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DEVELOPMENTAL  
DISABILITIES

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# VISIONS & VALUES

Newsletter of the Idaho Council on Developmental Disabilities

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**The Council Has a New Address**

We are located in the Joe R. Williams Building (Hall of Mirrors)  
behind the Capitol: 700 W. State Street, First Floor West  
Boise, Idaho 83702-5868

# SELF-ADVOCACY CONFERENCE A HUGE SUCCESS!

Idaho's first statewide self-advocacy conference, ***Self-Advocacy – It's All About...We*** took place October 21-23 in Boise with 175 people attending from all over the state.

The Idaho Self-Advocate Leadership Network (SALN) co-hosted the conference with the Council, which was a huge success! "The conference was so meaningful to me and to the SALN. It gave the SALN more strength and power by teaching more people, especially young people, about the power of self-advocacy and self-determination," said **Larry Fries**, President of the Board of the SALN.

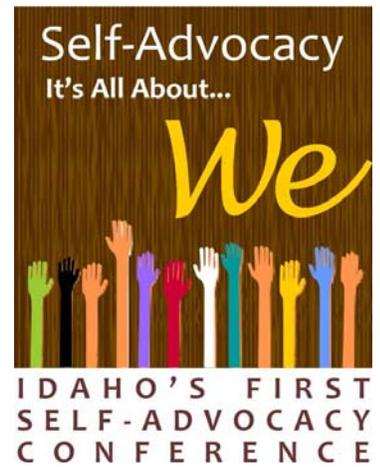


The SALN had the chance to honor **Senator Les Bock** of Boise for his work on the Respectful Language Bill that passed in the last legislative session. Two powerful presentations were made to recognize Senator Bock by SALN members **Joe Raiden**, and **Jen Magelky-Seiler**. Joe shared his reasons why the legislation was so important to people with intellectual disabilities. *"The reason I was so upset that the word*

*"retarded" was still in our laws is that it is a hurtful term. I remember being called retarded by kids in my class as early as when I was in Kindergarten. I don't think I truly understood what being called retarded meant until I was in the fourth grade when I could hear and feel what it meant. It meant being pushed down and pushed aside. It meant not having friends who would stick up for me. I didn't want to go near those kids – I was afraid."*

Jen Magelky-Seiler presented about her experience serving as the SALN representative on the legislative committee that worked on the law. "Whoever said words don't hurt and words don't matter had it all wrong. Words do matter and words are a powerful thing. I was excited to be part of a committee with legislators and I felt honored to have been chosen. I was able to feel what it's like to be at the table, to be involved in something that was important to me and other people with disabilities. I learned that it is important for people with disabilities to be at the table in things that involve them whether it is at their national, state or local level or just in their own life." Jen finished her presentation by honoring Senator Bock with an award to recognize his vision, courage, and work on the Respectful Language Bill.

Self-advocates presented over 20 workshops on topics including going to college; parenting with a disability; running your own meeting; how to be a public speaker; alternatives to guardianship; dating and relationships; how to start a self-advocacy chapter; the power of self-advocacy; and yoga to name a few.



**Jen Magelky-Seiler, Senator Les Bock and Joe Raiden**



The presentations were for self-advocates only which really gave people the chance to talk freely and ask any questions of presenters. *"I was able to open up because I was around other people with disabilities and it was safe. I didn't have to have fear and I wasn't alone,"* stated **Ritchy Cardwell**.

While everyone learned from each other in the workshops, there was also so much fun with karaoke, Basque Dancers, the SALN raffle, and the dance on Friday night.

The dance Friday evening was also the same date as **Arthur and Maria Sweet's** wedding anniversary. It was great to be with them to help them celebrate their 16<sup>th</sup> anniversary!

The conference really highlighted the power of the self-advocacy movement in Idaho. It was a historical occasion and one the Council was proud to be a part of. We would like to thank the Center on Disabilities at the University of Idaho, DisAbility Rights Idaho, LIFE, Inc., and LINC, Inc. for their tremendous financial and staff support. It would have never been the huge success it was without all of the great people involved. **THANK YOU!**



Art and Maria Anniversary Dance



Shiloh Blackburn



Dance, Dance, Dance



Keith Jones

All conference photos by Beau Stiles, Beau Stiles Creative, LLC

## LEADER TO WATCH: TED ROY



Ted Roy has worked for the U. S. Forest Service, retail sales, and small businesses. But the work he is most proud of is the help he has given other people with disabilities; first as a volunteer and now as an employee of the Idaho AmeriCorps Accessible Transportation Project. Because Ted is a person with a disability, he sees himself as a peer helping others attain the services they need.

