roberts, Ian Bott and Tom Ball share their experiences.



Toni Belknap-Brinegar, Program Specialist at the Council, visits McKay Elementary School in Pendleton.

## Visit to a SWIFT Inclusion Model

The Council sponsored a trip to a Pendleton, Oregon elementary school for an on-site observation of a SWIFT (**School Wide Integrated Framework for Transformation**) model for inclusive education. The group included Angela Lindig of Idaho Parents Unlimited, an Idaho school administrator, and Council staff. The group learned how the model is positively affecting the school district and were able to discuss strategies and receive technical assistance from SWIFT professional, Jessica Dunn. As a result, the group increased the Council's knowledge about methods and strategies that could be part of a plan for systems change work in order to change school culture.



# Employment

## Disability Mentoring Day 2014

Five local projects were awarded grant funds from the Council for their Fall 2014 Disability Mentoring Day (DMD) activities. A total of **138 students** participated and were mentored by community employers/businesses. The projects were coordinated by groups in the following communities: Moscow, Lewiston, Boise, Twin Falls, and Idaho Falls. Highlights include:



In Idaho Falls orientation for students and families began a full week of DMD events. At orientation the mayors of Idaho Falls and Ammon signed proclamations about Disability Mentoring Day and Disability Employment Awareness Month. Many students visited Eastern Idaho Technical College programs after their job shadow to tour the education program that aligned with their career of interest. In Twin Falls teachers joined event coordinators for a discussion about transition topics and planning future mentoring activities while students were being mentored in community workplaces.

Idaho Parents Unlimited hosted a new project called “**A Work of Art**” based on a program that has been successful in Colorado. Four students interested in art careers were mentored by a professional artist to create a piece of corporate art. The students developed artistic skills as well as collaborative teaming skills and learned about the business of being an artist. The project culminated in a First Thursday event and display in the Creative Access Art Center.



## Employment First Initiative

The Council continued to support meetings and activities of the **Idaho Employment First Consortium (IEFC)**. This multi-organization group worked on three goal areas over the year including:

- development of parent/family outreach materials that encourage parents to set high expectations for employment while their children are young;
- learning about the employment-related data currently collected by a variety of agencies to inform the development of strategies for a state data reporting system that reports employment outcomes of people with disabilities;
- drafting recommendations for adding employment support services to Idaho's Medicaid waivers/plan including development of provider qualifications and training.

The Council hosted training for individuals, family members, Vocational Rehabilitation staff and employment support professionals through **Discovering Personal Genius trainings** around the state in June and September. 141 participants learned about this model of person-centered, community-based employment evaluation and planning through a contract with Griffin-Hammis Associates.





# Celebrating the ADA



Christine Pisani and Shiloh Blackburn congratulate award winner Jim Mairs.



Who can resist a giant turkey leg lunch?



Lining up for *Hands Around the Capitol* to kick off the event.

The Council supported the Boise event to celebrate the **25th Anniversary of the American's with Disabilities Act** with funding, staff time devoted to the planning committee and event set-up. About 1000 people attended the event that included 44 information booths and guest speakers including; **Kelly Buckland**, Executive Director of the National Council on Independent Living, **Lawrence Denney**, the Idaho Secretary of State, and others. The Council nominated long-time ally **Jim Mairs** with the Office of the Secretary of State for his advocacy on behalf of voters with disabilities.

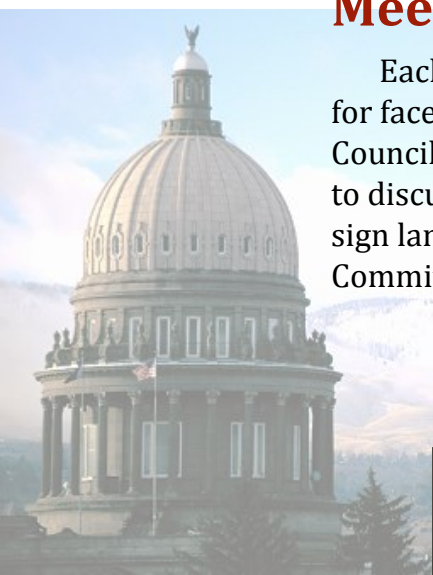
The Council also assisted the Secretary of State's office to conduct a public survey of various **accessible voting machines** inside the statehouse during the celebration . Event goers were encouraged to try each machine and provide feedback on accessibility and ease of use.



