



IDAHO COUNCIL ON
DEVELOPMENTAL
DISABILITIES

VISIONS & VALUES

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Spring 2009

ECONOMY DOMINATES LEGISLATIVE SESSION



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After 117 days and 35 vetoes, the First Session of the 60th Idaho Legislature finally reached a compromise of sorts on highway funding and adjourned May 8.

For Idahoans with disabilities, this was a disappointing session. A coalition of providers, advocates, and others, worked for increased funding in FY 2010 that would adjust community-based provider rates to more accurately reflect their costs. Time and again, the Council has heard from people with disabilities and their families that they were going to lose their services because the providers could not afford to stay

in business. Although the requested amount for FY2010 did not fully address the difference between costs and rates, it made a big difference. When these funds were not included in the final appropriation, Rep. Janice McGeachin (R, Idaho Falls) and Sen. Nicole LeFavour (D, Boise) attempted unsuccessfully to add intent language with the appropriation that would have designated any savings in 2010 toward this increase.

HB 322, the Medicaid appropriation bill, included several "key cost containment strategies", one of

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COUNCIL MEMBERS:

- Rick Betzer, Chair, Shelley
- James Steed, Vice-Chair, Pocatello
- Alonzo Statham, Consumer Rep, Boise
- Jim Baugh, Boise
- Toni Belknap-Brinegar, Nampa
- Shiloh Blackburn, Rexburg
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- Bob Jackson, Eagle
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- Chris Lynch, Boise
- Lisa Robbe, Bonners Ferry
- Mitch Scoggins, Boise
- Mike Smith, Moscow
- Joni Sullivan, Dalton Gardens
- C.L. "BUTCH" OTTER, GOVERNOR
- Marilyn B. Sword, Executive Director

Leader to Watch: Marilyn Cosho

"It may sound odd, but being told I had a disability came as a big relief", said Marilyn Cosho of Boise, who was diagnosed with Asperger Syndrome (AS) in 2006 at the age of 54. The diagnosis helped explain some of her past difficulties and guided her to resources to meet her needs.

As a certified teacher with five endorsements, Marilyn worked as a teacher's aide in the Boise Public Schools. Such work history is typical of people with AS; they usually are either underemployed or unemployed. Marilyn experienced both when she received a layoff

(continued on page 2)



Marilyn with one of her Fairy Chairs

COUNCIL PROJECTS

Partners in Policymaking Goes North

The 2009 class of Partners will be hosted between Moscow and Coeur d'Alene, with two sessions in Boise. Applications are being sought from people living in the areas north of Riggins to the Idaho/Canadian border. Parents of children with developmental disabilities and adults with developmental disabilities are encouraged to apply. The deadline to submit an application is Friday, June 26, 2009. To download a Partners application please go to:

<http://www.icdd.idaho.gov/>

Idaho Partners in Policymaking is an innovative, competency based leadership-training program for adults with developmental disabilities and parents of young children with disabilities. The Partners program trains participants in the most effective strategies for successful advocacy, provides state-of-the-art knowledge from local, state, and national leaders about today's disability issues, and creates partnerships between participants and policymakers at all levels of government. According to Joni Sullivan, 2003 graduate, "Partners is an empowering program full of relevant information. It was also a lot of fun. It was so rewarding to spend time with a group of people that had a common interest- that people with disabilities should be treated with dignity and respect." To learn more about what over 9,000 Partners in Policymaking graduates are doing nationwide go to: <http://www.partnersinpolicymaking.com/>

Idaho Partners in Policymaking is sponsored by The Idaho Council on Developmental Disabilities, The Idaho State Department of Education, and The Idaho Department of Health & Welfare.

Tools for Life Fair 2009

472 attendees, including 167 students, enjoyed the 5th annual Tools for Life: Secondary Transition and Technology conference that was held in Coeur d'Alene March 2-3. Keynote speakers included LeDerrick Horne - nationally recognized poet and youth mentor, Michael Beers - comedian from Montana, and Logan Olson - entrepreneur and creator of Logan Magazine, all individuals with disabilities serving as role models to youth.