Ted is a lifelong resident of Twin Falls. He is very grateful for the encouragement he has received from family and friends to “be all he can be”. He credits mainstream education, and the philosophy and supports of the Living Independence Network Corporation (LINC) with him living independently and successfully. He is a Business Computer Science graduate of the College of Southern Idaho. He now resides in his own home, which has been adapted for access with his wheelchairs. Ted also owns and drives an accessible van, which gives him tremendous freedom and access to his community.

Since 1993 he has served on the Advisory Board of the Idaho Assistive Technology Project. He is now serving as Board Chairman. At the “We” Self-Advocacy Conference in Boise, Ted was a co-presenter on assistive technology used in daily living.

Listening and dancing to music are some favorite pastimes, and as he was seen at a recent dance, Ted can “hang” with the best of them. When asked about his dreams for the future, Ted said he would like to find a good woman willing to “settle down” with him. And of course, Ted wants to continue helping other people with disabilities as an advocate.

Ted can be contacted by telephone at the LINC office in Twin Falls at (208) 733-1712 or by e-mail, [troy@lincidaho.org](mailto:troy@lincidaho.org).

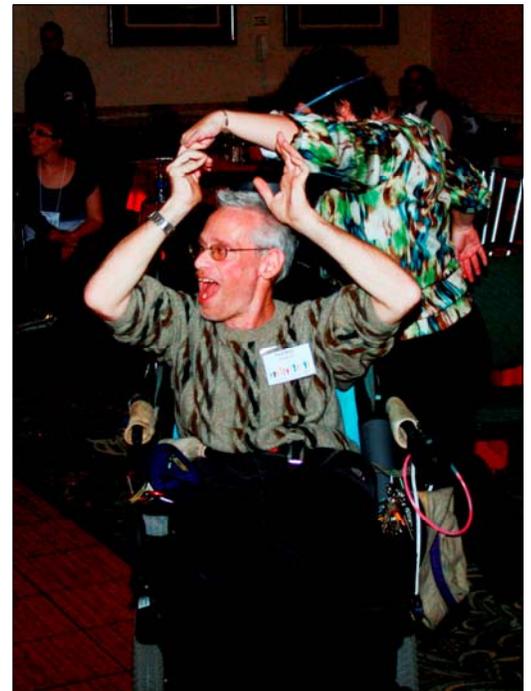


Photo by Beau Stiles

# COUNCIL PROJECTS



## DELEGATES WANTED FOR YOUTH LEADERSHIP FORUM 2011



Elysia Hargrave

The Council on Developmental Disabilities is seeking student applicants for the summer 2011 Idaho Youth Leadership Forum scheduled for **July 11-16**. This week long leadership development program is held on the Boise State University campus. Student delegates develop leadership skills, spend time with a job mentor in their career of interest, and learn about independent living, going to college, and how to make a difference in their community and state.

2010 YLF Delegates spent time with policymakers at the Capitol, talking with them about issues they are concerned about including affordable college education and jobs for people with disabilities. They also had fun at a concert by local band "Workin' on Fire" and African drumming in the park with a barbecue. Many new **friendships** were formed and delegates continue to stay connected through Facebook and many other ways.

Comments from some of last year's delegates:

- *"I will miss the leadership forum very much. It improved my future plans, what is expected (for me)."*
- *"I've been to leadership camps before but they weren't as good as YLF. They were too big. This is great because you get more one-on-one time with presenters and staff."*
- *"I just want to write a thank you to all the staff and you. You impacted my life, giving me the tools for college! Thank you for helping me! I had fun there and I learned how to work with other kids with the same disability that I have. You did an awesome job, thank you all for impacting my life!"*



Greg Hogue



Tanner Traugber

### High school students with disabilities who have

**leadership potential** and are between the ages of 14 and 20 are encouraged to fill out an application. It does not matter what their disability is, all students are welcome and accommodations will be made to meet student needs. Delegates are chosen based on their application and an interview with YLF Planning Committee members. About 25-30 students will be selected to represent their communities at the forum.

**There is no cost to students.** All expenses are paid through funding from the Idaho DD Council, State Department of Education, and with contributions from additional partners: Idaho Department of Labor, Division of Vocational Rehabilitation, Assistive Technology Project, and Disability Rights Idaho. Travel arrangements for students to come to Boise from communities around Idaho are made by the forum. Next page...