# Members Active in Advocacy

## Meeting with Policymakers

Each fall, Council members contact their district representatives and prepare for face-to-face appointments with legislators at their January meeting. Fifteen Council members visited with 12 Senators and 23 Representatives in January 2015 to discuss Council policy agenda issues including Medicaid expansion, licensure for sign language interpreters in Idaho and a request of a Joint Legislative Oversight Committee study on the Mental Health Managed Care contract.



Denise Wetzel and Joe Raiden met with Rep. Paulette Jordan (Plummer)



Sen. Roy Lacey (Pocatello) spent time with Shiloh Blackburn



Ian Bott and Shiloh Blackburn and staff Laurie Lowe meet with Rep. Mark Nye (Pocatello)



Ian Bott with Rep. John McCrostie (Garden City)



## Asset Based Community Development

One of the strategies used in our community development work in Caldwell is listening conversations with members of the community. During one of these conversations a relationship was developed with Mrs. **Griselda Camacho**. Mrs. Camacho shared her dream of bringing a Spanish speaking professional with a disability to Caldwell to present to Spanish speaking parents of children with disabilities. Mrs. Camacho has established a group of community-minded mothers called “The Senoras.” Through collaboration of The Senoras, Idaho Parents Unlimited, and the Council, a successful family educational event was held - “**Abriendo Caminos un Mundo Diferente**” and was attended by 50 parents and their children. The success of this event has led the Council to identify a Spanish speaking community connector that will serve the greater Caldwell area.



The Council utilized **community dinners** as another strategy to assist in building community in Caldwell. The Council hosted community pot-luck dinners throughout the year. Each dinner

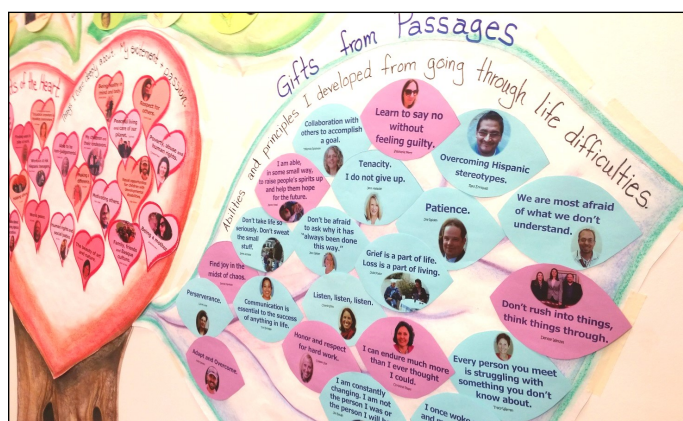
featured an introduction to ABCD concepts and activities to build trust and relationships with new people in attendance. Council staff met Mrs. Sonja Ruble, a certified ropes course instructor, through a community listening session. Mrs. Ruble has become an integral part of team building activities for the community dinners.



*Things that matter most  
must never be put at the mercy  
of those that matter the least.*

## Asset Based Planning: Focus on Gifts & Strengths

To continue our focus on assets, the Council engaged in activities to identify the talents, skills, and strengths of our members and staff. Each member completed a “**Three Gifts**” worksheet and staff created a graphic to emphasize the variety of assets we have at our disposal. Moving forward we will be reviewing the strengths of the Council from past work that has created positive impact in Idaho and use those strengths as strategies in our next 5-year plan.





## Medicaid Services Systems Change

The Council continued to facilitate and support the activities of the **Collaborative Workgroup on Adult Developmental Disability Service Redesign** (CWG). Membership includes multiple agencies and stakeholders invested in positive systems change in the developmental disability service system. In fall 2014 the CWG Steering Committee drafted a report with findings and recommendations that the **Council Director presented to the 2015 Health and Welfare House and Senate committees**. A narrated version of the report is available on the Council website at <http://www.icdd.idaho.gov>.



CWG Steering Committee members with Senate Health and Welfare Committee Chair, Senator Lee Heider.

The CWG indicated a desire to revise the current assessment and resource allocation system to ensure a method that aligns resources with actual individual needs as indicated by the person centered planning process.

After research of different assessment and resource allocation models the CWG generated a recommendation on preferred characteristics for an **Assessment and Resource Allocation process** for adults with developmental disabilities in the Medicaid system. The recommendation to IDHW encouraged the use of budgeting based on person centered planning. Through person centered planning, the participant and their team determine the individual participant needs and identify the hours and level of support required to meet those needs. The resource allocation process should:

- be transparent, easily understood, and welcoming
- be comprehensive in its definition of needs
- generate a budget that is fair and equitable
- feature flexibility to respond to changing needs

CWG recommendations regarding Resource Allocation were included in the packet for consideration by the IDHW Administrative Team and awaits a response.

