

Idaho Council on Developmental Disabilities



DEVELOPMENTAL DISABILITIES

An estimated 26,000 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.



2017 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 and advocating for 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.

What We Do Best

From stakeholder and partner feedback, past experience, and measuring outcomes, the Council has learned what it does best to be most effective in creating positive change for people with disabilities and their families in Idaho:

Interagency Collaboration

Whether joining meetings with partners and other agencies or forming a working group from the ground up to address key issues, this is one of the greatest strengths of the Council.

Community NOW! members presented a final report with recommendations for improvement to adult DD Services to the Dept. of Health and Welfare and Medicaid Administrators.





Leadership Development

The Council has greatly increased the number of people with intellectual and developmental disabilities and family members to be effective advocates, through the Partners in Policymaking leadership development program, developing curriculum and training individuals how to advocate for themselves, and building the awareness of best practice and how to effectively make change with policymakers.

Partners in Policymaking participant, Jessilyn Matthias



Introducing New Ideas and Promising Practice

The Council leads and funds innovative projects that demonstrate best and promising practice in working with, serving, and supporting individuals with developmental disabilities and their families. We advise state agencies on the development of new programs and work in collaboration with partners that can sustain new practices into the future.

Transition program teacher, Karen Gillette and Dept. of Labor staff, Kathy Drabek practice Core Gift interviews.

Informing and Working with Policymakers at All Levels

The Council has a long standing reputation for providing policymakers with accurate information and supporting individuals and families to participate in policy discussions. Staff and member connections to legislators, local government officials, and state agency administrators has increased our ability to achieve outcomes that matter.

The Council connects citizens to state and federal government:

- Educates individuals how to advocate for themselves in their own lives, local communities, and in having a voice in making positive systems change. Helps individuals learn how to communicate with their legislators and other policymakers.
- Explains regulations and policies to individuals and families.
- Ensures the voice of individuals with developmental disabilities and families in policy discussions and in comment on regulations and policies.
- Provides opportunities for public forums on disability issues.

Senator Marianne Jordan presents House Bill 43 to fund mental health services for children with serious emotional disturbance.



Griselda Camacho and TeRonda Robinsons meet with Representative Jason Monks, Nampa.





People rally in Idaho Falls in support of Medicaid programs.

2017 Goals and Objectives

In September 2017 the Council began the first year of a new five-year strategic plan that drives all projects and activities. The plan was developed by our Council members after seeking information from stakeholders, reviewing service system quality assurance data, and keeping track of other pertinent state data to create an overview of the status of Idahoans with developmental disabilities and their families.

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

This past year...

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:

- Worked with the Idaho Dept. of Health and Welfare to establish the **Community NOW!** stakeholder collaborative focused on planning for improvement of Medicaid services available to individuals with developmental disabilities.
- Led discussions with adults with developmental disabilities and family members through Community NOW! Listening Sessions around the state in spring 2017. Over 265 individuals attended the sessions and provided input about ways to improve their services.
- Supported individuals with developmental disabilities and family members to participate in Community NOW! working groups and present the final Community NOW! report with recommendations to Idaho Dept. of Health and Welfare administration, state legislators and other policymakers.

Director Russ Baron and Deputy Director Lisa Hettinger after hearing the Community NOW! final report.



The final report was presented by self-advocates and family members (from left to right): Ian Bott, Nora Jehn, Jeri Hyslop, Ned Fowkes, Larkin Seiler (in front) and Richelle Tierney (pictured bottom right).







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.

This past year...

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:

• The publication "Expecting a Bright Future - Growing Towards Employment and Future Success" was completed, printed and distributed statewide. This booklet, aimed at parents, students and educators, provides information to encourage families to set high expectations for their sons and daughters with developmental disabilities.



Training was provided to high school and secondary transition program teachers as well as Dept. of Labor (DOL) disability coordinators, and parents to learn how to conduct Core Gift interviews and use related tools to help students identify their gifts and strengths and how to use them in planning for employment and in their community. Faculty and students at Idaho

State University were also trained and they used the techniques with students attending their summer Academy NexT camp held on the ISU campus.