YLF photos by Beau Stiles, Beau Stiles Creative, LLC

**YLF student applications are now available** on the Council website at [www.icdd.idaho.gov](http://www.icdd.idaho.gov) by going to “Projects” and clicking on Youth Leadership Forum. Check out Idaho YLF on Facebook and Twitter. This year the Council welcomes Beau Stiles as our 2011 Youth Leadership Forum Coordinator. Beau has experience with Idaho YLF as a staff member over the past two years and is excited to be on board and promoting the program. You can reach Beau through email: [beau.stiles@icdd.idaho.gov](mailto:beau.stiles@icdd.idaho.gov) or by calling the Council office at 1-208-334-2178 or 1-800-544-2433.

## PROJECTS WITH PARTNERS IN THE COMMUNITY HELP EXPAND IMPACT OF PERSON-CENTERED PLANNING GRANT

The Council has begun two new projects that will help provide support and resources to more individuals and their caregivers through the Council’s Person-Centered Planning Grant. Six individuals recruited by the Council for the project recently completed Class Leader training to conduct “**Powerful Tools for Caregivers**” classes for informal caregivers who provide support for individuals with developmental disabilities. The Class Leader training was provided by Friends in Action, a non-profit organization dedicated to sustaining quality of life for frail elders and their families. Class leaders will work in teams to provide the six-week caregiver educational program to informal caregivers in three local areas: Idaho Falls, Caldwell/Payette, and Boise.

The “Powerful Tools for Caregivers” classes are intended for the many hard-working families and friends who devote time and energy caring for and supporting individuals with disabilities and people with chronic health conditions. The class curriculum is designed to provide caregivers with “tools” to increase their self-care and their confidence to handle difficult situations, emotions, and decisions. The Council hopes the program will help caregivers identify their needs and find ways to make connections to others, to community resources, and re-energize themselves in their caregiving role. This enhances the efforts to address informal caregiver needs as outlined in our PCP grant.

The caregiver classes will be scheduled in early 2011 and information about classes in the three areas will be available soon on the Council website or by calling the Council office.

The Council is also excited to be collaborating with Community Partnerships of Idaho (CPI) on their **Neighbor to Neighbor** project. The Neighbor to Neighbor model has been developed by CPI to address the unmet need for natural supports and community relationships for individuals with disabilities. Natural supports don’t always just happen. Actual assistance is sometimes needed to discover the supports and make connections that can lead to friendships or relationships that are ongoing. One component of the model is to provide opportunities for individuals with disabilities to give back to their community and play an important and valued role there.

CPI staff will work with individuals in the Boise and Emmett areas to help them identify natural supports in their local community. Staff will help create a flexible system of “matches” that come from the individual and are adapted to their needs. This system will be ongoing and changing depending on the needs of the individual. Staff will start with the person and look for supports around them. If there are none, they will focus recruitment of neighbors/matches on the individual’s specific interests. They will use interests and volunteer opportunities to find, match and build relationships that can lead to additional relationships. Efforts will also be made to empower the person by providing opportunities for them to be givers and not just receivers.

## PCP SPECIALISTS CONTINUE TO WORK WITH TRANSITION-AGE YOUTH AND ADULTS

If you are at a place in your life when big changes are about to take place, you would like to try something new, or you would like the people in your life to understand you better and know how to support your goals, then give person-centered planning a try. Person-Centered Planning Specialists are available to work with transition-age students and adults with developmental disabilities.

As the Council finishes its Person-Centered Planning grant activities in 2011, four Specialists will continue to work under the grant in the Boise and Caldwell/Nampa area over the next several months. They will be helping the Council identify systems change opportunities that will embed person-centered planning practice in the education, disability services, employment support, and institutional discharge systems in Idaho.

**Trina Balanoff** and **Dawn Sauve** in the Boise area are focusing their work with transition-age students and individuals who are self-directing their services. **Judy Secrist**, also in Boise, is available to work with transition-age youth and people accessing employment services. **Tom Snyder**, in Nampa/Caldwell, is working with individuals who are transitioning out of institutional care and moving into the community. For a complete list of PCP Specialists that have been trained and are experienced in facilitating planning, please visit the Person-Centered Planning Project website at <http://www.idahocdh.org/dnn/personcenteredplanning>.