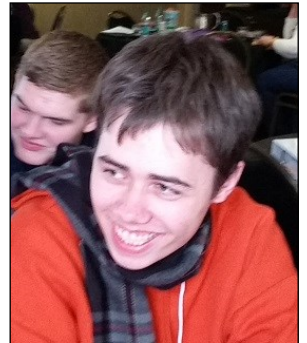
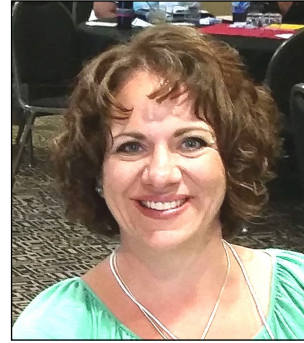


# Leadership Development

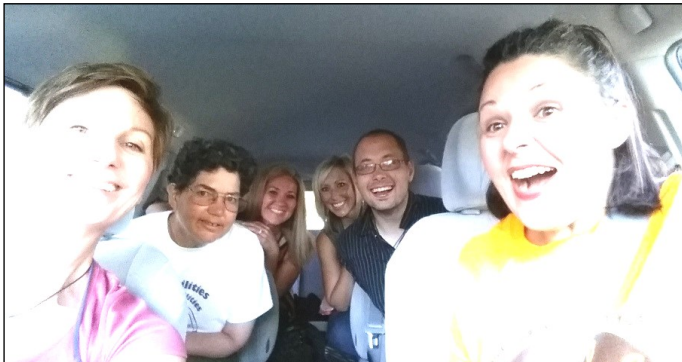
## Idaho Partners in Policymaking 2015-16 Class Begins



The Council is excited to be hosting the 9th class of Partners in Policymaking which began in September with 26 participants - 14 self-advocates and 12 parents. With this class we are experiencing many “firsts” for Idaho Partners in Policymaking: first time a child of a Partner graduate is attending; first time there are more self-advocates than parents in attendance; and the first time the Council is providing Spanish translation during class sessions.



*From top: Dennis Miller; Kevin Swearingen and Korynne Donehey, Jack Hansen, Camille Ashcraft and Kaleb McCloughan*



## Council Members and Staff Attend National Conference

The National Association of Council on Developmental Disabilities held their national conference and technical assistance institute in Reno NV last summer. Council Chair, Debra Parsons, attended new chair training and staff learned about new federal requirements and received guidance in the development of the Council’s next 5-year plan. Members also attended sessions on supporting self-advocacy and how to ensure the Council operates and engages in projects in a culturally and linguistically competent way. To save on travel costs, staff rented a van and the Idaho group made the long rode trip from Boise to Reno which created some time for teambuilding and fun together.



# Policy Involvement

## Keeping an Eye on Rights and Access

Because of concerns about due process issues within the state's Mental Health Managed Care contract related to **children and adults who experience dual diagnosis** (mental health and developmental disability), the Council has become increasingly concerned about the high rate of people with dual diagnosis, lack of qualified service providers that can address their needs, and limited access to services. The Council spent considerable time during the 2015 session educating the eight member Joint Legislative Oversight Committee (JLOC) about the need for a **performance evaluation** of the Mental Health Managed Care contract with Optum Idaho from the Office of Performance Evaluations (OPE). The committee unanimously voted in favor of a performance evaluation. Findings from the evaluation will be presented to the 2016 JLOC committee.

Council staff and members provided written and verbal testimony to educate policy-makers about Council positions on its **policy agenda issues** including: Establishing the Idaho Caregiver Alliance, Criminal History Background Checks - Rap Back program (related to prospective and current guardians), Licensure of American Sign Language Interpreters and the Anti-Bullying Legislation.

The Council hosted a listening session of a national webinar on the federal **ABLE Act** for Idaho stakeholders. We also worked to identify agencies and organizations interested in collaborating to draft ABLE Act legislation in Idaho to align with the federal law. The ABLE Act allows individuals with disabilities to save money without impact on their benefits. The Council coordinated with the Executive Director of IDEAL, the College Savings Plan, to host an initial meeting between policymakers, state agency personnel, the Governor's office, and disability advocacy organizations. This stakeholder group is working toward drafting legislation for Idaho.



Council members enjoyed a little "hat fun" during their fall Council meeting.