Students enjoyed a new workshop at the conference this year, "That's Life" a real life simulation focused on financial literacy. Mountain View High School (Meridian) flew 36 students to the conference with funds the students raised for their travel by selling cookie dough balls, coffee before school, and holding a silent auction. Each student typed thank you letters to the conference organizers after returning home. Way to go students and teachers at Mtn. View! The March 2010 conference will be held in Boise.

Marilyn Cosho

(cont'd from pg. 1)

notice last year. She was devastated because, like most people with AS, Marilyn cherished being encouraged and praised for a job well done. "Employers and fellow employees are often unaware of how hard most people with AS struggle to maintain normal job expectations".

Getting a diagnosis also gave Marilyn the courage to begin to share her collages which she had kept to herself for almost 15 years. While people knew her fairy chairs from the 350 she had crafted over the years, no one had ever seen her collages. She believed they would be of no interest to anyone until one day she showed several to someone who encouraged her to let the world see them. This past January both collages and fairy chairs were exhibited at the "We Are Family" conference in Boise. The compliments she received encouraged her to enter four of her art pieces in an Idaho VSA Arts competition and to display her work at a major regional conference in July.

Remaining true to her teaching roots, Marilyn is creating a short video explaining what it is like to live with AS. The video will include samples of her artwork in order to allow fragments of her invisible disability to be seen by others. Two years ago Marilyn's story was featured in "Idaho Health" magazine. The story can be found by searching "Marilyn Cosho" online and clicking on "Unraveling a Mystery".

COUNCIL PROJECTS

Person-Centered Planning Specialists Trained

Thirteen Person-Centered Planning Specialists have just completed a 5-week web-based training and 3-day face-to-face training through the Idaho PCP Grant from the Centers for Medicare and Medicaid Services.

The trained PCP Specialists are ready to work with adults and transition-age youth with developmental disabilities around Idaho to facilitate person-centered planning. The purpose of this planning is to connect people to their communities and find the resources and supports they need to reach their goals. Another focus of the planning process is to find out how the informal support caregivers in a person's life are doing and what kinds of support and resources they need to continue to provide support to the individual.

The IdahoHelp web-based community resource directory is now live and available to the public.



*Back Row L-R: Trainer Matt Wappett, Jill Young, Dawn Suave, Bonnie Connell, Corinne Johnson, Trina Balanoff, Melanie Scott, Judy Secrist
Front Row L-R: Tom Snyder, Shelly Nelson, Jill Smith, JoLynn Garrison, Amber Betzer, Trainer Meg Gag*

This comprehensive resource directory includes over 8,000 resource listings in content areas and a search option using keywords related to the needs of individuals with disabilities and their families. Check it out at www.idahohelp.info.

2008 Disability Mentoring Day Projects

Last fall the Council provided grant funds to Disability Mentoring Day (DMD) projects in Idaho Falls, Filer, and Boise. This was the 6th consecutive year that the Idaho Falls Community Transition Team has hosted a DMD project. The Filer School District and the Boise Living Independence Network Corporation (LINC) were sponsors for the first time.

National Disability Mentoring Day takes place annually on the third Wednesday in October and provides opportunities for high school students with disabilities to work their "dream jobs" for a day. In the process students learn job exploration skills while studying possible career paths and developing meaningful relationships with job mentors. The program is sponsored nationally by

the American Association of People with Disabilities on their website www.aapd.com.

26 Idaho Falls area students from 4 different high schools participated in that community's activities. Twenty (20) students in the Filer School District's STRIVE program hosted an open house where they met prospective employers and gained information about becoming a good employee. The Boise LINC project hosted 4 students who enjoyed experiences at Idaho Power Company, Boise Town Suites, Bench Animal Hospital, and Channel 2 Television.

Announcements for 2009 DMD funding grants will be released in late July. Information and applications will be available on the Council website and from the Council office.

STATE NEWS

The Idaho Self-Advocate Leadership Network: Newly Elected Officers and New Chapters

SALN just elected some new officers for their state organization. Larry Fries of Pocatello was elected President; Shiloh Blackburn of Rexburg, was elected Treasurer; and Jen Magelky-Seiler, of Moscow was elected Sergeant-At-Arms. Congratulations to all the newly elected leaders!