## FIVE COMMUNITIES HOST DISABILITY MENTORING DAY

The Council awarded 5 communities grants totaling \$4,000 to conduct Disability Mentoring Day (DMD) projects in October. More than 200 high school age students participated in this project which provides them with the opportunity to spend time mentoring in a job of their choice. It also provides local businesses and organizations with a chance to share employment strategies and experiences with potential young workers with disabilities. 2010 marks the 10<sup>th</sup> anniversary for DMD in Idaho Falls and the 2<sup>nd</sup> for Boise-Meridian. First time awards went to Magic Valley-Twin Falls, North Central Idaho-Lewiston-Moscow and Coeur d'Alene. Council member Joe Raiden, Moscow, was the keynote speaker for the North Central Idaho event. The Idaho Department of Labor was a key player in this year's state wide collaborative effort.

## INCLUSION AWARDS

Do you know a teacher, school, community program, or group that does an outstanding job including people with developmental disabilities in activities and events? The Idaho Council on Developmental Disabilities wants to hear from YOU! We are accepting nominations to recognize programs (community-based or education) that go above and beyond to make people with developmental disabilities feel welcomed and have the opportunity to participate in meaningful ways.

Nominations are due by January 31, 2011. The flyer and nomination form are available to download on our website [www.icdd.idaho.gov](http://www.icdd.idaho.gov).



## DETERMINED TO VOTE!

The Idaho Council on Developmental Disabilities and DisAbility Rights Idaho had the chance to work together on a third voter education campaign for Idahoans with disabilities. The non-partisan voter education is called Determined to VOTE! and is funded by a Federal grant from Health and Human Services as part of the Help America Vote Act through the Office of the Secretary of State.

To get this training to more Idahoans with disabilities, representatives from the Commission for the Blind, Council for the Deaf and Hard of Hearing, the State Independent Living Council and each of the three Centers for Independent Living were invited to attend a two-day train-the trainer in August. Each agency representative was provided training materials that have been specifically created to teach Idahoans with disabilities, including:

- Why Vote
- Voter Rights
- Accessible Voting Options
- How to Register to Vote
- New Voter Identification Requirement

The Council thanks the following agency representatives for their participation in the training and their commitment to teaching people with disabilities this important and valuable information:

- **Amber Mausling**, LINC, Inc.
- **Bettina Briscoe**, Commission on Aging
- **Candy Harris**, Commission for the Blind and Visually Impaired
- **Mickey Palmer**, LIFE, Inc.
- **Stephanie Jensen**, State Independent Living Council
- **Steven Snow**, Council for the Deaf and Hard of Hearing

Inviting the agency representatives was a tremendous success in many ways. Not only did the cross-agency participation build relationships but it helped better reach groups that had underserved or unserved through this project. The exchange of information about what works and what doesn't work for certain populations was extremely valuable for the Council and the other organizations.

The project held 16 Determined to VOTE! trainings around the state serving transition-age students, students at the School for the Deaf and Blind, residents at Idaho's three state institutions, and self-advocates who came to the statewide self-advocacy conference in October. Of the 373 people with disabilities trained this year, 194 were eligible to vote. Seventy of those 194 voted in the November election, with 11 using the ballot marking device and 6 requesting the ballot be read to them by a poll worker. 179 were transition-age students under the legal voting age of 18. As a result of Determined to Vote, **36.1% of the people trained who were eligible to vote, voted in the 2010 election.**



**Jim Mairs teaching how to use the ballot marking device**

The project staff continues to be the strength of Determined to Vote. There are no better role models for youth than accomplished, determined adults with disabilities providing the training. While the training focuses on voting rights and accessible voting options, the secondary message



taught by the presence of these trainers is the power of self-advocacy and community involvement.

The Council thanks the following people for their work with Determined to Vote! this past year:

**Shiloh Blackburn, Angie Eandi, Lynn Erickson, Kristyn Herbert, Mel Leviton, Cathy Sherman, James Steed, Corinna Stiles, Beau Stiles, and Joe Raiden**

**DisAbility Rights Idaho and the Council on Developmental Disabilities would like to recognize the ongoing commitment by the Office of Secretary of State to serving Idahoans with disabilities.** This commitment provides the ability for the Council to have direct contact with the people of Idaho about the electoral process. There is no substitute for meeting people face-to-face to hear their stories, learning of their perseverance, and hearing how little people really ask for. There is magic in being able to share information with people that translates into comments that read: *“As a person with a disability, I never knew I had the right to vote.”* Knowledge is power and that is powerful.