Tools for Life Pocatello March 2017

To help overcome one barrier to employment - the fear of losing benefits - six animated videos explaining Social Security work incentives were produced and made available to teachers, Vocational Rehabilitation counselors, Dept. of Labor staff and others who work with transition age students and their families. Funding from the Idaho DOL Disability Employment Initiative grant supported the project. The videos can be viewed on the DOL website at:

https://www.voutube.com/user/IdahoDeptofLabor

- Council staff hosted a photo booth at the annual state **Tools for Life**: Secondary Transition and Technology Fair held this year in Pocatello. The Council surveyed both students in special education and parents about their knowledge and experience with planning for transition to determine needed strategies in future systems change work.
- Council staff participated in planning with Vocational Rehabilitation to implement a **Customized Employment pilot** in Idaho. Training was provided to teams of teachers/school district staff, Vocational Rehabilitation Counselors, and Community Rehabilitation Providers from local areas in three regions of the state.

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.

This past year...

Council staff prepared to implement another Partners in Policymaking leadership development program that began in September. The Council also worked with a grassroots organizer through a sub-grant to help build the basis for a statewide policy coalition starting in one area of the state. Strategies were adapted when it became critical to educate our congressional delegation about the importance of Medicaid services to Idahoans and their families. Groups were informed and activated to advocate for the protection of Medicaid funding and programs at the federal level:

- Activated the newly formed **Idaho Advocacy Coalition** with information about proposed cuts to Medicaid at the federal level and supported individuals with developmental disabilities and family members to advocate and share their stories with congressional representatives.
- Supported Council members, Partners in Policymaking graduates, and many other disability advocates to inform Idaho congressmen and state legislators about the importance of Medicaid in the lives of Idahoans with developmental disabilities and their families.
- Followed **past Partners in Policymaking graduates** who are achieving goals they set during their program, including **Erin Rosenkoetter** who met with pre-service teachers at Boise State University about her experience being a special education teacher and the parent of a child with a disability.







The **2017-18 Partners in Policymaking** program began in August with 27 participants including 14 adults with developmental disabilities and 13 parents of children with developmental disabilities.



Impact

Over the past year the Council...

... provided training in innovative approaches:

• **Core Gift Discovery** is a promising practice to help youth identify the most important contribution they can make to their community. Gifts can be used to

help a young person decide on a vocational path that is meaningful to them, increase self-esteem, and be welcomed into a group. The Council collaborated with the Idaho Dept. of Labor Disability Employment Initiative to provide training to special education teachers, Dept. of Labor career counselors, Idaho State University faculty and students, and parent education coordinators in how to facilitate the Core Gift Discovery process. These certified Core Gift Master Facilitators conducted interviews with students, educational staff, individuals and parents to help them identify their gifts, strengths and contributions.

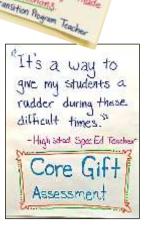
Community NOW! meetings and other systems change activities followed a
practice and format new to many state agencies – the ideas of people with
developmental disabilities and family members were the focus and main voice in
meetings and presentations. Planning and supporting full and meaningful
participation by ensuring preparation, accessible/plain language materials, and
taking the time needed in discussions were some of the practices demonstrated
by Council staff and embraced by state agencies throughout the process.





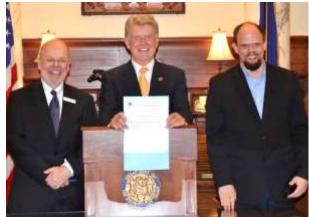






... developed or improved state policies and processes:

• As a member of the state ABLE planning committee, the Council drafted proposed legislation for a parttime technical assistance position to provide financial literacy education to people with disabilities and to educate Idahoans with disabilities and families about the opportunities to open savings accounts because of the federal **ABLE Act**. The Council negotiated with the State Independent Living Council to house the position and worked collaboratively to advocate for the position within the legislature. Council members, Advocacy Coalition members, and Partners in Policymaking



graduates (*Jack Hansen pictured right with Governor Otter and Sen. Grant Burgoyne*) worked diligently to inform legislators about the benefit to Idahoans with disabilities and families to have a position dedicated to provide ABLE program technical assistance and financial literacy.