Thank you goes out to John Russell, former President; Bob Quast, former Treasurer; Lia Haile, former Sergeant at Arms; and Erick Yeary, former Team 7 Representative. Your service to SALN was tremendous. Fortunately, John and Erick will continue to work in their home towns to create chapters for others to experience what self-advocacy is all about.

The SALN also has three new chapters beginning soon: Idaho Falls, Moscow, and Nampa! A chapter is a group of people that live in the same area who get together regularly. The group is usually made up of people with disabilities who want to be a part of something, make friends, and want to try and make things better for all people.

A local self-advocacy chapter promotes self-advocacy, creates friendships, and works together to give back to the community. Activities are different for each chapter but they all focus on being informed about local, state, and national issues. Some examples include:

- ◆ Helping people with disabilities understand how to use their voice to make positive changes
- ◆ Raising money for needs in the community
- ◆ Starting a local coffee group for people to meet and talk
- ◆ Telling people with disabilities about voting
- ◆ Learning how to work together to improve how your town includes people with disabilities
- ◆ Having a potluck and enjoying the friendships you create

If you would like more information about SALN or its new chapters, contact the Council at 1-800-544-2433.



Mr. Buckland Goes to Washington

This June, Idaho will lose one of its finest disability advocates as Kelly Buckland leaves his job as Executive Director of the Idaho State Independent Living Council to move

to Washington, DC to assume the position of CEO of the National Council on Independent Living. It should be a smooth transition as Kelly has served as president of NCIL for the last two terms.

Kelly has been a well known member of the disability advocacy community in Idaho since 1979. Before becoming a leader in the independent living movement, Kelly worked on the staff of the Idaho Council on Developmental Disabilities in

1988-89. Over the past two and a half decades, he has worked closely with the Idaho State Legislature on a variety of issues affecting people with disabilities, including passage of the Personal Assistance Services Act and the Fathers and Mothers Independently Living with their Youth (FAMILY) Child Custody Laws. Kelly has testified before Congress several times on issues such as universal health care, Fair Housing, and appropriations for centers for independent living. He has been closely involved with the all aspects of the Independent Living movement. He has a long history of political activity in Idaho and ran for the State Senate in 1992 and the State House of Representatives in 1994.

The DD Council wishes Kelly and his family success in their new national adventure.

STATE NEWS

Idaho Legislature *(continued from page 1)*

which requires the Department to "establish cost sharing requirements based on ability to pay for families whose children are eligible for Home Care for Certain Disabled Children (commonly known as the Katie Beckett program)." This language will impact many families of children with significant disabilities who now rely on this support to keep their child at home instead of in an institution. Implementation of this intent language would probably require a change in state law. It may also violate provisions of the American Recovery and Reinvestment Act of 2009 (the federal stimulus bill) which requires that states maintain "eligibility standards, methodologies, and procedures in effect on July 1, 2008" as a condition of their receiving additional federal Medicaid funds.

The economy wreaked havoc with most budgets. Current year budgets were cut as were 2010 requests. Federal stimulus money provided some relief but not enough to prevent services for people with disabilities from being reduced.

A bill dealing with medical consent and futility in end-of-life or other medical decisions was introduced after 2 years of work by members of the medical community and disability advocates.

SB1114 passed the Senate without difficulty but was stopped in the House by pressure from the Right-to-Life advocates who wanted open-ended treatment of a person until death or transfer to another facility. The issue will see further work and perhaps reintroduction in the 2010 session.

There were a couple of small victories. Co-Ad was successful in getting HB145 passed, correcting language in the involuntary sterilization law. Before the correction, children did not have the same protection as adults in being subjected to these procedures. Now they do.

The Council and other advocates were pleased with the addition of intent language to the appropriation for Idaho State School and Hospital that calls for a committee to come together after the session to gather information on the needs, service costs, and alternatives for people who are living at the institution. The committee will present a plan to the 2010 legislature for transitioning residents to community services or alternative placements.

The 2009 session was long on days and short on positive outcomes. Hopefully, an economic recovery will provide more options in 2010.