## COUNCIL CHANGES

Since the spring edition of our ***Visions and Values*** newsletter, there have been several notable changes at the Council. In late August, the Council moved its offices from the historic Hoff Building to the Joe R. Williams Building. Although we enjoyed our 10 years at the Hoff and really appreciated the support of building owner/partner, **Jim Tomlinson** of Tomlinson and Associates, moving back into state-owned space saves us on our lease costs in this very tight economy. We can now be found at 700 W. State Street, on the first floor.



In addition to our move, we have also seen some changes in membership and personnel. This fall, our Council Chair, **Alonzo Statham**, moved to Friday Harbor, Washington, to join with his brother in a new business venture. On November 30, we received word that **Mitch Scoggins** has taken a new position and will no longer be representing the Maternal and Child Health program on the Council. And on January 10 we learned that **Jacque Hyatt** has taken a new position at the State Department of Education and will no longer be representing Special Education as a member. Good luck and best wishes to all of these valuable Council members.

In mid-December, our planner and long-time state employee, **Ron Enright**, retired. Ron's humor, patience and considerable knowledge will be missed. Planning activities will now be guided by **Tracy Warren**. **Beau Stiles**, a former volunteer with the Idaho Youth Leadership Forum, has come on board for the next 10 months to coordinate this year's YLF.



**Ron Enright**

## NEWS

### HAPPY 20<sup>TH</sup> ANNIVERSARY ADA!

On July 26<sup>th</sup>, several communities across Idaho (and the rest of the nation) celebrated the 20<sup>th</sup> anniversary of the Americans with Disabilities Act (ADA) which was signed into law by President George H. W. Bush in 1990. Mayoral proclamations were signed and announced in Idaho Falls and Pocatello and participants in both cities enjoyed a celebratory picnic. In Coeur d'Alene, residents surrounded City Hall and then went for a barbeque in Maribou Park in nearby Spokane.



In Boise, people gathered in Capitol Park for music, displays, speeches, and birthday cake. Nearly 700 people joined hands around the state capitol to demonstrate the abilities and independence of people with disabilities and to recognize the contribution of our veterans. Secretary of State Ben Ysursa read a state proclamation signed by Governor Otter.

Returning to Idaho from his new position as Executive Director of the National Council on Independent Living, Kelly Buckland greeted the crowd. In his remarks, Kelly said, *"For 20 years, I experienced life in America as a person with a disability who had little to no rights. Now it has been 20 years since the ADA was signed, and I have lived 20 years as an American with a disability with my rights guaranteed under the ADA."* Kelly is the former head of the Idaho State Independent Living Council.



Secretary of State Ben Ysursa with Kelly Buckland, NCIL Director

A number of awards were presented, including one to the Council on Developmental Disabilities "for leadership and dedication in the empowerment of Idahoans with developmental disabilities".

Boise Mayor David Bieter presented a City of Boise ADA proclamation and Richard Pimentel, noted disability rights advocate and subject of the movie, "The Music Within", shared his thoughts about the significance and meaning of the ADA.

### DISABILITY ADVOCACY DAY

On December 11, members of the Consortium of Idahoans with Disabilities (CID), in collaboration with Community Partnerships of Idaho, conducted their first Disability Advocacy Day. The day consisted of a series of workshops put on by CID member organizations. The topics ranged from primers in advocacy, the legislative process and Medicaid to the redesign of children's DD services and behavioral health transformation. All the sessions were provided at no cost and were presented in the Auditorium on the Garden Level of the Capitol, giving attendees an opportunity to not only learn the information but see where the legislative and advocacy work takes place. More than 125 people took advantage of the training, a sign of interest in the legislature and its impact on people with disabilities. Plans are underway to make each of the presentations available on-line to those who were not able to attend.

## REDESIGN OF DEVELOPMENTAL DISABILITY SERVICES

In 2009, the Divisions of Family and Community Services and Medicaid began a process of redesigning the service system for children with developmental disabilities. Meetings were held that year with a variety of stakeholders to discuss, research, and make recommendations regarding what the new service system should look like. The intent was for there to be a range of services from basic supports to intensive interventions that would best meet the child's needs. These new services would replace the developmental therapy and intensive behavioral



intervention (IBI) services that some children now receive. Personal care services and various therapies like occupational and physical therapy and general medical care are not included in this redesign. Those will continue to be provided as they are currently.

Under this new system, after the child is assessed, s/he will be placed in a specific budget category which will decide the amount and, in some cases, the types of services s/he may receive. Currently, services are managed by limiting the number of hours of a service that a child may receive.