• Council member, Jessica Rachels and her family worked tirelessly on a bill to increase education about **cytomegalovirus** (CMV) through the Idaho Dept. of Health & Welfare. CMV is a typically harmless cold virus but can cause permanent disabilities to an unborn child. The CMV legislation was passed and aims to provide education to healthcare providers, increase public awareness, and mandate CMV testing for infants who fail their newborn hearing screenings.



• ICDD worked to gather information from people with disabilities and families experiencing difficulty with the newly implemented contract for Non-Emergency Medical Transportation, Veyo. Council staff educated system administrators and other policymakers about significant issues related to transportation services provided by the contractor and proposed improvements to the overall service system that have been implemented.

> ...the Idaho Council on Developmental Disabilities has long been respected for its work helping Idahoans with intellectual and developmental disabilities live independent lives. The Council works diligently with them to be strong self-advocates in the policy making process and to improve services. This is especially important in a state like Idaho, where many reaches of the state do not have reliable internet access and in-person assistance is required. The DD Council is uniquely qualified to meet these needs.

> > ~Senator Michelle Stennett

... developed leaders and established a statewide Advocacy Coalition:

The first year of our Advocacy Coalition had to run hard right out of the chute. The intentional work of fostering leadership over time to build a statewide coalition took a backseat to keeping pace with the many challenges this past year to Medicaid at the national level. It was critical to mobilize the coalition members, and each person rose tirelessly to the occasion each time. However, the structure hoped to have been put in place last year to promote sustainable statewide growth of the coalition did not get set up. Instead the focus was working with our advocacy leaders and allies to host large state rallies, meetings with congressional staff, letter writing, phone calls, and keeping the issue in the press.

The Council is proud of the work of our Advocacy Coalition members with over 200 people attending Coalition hosted rallies in Idaho Falls and 125 people in Twin Falls. Members



Photo credit EastIdahoNews.com



also met personally with congressional staff multiple times in Idaho Falls, Twin Falls, and Boise. The Coalition also produced numerous videos featuring people with developmental disabilities and families to educate policymakers and community members about what was at stake with healthcare. You can view the videos on the Council's YouTube channel by clicking on the YouTube logo (left).

The Coalition kept the perspective of people with developmental disabilities and families in the media as the various healthcare bills presented themselves. These provide a few examples of the strong leaders in our state:

- Advocacy Coalition members and other local advocates held a large rally outside of Rep. Mike Simpson and Sen. Mike Crapo offices in Idaho Falls to get the word out about how much Medicaid offers Idaho including supports for students with disabilities in public education.
- Testimony at regional Idaho Dept. of Insurance and Dept. of Health and Welfare hearings on the proposed dual waivers by **Council members and Advocacy Coalition** members.



• Moscow Pullman Daily News story about Mike Smith who lives in his own apartment in Moscow with support from Medicaid-reimbursed services. Mike is a former DD Council member, Partners in Policymaking graduate, and works for the Center on Disabilities and Human Development at the University of Idaho.

• Advocacy Coalition members and partners held a sit-in at the Boise office of Sen. Mike Crapo and met with his staff.

- Idaho Statesman interview and a local television news story about Kristyn Herbert, a Boise woman with cerebral palsy who depends on Medicaid services to live in her own apartment. Kristyn is a former DD Council member and Partners in Policymaking graduate and Advocacy Coalition Member.
- ICDD and the Advocacy Coalition collaborated with the Idaho Close the Gap and Brian Whitlock, CEO of the Idaho Hospital Association on news conferences and a policymaker luncheon. Council Chair, Debra Parsons, talked about newly proposed state dual waivers to provide health care coverage to 35,000 Idahoans without access to healthcare coverage and the importance of Home and Community Based Services through Medicaid in individual's lives.

The policymaker luncheon hosted at BYU-Idaho in Rexburg included the Mayor Jerry Merrill, state legislators, and staff from Idaho's congressional delegation. A similar news conference and policymaker luncheon was held in Boise with Council members, state legislators and congressional staff in attendance.