# New Faces in Membership and Staff



Jacob Head



Stephanie Perry



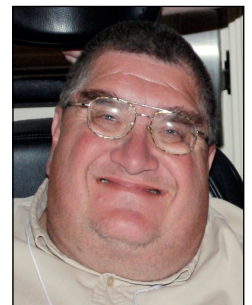
Jean Weber



Kelby Selders



Charlie Silva



James Steed



Bonnie Markham

## Changes in Membership

At the April 2015 meeting, the Council said goodbye to some long serving members (above from left holding certificates): **Shiloh Blackburn** (self-advocate/Chair) served for 9 years; **Paul Tierney** (parent) served 6 years; **Jean Christensen** who represented Medicaid on the Council for 4 years and is celebrating her retirement; and **Dona Butler** (guardian) serving over 10 years.

In July the Council welcomed newly appointed members including: **Jacob Head**, self-advocate from Rexburg; **Kelby Selders**, parent from Meridian; **Charlie Silva**, Director of Special Education at the State Dept. of Education; and **Stephanie Perry** to represent Medicaid. We also welcomed **James Steed** from Blackfoot who is filling the position of an individual living in an institution. James served on the Council for a short period in the past and for part of that time as Council Chair.

## Council Office Welcomes Two

**Jean Weber** joined the Council as a Management Assistant replacing Debbie Daniels who moved to Florida. Jean helps with managing our financial responsibilities, coordinates the Council budget, and supports the Executive Director among other duties.

Also joining the Council office is **Bonnie Markham** as our Partners in Policymaking Program Coordinator. Bonnie is a parent, Partners in Policymaking graduate and a Masters in Social Work student. Bonnie brings her knowledge and experience as a PIP graduate to the job of coordinating this leadership development program.

*What disability means matters.  
What it doesn't mean matters more.  
David Hingsburger*



# 2014-2015 Council Members

Shiloh Blackburn, **Chair** (until June 30), *Self-Advocate, Pocatello*  
 Debra Parsons, **Chair** (beginning July 1), *Parent, Victor*  
 Jenniffer Halladay, **Vice Chair**, *Parent, Kuna*  
 Jim Baugh, *Disability Rights Idaho*  
 Ian Bott, *Self-Advocate, Boise*  
 Dona Butler, *Guardian, Nampa*  
 Jean Christensen, *IDHW-Division of Medicaid*  
 David Dekker, *Self-Advocate, Jerome*  
 Tisha Dillon, *Parent, Nampa*  
 Jane Donnellan, *Vocational Rehabilitation*  
 Raul Enriquez, *Commission on Aging*  
 Julie Fodor, *Center on Disabilities and Human Development*  
 Rebekah Forster-Casey, *Parent, Coeur d'Alene (new V.Chair)*  
 Louis Garcia, *Self-Advocate, Boise*  
 Jill Mathews, *Department of Education*  
 Natali Pellens, *Parent, Post Falls*  
 Lance Pounds, *Self-Advocate, Nampa*  
 Joe Raiden, *Self-Advocate, Moscow*  
 TeRonda Robinson, *Community Partnerships of Idaho*  
 Colleen Sisk, *Partnerships for Inclusion*  
 Paul Tierney, *Parent, Nampa*  
 Jacquie Watson, *IDHW-Maternal and Child Health*  
 Denise Wetzel, *Parent, Moscow*



Chair Shiloh Blackburn accepts a certificate celebrating her 9 years of service to the Council.



Jenn Halladay, TeRonda Robinson, Dave Dekker and Shiloh Blackburn after meeting with legislators at the Statehouse.

## ***Boards, Councils, and Special Committees on which the Council is represented:***

- Aging and Disability Resource Center Advisory Council
- Center on Disabilities and Human Development Consumer Advisory Council
- Children's Service System Redesign Access Committee
- Community Care Advisory Council
- Consortium for Idahoans with Disabilities
- Early Childhood Coordinating Council
- Idaho Community Care Council
- Idaho USE Council
- Idaho Employment First Consortium
- Idaho Interagency Council on Secondary Transition
- Interagency Workgroup on Public Transportation
- Self Direction Quality Assurance Committee



Alan Aamodt, new representative for IDVR and Kelby Selders at the fall meeting.



# Vision

*All Idahoans participate  
as equal members of society,  
empowered to reach their full potential  
as responsible and contributing citizens  
of their communities.*



We celebrate our Council Member, Jean Christensen, on her retirement from 30 years of public service to the state of Idaho and her commitment to improving systems for people with developmental disabilities. Jean played a critical role in the implementation of the Medicaid self-direction option.  
**Thank you Jean!**

*Pictured on the front cover:* Council member **James Steed** at the ADA celebration with **Abigail Echevarria Selders**, daughter of Council member Kelby Selders.



## Idaho Council on Developmental Disabilities

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# Values

Independence  
Respect  
Equality  
Participation  
Integration  
Choice  
Partnership  
Responsibility  
Inclusion  
Community  
Quality of Life