Employment Resources for You

Two publications are now available to people with disabilities who are currently working or who want to go to work. ***Willing and Able: A Job Hunting Guide for Idahoans with Disabilities***, developed by the Idaho Department of Labor is an A-Z guide for everything you need to know about applying for a job, putting together a resumé, preparing for an interview, and where to look for assistance. The guide also discusses whether or not to disclose a disability, reasonable accommodation, and your rights as a person with a disability under the Americans with Disabilities Act (ADA). The guide can be downloaded from the Idaho Department of Labor Website www.labor.idaho.gov. Look for "Publications" then "Work Services".

The second publication is the ***U.S. Social Security Administration's Redbook***. In it you will learn about Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). People enrolled in SSI or SSDI are eligible for the supports for employment that are described in detail in Redbook. Want to know about a PASS Plan or an IRWE? It's in Redbook and available in English and Spanish at www.ssa.gov/redbook. Information can also be obtained from a Benefits Planning, Assistance and Outreach Specialist at Comprehensive Advocacy, Inc., (CO-AD); telephone toll free at 866-250-7974.

NATIONAL NEWS

Mobilizing to End the Use of the 'R' Word

After years of people hearing the term "mental retardation" and its negative slang spin-off "retard", action is taking place across the country to eliminate these words.

At the request of self advocates and others, the American Association on Mental Retardation (AAMR) changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD). States are starting to review their laws to replace mental retardation with the term "intellectual disabilities." This year, Washington State introduced HR1835, a code reviser bill that replaces the term "mental retardation" with "intellectual disabilities" wherever it appears in the state's laws. In Maryland, comparable action is taking place with House Bill 20. Idaho State

Senator Les Bock is gathering information to push for a similar change in the 2010 Idaho Legislature.

Following the 2009 Special Olympics World Winter Games in Idaho, a new campaign has emerged. Entitled "Spread the Word to End the Word", the goal of this campaign is to make people stop and think about their hurtful and disparaging use of the word "retard". Instead, it encourages people to think of a new "R" word: respect. Rallies, news coverage and political action are all part of the effort to educate the public about the impact of this cruel and offensive term. View the Spread the Word to End the Word video at www.youtube.com/endtherword or go to www.r-word.org to take the pledge or get involved.

Disability Legislation in the 111th Congress

Several bills dealing with disability issues have been introduced in the new Congress. Among those of interest are:

Community Choice Act of 2009 - Establishes a national program of community-based attendant services and supports for people with disabilities, regardless of age or disability.

Community Living Assistance Services and Supports (CLASS) Act of 2009 - creates an insurance program for adults who become disabled.

Better Life Experience Act (ABLE) of 2009 - Gives individuals with Down syndrome and their

families the ability to save for their child's future by creating a disability savings account that would accrue interest tax-free.

Autism Treatment Acceleration Act of 2009 - Provides funding and authorization for demonstration projects of Autism Care Centers and a variety of services for adults with autism.

Ending the Medicare Disability Waiting Period Act of 2009 - Would eliminate the two-year delay in coverage for people with significant disabilities who are waiting to become eligible for Medicare coverage.

For more in-depth information about this legislation go to the Council website at www.icdd.idaho.gov.

Stop Bullying Now!

There are many forms of bullying including hitting, kicking, shoving, teasing, name-calling, intimidation, and social exclusion. These days bullying can also take the form of sending hurtful or intimidating messages by text message or email. Research shows that children with disabilities may be at greater risk of being bullied by their peers. The US Department of Health and Human Services Health Resources and Services Administration has a national campaign on bullying prevention. Information can be found on the HRSA website and www.stopbullyingnow.hrsa.gov including: What We Know About Bullying Activities Guide, Stop Bullying Now! Tip Sheets, information for parents and children, and information for educators and school staff.

EDITORIAL



*Rick Betzer,
Council Chair*

The Time Has Come

For the past several years, I have had the privilege of working with a talented group of individuals dedicated to improving the lives of people with disabilities. I am speaking of the Idaho Council on Developmental Disabilities.