Group at BYU-Idaho reviews health care landscape state action to provide health coverage to the roughly 78,500 idahmans in the Med-

Calls for state action on Medicaid

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were in attentions, as were members of BOU-blacks social work program. Whiteks and state least for policy had been clouded recently by uncertainty from the federal level, and other arenes of failed halfs care mackages composed action rky. Ceap off h The talk also highlights the trie of Medicard







~Ian Bott, Council Vice-Chair and Advocacy Coalition member.

I am able to live in my own home and direct my own Medicaid services because of the work of the Idaho Council on Developmental Disabilities. The Council was a major part of educating both policymakers and self-advocates on the My Voice, *My Choice Self-Direction Medicaid option, and changing Idaho law so that the* option was available to adults with disabilities like me.

~Larkin Seiler

...listened and continued to learn how to be culturally competent:

Supporting All Idahoans and Ensuring Equal Access

As part of our federal mandate to do work to address identified targeted disparities, the Council contracted with a **Cultural Broker**, Griselda Camacho who did outreach to the Latino 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. In addition, educational events for families took place including:

- Workshop for families on the Home and Community Based Services rules and how they affect Certified Family Home providers presented by Medicaid staff, Donnie Jardine.
- Training was provided in Spanish to families on the topic "Work and Its Impact on Social Security Income" and was presented by Scott Hoover from Disability Rights Idaho.



Medicaid staff, Donnie Jardine, with families who attended the HCBS rules workshop.

Pictured below: Scott Hoover of Disability Rights Idaho with ICDD Cultural Broker, Griselda Camacho and families.





The Idaho DD Network was one of eight states selected by the Administration on Intellectual and Developmental Disabilities to attend a week long training to address disparities in access to, utilization of, and outcomes in services and supports experienced by varying cultures of people with intellectual and developmental disabilities. The week provided tremendous learning from the University Center for Excellence at Georgetown University and the ability to work closely with our DD Network Partners, Disability Rights Idaho and The Center on Disabilities and Human Development at the University of Idaho.

Amazing Accomplishments

Jack Hansen Passionate disability advocate and spokesperson.



Jack Hansen is one of the many people the Idaho Council has relationship with through our Idaho Partners in Policymaking program. Since graduating from Partners in 2016, Jack has been active in advocacy working to educate policymakers about the benefits of the state ABLE technical assistance and financial literacy position (*pictured at left with Sen. Grant Burgoyne*). He has also been involved in Community NOW!, a collaborative stakeholder group working to design an improved Medicaid service system for adults with developmental disabilities. Jack is one of the many people who has dedicated hundreds of hours to this work.

Last year ACLU Idaho was looking for a dynamic host for a video show that would provide updates of the K.W. *vs.* Armstrong work on the settlement. The Council knew Jack was knowledgeable about the lawsuit and the settlement, would provide great leadership for the show, and would fulfill a

lifelong dream of Jack's. The ACLU works with Jack to create regular videos about the changes to adult developmental disability Medicaid services. The Council is proud of Jack Hansen for his leadership in our state. Check out his show. https://www.youtube.com/watch?v=6LM71Ffgcr8





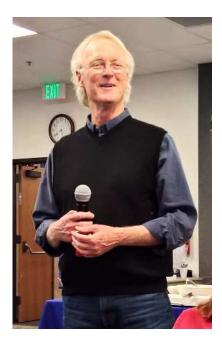
John Thomas

Active political pundit and disability advocate.

This fall we celebrated the retirement of John Thomas who has been a fixture in state offices for 44 years and involved in state politics even longer. John's passion for politics began while watching congressional hearings about the Vietnam war. While his siblings were into sports, John's passion became politics. He volunteered for U.S. Senator Frank Church's campaign in 1968 and Cecil B. Andrus' 1970 gubernatorial campaign. John's passion for the political process and keen memory make him a 'go to' person if

you want to know about what's going on (or has gone on) in Idaho politics.