The proposed system includes three categories. The first would be for any child birth through 17 with a developmental disability. These children would

be eligible for respite, habilitative supports (not skill training), and family education – all provided as Medicaid state plan services. Medicaid estimates that about 15% of children with developmental disabilities would fall into this category. The annual budgets for children in this category would be \$4,900 (compared to \$8,100 currently).

The next category of services is a new children's waiver for children with developmental disabilities who meet ICF/ID (institutional) level of care. Seventy percent (70%) of the children are expected to fall within this category. They will be eligible for the supports that children on the state plan get plus habilitative intervention (similar to the current IBI), crisis intervention, family training (different from family education), therapeutic consultation, and interdisciplinary training. The annual budgets for children in this category will range from \$6,200 to \$14,900 depending upon the level of behavior support needed by the child. This range compares to current average costs of \$7,200-\$18,700/year.

Families with children in either of the above categories will have the option of directing their child's services. This will be similar to the self-directed services option for adults except the budgets for children will not be individualized

The third category of services in this redesign is for children with developmental disabilities aged 3-6 with autism and/or challenging behaviors. This Act Early waiver is intended to be very intensive, time-limited, and requires ongoing active parental participation for at least 20% of the time the child is receiving intervention services. This category is expected to include 15-20% of children with developmental disabilities and, because of the clinical intervention focus, the budget is higher at \$29,300/year compared to the average \$10,404 spent each year on these children currently. Families with children on the Act Early waiver do not have the option to direct their child's services.

The funding for this redesign is based on the 2012 projected funding level for children's Medicaid developmental disabilities services minus some system costs. That leaves \$39,416,474 to serve an estimated 3,195 children with developmental disabilities, an increase of 5% over the average number of children with developmental disabilities receiving services in 2011. The funds are distributed across the 3 categories discussed above based on a 2006 survey of 126 children. This redesign does not save money even though many children will receive less services.

This redesign is being done through rules which must be approved by the Legislature in the 2011 session if they intend to "go live" with the changes effective July 1, 2011. Children will be phased in to the new service model on their birthdays, beginning October 1, 2011.



Because two types of services and service providers are being replaced with new services and providers with different qualifications, there has been much concern about whether children will have access to the service providers they need when they are moved to the new model. A dual system with both types of services will be in place for one year to allow providers to meet the new requirements.

School-based services will remain as they currently are for the 2011-12 school year, but it is uncertain what will happen from that point forward. Although schools are required to provide certain services to children, if they are not able to use their funding to match federal Medicaid funds to pay for these services, children may be at risk of losing services. In addition, waiver services cannot be provided in schools.

With the elimination of developmental therapy, adults will also be impacted. Rules regarding adult services are not being changed at this time. The Department has indicated that it expects to collaborate with stakeholders in 2011 to begin discussing these changes.

Many providers, advocates and families are concerned about the redesign. While they may support the concept of developing a range of services that adequately meets an individual child's needs, there are a number of unresolved issues. These issues are even more of a concern because they are not being adequately addressed or solved before implementation. Stakeholders have urged the Department to slow down the implementation to resolve these design and structural issues before starting to use this model. Until the issues listed below are addressed, this is not an improved service system for children (or adults) with developmental disabilities. The concerns include:

- this redesign does not save money but it does reduce services to most children
- the use of budget categories instead of individual budgets means that some children may get more than they need and some may get less; in this model, there will be no allowance for reconsideration of budget amounts for extenuating circumstances; if their needs change, children can be reassessed to determine if they fall into a higher budget category or, for some, can apply through the Early Periodic Screening Diagnosis and Treatment (EPSDT) process if the services needed are medically necessary
- for the distribution of funds across eligible children to be valid, it should be based on a larger and more recent sample, not one taken from 126 children more than 3 years ago
- adequacy of budget amounts; a child now receiving 22 hours of developmental therapy (including skill training) each week may only be able to get 7 hours of respite or 5 hours of habilitative supports (neither include skill training) based on their budget

- children on state plan services are not eligible for intervention services or crisis services when needed
- given the July 1 implementation date, there is concern that providers will not be able to get the training they need to meet the new requirements due to the cost and/or availability of classes; this could result in a shortage of providers to meet support and service needs
- availability of school-based services after the 2011-12 school year is uncertain; if the majority of services are put into a waiver, these cannot be provided in the schools, potentially substantially reducing available services

The Council recommends that the rules not be approved until the Department, in partnership with stakeholders, can resolve the current issues before implementing this model.