For me, this experience was life-changing. I first became involved when my wife, Tina, and I began adopting the first of 13 children with 'special needs'. I learned quickly that there was (and still is) a need for improved services, rights, choice, access, educational opportunities, transportation, housing... the list goes on - for people with disabilities of all ages.

One of my children brought home information about the Council's Partners in Policymaking program. I was intrigued and applied. As I would learn, that was one of the most significant events of my life. The training I received got me motivated to get involved, to not sit idly by and expect others to do the work.

I have been a Council member for 9 years now,

three as Chair. I have (usually!) enjoyed it. My Council involvement pushed me to finally get my degree - after 15 years on hold. Doors were opened, employment opportunities became available, and, of course, many more children came home. Many, maybe all of these positive events would not have happened without that first step of applying to the Partners program.

Over the years, Council members and staff have changed. Political winds have shifted. Budgets were strained, never enough money to do all the things we want to get done. Throughout the changes, one overriding commonality remained: the unwavering commitment to improve the lives of people with disabilities!

Leaving the Council has been a hard decision to make. Many of you are like family to me. I'll miss you, your talents, humor, and abilities.

It has been an honor to work with you and I hope you will continue to be in touch. I know the Council is in good hands and look forward to the ongoing success in disability advocacy.



*Alonzo Statham,
Consumer
Representative*

My Wheels

My name is Alonzo Statham and I am a member of the Idaho Council on Developmental Disabilities. When I was a 16-year-old high school sophomore, I lost the ability to walk because of Guillain-Barre.

Since age 18, I have worked because I had a power wheel chair and could get around. It made it possible for me to have my own business. My life is totally dependent on being able to get around in my chair. Without it, I can't get out of bed in the morning or get into my pickup.

On February 19, my wheelchair was stolen from in front of my apartment. I was frantic! My first thought went to my work responsibilities and keeping my job in this economy. I was embarrassed that people would think this was my fault. The theft had reduced me from an independent, hard-working member of this community, to a

person who would need help to get in and out of my house and my truck. The chair was located about half an hour later, but the people who had taken it had done \$2,500 in damages.

Some might think this is not such a big deal. Well, it is. This chair is my mobility. It's my legs! This is not the same as having your car or bike stolen. In those cases, you can walk or ride the bus. But these were not options for me. Without my chair, everything I do comes into question. It is a terrifying experience.

Crimes such as this against persons with disabilities must be treated for what they really are - crimes against the person. They are not property crimes and should not be treated that way. Punishment should be not only restitution but incarceration that will leave a lasting impression on the perpetrator and the public about the gravity of these crimes.

NOTE: A fund has been set up in Alonzo's name to help pay for his chair repairs. Contributions can be made at any Mountain West Bank location.

WHAT'S HAPPENING SUMMER/EARLY FALL 2009

JUNE

- 3 Consortium for Idahoans with Disabilities
- 10 Long-Term Care Symposium, Boise

JULY

- 1 Consortium for Idahoans with Disabilities
- 13-17 Youth Leadership Forum, BSU campus
- 22-24 DD Council meeting
- 23 Medicaid Community Care Council meeting
- 23-24 State Independent Living Council meeting
- 27-29 NACDD TA Institute, Wash DC
- 28 IWG Public Transportation meeting

AUGUST

- 5 Consortium for Idahoans with Disabilities
- 25-26 Idaho SALN Board Meeting, Pocatello
- 28-29 Partners in Policymaking, Moscow

SEPTEMBER

- 2 Consortium for Idahoans with Disabilities
- 10-11 Early Childhood Coordinating Council

OCTOBER

- 7 Consortium for Idahoans with Disabilities
- 14 Medicaid Community Care Council meeting
- 16 State Independent Living Council meeting
- 21-23 DD Council meeting
- 28-29 NACDD Annual Meeting, Albuquerque

**For updates on issues and more information about Council projects visit our website at:
www.icdd.idaho.gov**

Newsletter Delivery ~ Address Changes and Updates

If you have moved and your address has changed or if you would like to be removed from our mailing list please call or email the Council office to let us know.

To contact the DD Council: Phone: (208) 334-2178, Fax: (208) 334-3417, Email: icdd@icdd.idaho.gov
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