John served on the Idaho DD Council from 1983 to 1994. Over the years he has continued to stay involved in Council events and be a strong advocate for people with disabilities in our state. He has worked in various state offices and his most recent employment was with the Idaho Department of Health and Welfare central office in the Division of Family and Community Services. He has seen many changes over the years and remarked, "There's so many more services than when I first started." John plans to stay involved in the Idaho political scene and has been volunteering at the Council since retiring. His life experience and political knowledge brings a valuable perspective to his continued commitment to the Idaho self-advocacy movement.



Jim Mairs

Voting access and systems change agent.

Jim Mairs retired at the end of 2016 marking many years of advocacy for voting rights and access for people with disabilities. The Council and Disability Rights Idaho began working with the Office of the Secretary of State in 2003 to improve voter access for people with disabilities. In 2005 the two organizations collaborated on a statewide voter education proposal to the Office of the Secretary of State. It was at this time we had the good fortune of meeting and working with Jim Mairs, Idaho's Help America Vote Act Coordinator. Over the years Jim has done fabulous work in advocating for individuals with disabilities, and expanding the rights of an underserved population.

The working relationship that began with the voter education proposal marked the beginning of over a decade of work to improve voter education and access in Idaho to all citizens. Jim Mairs strongly believed in this work and the value of each person's vote. He championed

multiple funding proposals with the Council through each Federal election cycle from 2006 to 2012. Jim's support enabled us to provide voter education to thousands of citizens statewide

and has resulted in over 500 people voting for the first time, as well as essential training for poll workers and the county clerks. The work was personal for him as he went to great lengths to help make each voting project a success in his support and advocacy through the Office of the Secretary of State.

Vote no matter what iday, Ocl. 24. I voted in id in full for all of us di able to here do it, no matter v

Disability History

Educating the public about the history of disability as part of human rights education in Idaho.

The Council was approached by the Wassmuth Center for Human Rights Education and home to the Anne Frank Human Rights Memorial when they had decided to **add Idaho Disability History to their human rights education collection**. The Council provided numerous reference documents, images of disability rights champions, and connected them to John Thomas to narrate the history for the newly added kiosk at the Center. Special thanks to Erin Ake who worked tirelessly on behalf of the Wassmuth Center to collect this valuable history.

Professional Recognition

Griselda Camacho – Building Bridges Award Winner

The Council is very proud of our Cultural Broker, Griselda Camacho, who was the Commitment to Community Building Bridges Award winner at the 2017 Human Partnerships Conference. This award recognizes a candidate who understands the value of inclusiveness in a community and works to enhance the individual perspectives and contributions of all community members. Ms. Camacho is truly an individual who breaks down barriers and builds bridges through her work with Latino families. Her work includes coordinating a conference in 2015 designed by parents for parents of children with developmental disabilities, working closely with the



Department of Health and Welfare and Latino families to discuss the specific needs of this population, including language barriers, to increase access to services. Griselda has also organized several trainings delivered in Spanish to ensure Latino families have current information related to developmental disability services. This award confirms what the Council knows about Griselda – that she is a true leader, an inspiration for many, and a person that is genuinely interested in building bridges. See more about Griselda's work on page 11.



Suzie Hanks – Lifetime Achievement Nominee

Suzie Hanks has been a life-long and tireless advocate for individuals with disabilities throughout her career. Being nominated for the Commitment to Community Lifetime Achievement Award honors her contribution to enriching the lives of individuals with disabilities and confirms how she embraces the values of inclusion, collaboration, and advocacy. Suzie is known to go the extra mile in providing comprehensive support to individuals with disabilities no matter the need. Her accomplishments in the disability community over the last 30 years is numerous and varied. She has served individuals and families through her work at Idaho Parents Unlimited, Disability Rights Idaho, the Council on Developmental Disabilities, and through her roles on various boards, councils, committees. An excellent problem solver and complex thinker, Suzie is that "go-to" person many think of when tasked with tackling difficult issues and developing solutions that

involve many variables. Her lifelong commitment to providing individuals the opportunity to be included in the decision-making process and her collaboration with both federal and state agencies to ensure appropriate advocacy is exemplary.