## HOW OPTIONAL MEDICAID SERVICES SAVE IDAHO MONEY

By Jim Baugh, Council Member, Executive Director of Disability Rights Idaho

Medicaid is a state and federal program which provides federal funding for medical care for people who cannot afford it and a range of services for poor people with disabilities which allow them to live safely in their homes. The State of Idaho provides about 30% of the cost of this care and the federal government provides about 70% of the cost. For the last three fiscal years the federal share was increased to about 80% due to stimulus funds. In 2011, the federal share will gradually return to about 70%.

To participate in Medicaid, Idaho must cover certain federally mandated services. Another set of services are "optional" under the federal law. These "optional" services were added to save the states money, and to provide federal financial assistance for services which states were providing with state funds only. Idaho has chosen to cover optional Medicaid services to reduce costs in mandatory services or to obtain federal matching funds for services previously paid for with state dollars.

### **"Optional Services" include lower cost alternatives to mandatory services.**

Many optional services are lower cost services which reduce the use of higher cost, mandatory services. For example nurse practitioner services and licensed professional services such as podiatrists, psychologists, and nurse anesthetists are "optional" but reduce the use of higher cost, mandatory physician services. Similarly, optional Home and Community Based Services (HCBS) replace more expensive mandatory nursing home services.

**Intermediate Care Facilities for people with Intellectual Disabilities** (ICF/ID) services are optional but through this Medicaid service the federal government pays for 70% of the \$22,000,000 per year cost of Idaho State School and Hospital (ISSH) including the payments on the bond issued to build the new buildings on campus. Through private ICFs/ID and Home and Community Based Waiver Services for people with developmental disabilities(HCBS/DD), Idaho has been able to reduce the average population at ISSH from about 1,000 people in 1960 to about 68 today. The average cost of care at ISSH is now about \$700 per person per day while the cost in private ICF/IDs is about \$240 per day, and the cost of care in the community with HCBS is about \$129 per day. Since the introduction of HCBS/DD, the population at ISSH has decreased significantly and the population in private ICF/IDs has been held steady in spite of a significant increase in the number of people with developmental disabilities who are eligible for institutional care in Idaho. By absorbing these people into the HCBS/DD waiver, Idaho has saved huge sums of money over the years.

**HCBS services for people who would otherwise need mandatory nursing home services (the HCBS/A&D waiver)** is an even bigger savings. This waiver saves Idaho taxpayers money in two ways. First it saves millions by providing less expensive home based care. Currently, there are 7,813 adults on the HCBS/A&D waiver with an average per person, per month cost of \$1,561. The average per person per month cost for nursing facility care was \$5,349, saving Idaho about \$29,600,000 per month or about \$355, 000,000 per year if all eligible people moved to nursing facilities. HCBS/A&D services keep people out of nursing homes entirely or at least for a longer period of time. HCBS/A&D services have also saved the state millions in reduced Aid to the Aged Blind and Disabled (AABD) payments. The AABD program is mandated for states participating in Medicaid. Prior to the HCBS/A&D waiver, Idaho used state funds to pay the cost of residential and assisted living homes for people without the financial resources to support themselves. With the HCBS/A&D waiver, much of the cost of care for these people is now shared by the federal government.

***Eliminating “optional” Medicaid services will increase Medicaid costs by driving people to higher cost mandatory services or by losing federal matching funds for services the state would need to provide with general fund dollars.***

## BUSINESS LEADERSHIP NETWORK

The Idaho Business Leadership Network (BLN) held its first state conference October 15<sup>th</sup> at the Boise Centre on the Grove. While small in comparative size to other types of statewide conferences the first time event was very significant. It marked the intention by organization members to establish and grow the Idaho BLN Chapter. Idaho Power, Key Bank, St. Luke’s Regional Medical Center, and Micron are some of the 17 businesses that are now members of the Idaho chapter. Stephanie Jensen from the State Independent Living Council spearheaded the project and served as secretary prior to her relocation to another position in Wyoming. The Idaho Council on Developmental Disabilities provided funding that helped the organization with initial start up costs.

On its national website the BLN mission *statement* “recognizes and supports best practices in the employment and advancement of people with disabilities; the preparedness for work of youth and students with disabilities; marketing to consumers with disabilities; and contracting with vendors with disabilities through the development and certification of disability-owned businesses.” For information about the Idaho BLN Chapter contact the Idaho chapter president [Debbie@cascade-enterprises.com](mailto:Debbie@cascade-enterprises.com).

## HOUSING SUMMIT

In September, John Shea of Alan, Shea and Associates of California presented a one day housing workshop in Boise that was attended by approximately 60 individuals. The workshop was co-sponsored by the Council and Community Partnerships of Idaho. Many of the participants were parents of older children or adult children who were at or nearing transition age when having safe and affordable housing becomes important.