Ian Bott – Building Bridges Award Nominee

Council member, Ian Bott, has been involved with and advocated for a variety of organizations such as Autism Campus Inclusion, Special Olympics, Consortium for Idahoans with Disabilities, Idaho DD Council and the Council's statewide Policy Advocacy Coalition. Ian has been a member of the Idaho Self-Advocate Leadership Network since 2009 and has served in a number of local and state leadership roles as well. Ian works hard to educate others about disability issues and is quick to dispel myths. He truly cares about making a difference in the lives of others and creating a level playing field.



Larry Fries

Lifelong disability advocate, mentor, and friend.

In the spring of this year Idaho lost a great leader in Larry Fries. Larry served as the second President of the Idaho Self-Advocate Leadership Network. He testified a number of times in legislative committees, was part of the creation of the My Voice, My Choice selfdirection waiver option, presented at national conferences in Washington DC and at the national self-advocacy conference held in Atlanta, GA.



Larry shared wisdom with ease and humility. He had a natural gift for public speaking and could move legislative committees with his eloquence. He worked to break through every barrier society put in front of him. He blew the roof off of people's expectations of him by living his life on his terms. Larry made a real difference in this world with his many contributions. He provided a living example of the lives people with disabilities can have when treated with respect and provided opportunities. Thank you for the courage you showed in taking a stand on issues when it was hard, but your voice was needed. Your mark has made a lasting and permanent impression on our state.





Use of Resources

The Council receives federal funding as appropriated under the federal Developmental Disabilities Act and a state appropriation under the Idaho law for the Idaho State Council on Developmental Disabilities – 67-6701. This chart shows how Council resources, including program staff time, were used over the past year to make progress towards goals.



Council Staff

Christine Pisani, Executive Director Toni Belknap-Brinegar, Program Specialist Suzie Hanks, Office Assistant/Customer Service Laurie Lowe, Office Assistant Paty Orozco-Regalado, Intern Tracy Warren, Program Specialist/Planner Jean Weber, Management Assistant

Council Staff take a break to watch the eclipse in August.



Council Members:

Debra Parsons, Chair, Parent, Victor Rebekah Forster, Vice Chair (through April 2017), Parent, Coeur d'Alene Ian Bott, Vice Chair (beginning July 2017), Self-Advocate, Boise Alan Aamodt, Vocational Rehabilitation Jim Baugh, Disability Rights Idaho David Dekker, Self-Advocate, Jerome Korynne Donehey, Self-Advocate, Idaho Falls Raul Enriquez, Commission on Aging Art Evans, IDHW-Division of Medicaid Julie Fodor, Center on Disabilities and Human Development, U of I Holly Giglio, Parent, Ammon Jacob Head, Self-Advocate, Rexburg Kristie Oaks, Parent, Eagle Emily Petersen, Parent, Kimberly Jessica Rachels, Parent, Coeur d'Alene Joe Raiden, Self-Advocate, Moscow Carly Saxe, Self-Advocate, Eagle Kelby Selders, Parent, Meridian Charlie Silva, Department of Education Colleen Sisk, Syringa Family Partnership, Community Provider James Steed, Person Living in an Institution, Blackfoot Claudia Saustegui, YMCA, Community Non-Profit, Nampa



Council Members, Korynne and Holly, meet with State Rep. Wendy Horman, Idaho Falls



Council Members, Kristie and Kelby, meet with State Representative Gayann DeMourdant, Eagle

Jacquie Watson, IDHW-Maternal and Child Health



Council members attend a press conference in support of Medicaid programs.



Community NOW members prioritize issues and develop recommendations.

Senator Grant Burgoyne debates in support of House Bill 41, the ABLE T.A. & Financial Literacy Education legislation.





Contact Us

The Idaho Council on Developmental Disabilities is located in the Joe R. Williams Building just north of the Idaho statehouse.

Idaho Council on Developmental Disabilities 700 W. State Street, Suite 119 Boise, Idaho 83702

Phone: 208-334-2178 or 1-800-544-2433 Email: <u>info@icdd.idaho.gov</u> Web: <u>www.icdd.idaho.gov</u>

Department of Health and Welfare, DD Council, in accordance with 60-202, Idaho Code; 21800C18