Dr. Shea emphasized the importance of giving people choices to live in their own homes, using examples from the North Bay Housing Coalition in California. He explained pooled trusts using the example of 3 individuals residing in their own home as result of their parents agreeing to pool their children’s social security income to purchase a home and pay the ongoing associated expenses.



Pooled trusts are special needs trusts for individuals with disabilities where their income is combined and managed for their own benefit without losing Medicaid eligibility. Special needs trusts cannot give cash directly to individuals, but they can pay for services and certain exempt resources.

To learn more about special needs trusts and pooled trusts, visit the Golden State Bank website [www.gspt.org](http://www.gspt.org)

## IDAHO STATE SCHOOL AND HOSPITAL

In 2009 in response to legislative direction, a large group of stakeholders, including the DD Council, met several times to examine and discuss the current role of Idaho State School and Hospital and to develop recommendations regarding the future of the facility given its decreasing population. The report from these meetings was presented to the legislature in 2010. Recommendations included the development of a statewide crisis network plans for further downsizing at the institution. This was stalled by the sagging economy and budget reductions. Also recommended was statutory direction regarding the admission and discharge procedures. Legislation to do this, and to change the name of the facility to the Southwest Idaho Treatment Center, was drafted and is expected to be introduced in the 2011 session. The Council has provided input into the draft and supports its efforts to reduce further admissions and create successful community transitions for current residents.

## TBI TRUST FUND

A traumatic brain injury or TBI is a blow to jolt to the head resulting in the disruption of normal brain function. It can mean loss of consciousness, amnesia, changes in brain functioning or even death.

The Centers on Disease Control (CDC) estimate that between 16,800 and 35,000 Idahoans are living with a severe TBI. Idaho ranks 7<sup>th</sup> in the nation for per capita hospitalization and disability rate due to TBIs. Because Idaho is a rural state, there is a higher risk for TBI because of limited access to and availability of health care. In addition, Idaho has a significant number of active-duty service personnel deployed to and returning from Iraq and Afghanistan. The numbers of service personnel returning to Idaho with a confirmed TBI are unknown but are suspected to be high.

Data collected in 2007-08 reveal that most of the brain injuries in Idaho affect language and communication, learning and memory, sensory processing and movement. Average hospital stays are brief with 40% of the patients discharged to self-care at home and another 29% requiring skilled nursing or home health care. Eighteen percent (18%) died.

Idahoans living with brain injury are in need of resources not readily available to them. In a survey conducted by ISU's Institute of Rural Health, it was found that 42% of the people who responded had incomes of less than \$7,500/year, significantly lower than their pre-injury income. Since 2001, Idaho has received funding from the Federal TBI Program to develop and promote services for people with TBI. The establishment of a TBI Trust fund for Idaho would assist these individuals to regain their quality of life through services, supports, and other resources that are currently not available.

Legislation to create such a trust fund for Idaho is expected to be introduced in the 2011 session. For more information on TBI or the trust fund legislation, contact Russ Spearman at 208-373-1769 or [spearuss@isu.edu](mailto:spearuss@isu.edu).

## HOME CHOICE – MONEY FOLLOWS THE PERSON GRANT

In early September, the Department of Health and Welfare submitted their proposal to the Centers on Medicare and Medicaid Services (CMS) stating their intent to request a Money Follows the Person grant for Idaho. That grant proposal, entitled ***Home Choice***, is being written by Medicaid staff and is due on January 7, 2011. Idaho is currently one of 20 states that does not have an MFP grant.

MFP grants provide an increase in FMAP (the federal portion of Medicaid funding) as an incentive to move people from institutional settings to community-based homes and services. Institutions are characterized as state facilities such as Idaho State School and Hospital as well as private Intermediate Care Facilities for people with intellectual disabilities (ICFs/ID) and nursing homes. People transitioning into communities must have resided in the facility for at least 90 days. Funds from the grant can be used to ensure the services and supports that the person needs for successful transition, including housing costs but states must ensure that those supports will continue after the conclusion of the grant.



Idaho's application has four different goals. These are:

- 1) Increase the use of home and community-based services (HCBS) and reduce the use of institutionally-based services;
- 2) Eliminate barriers and mechanisms in State law, State Medicaid plans, or State budgets that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive long-term care in the settings of their choice;
- 3) Strengthen the ability of Medicaid programs to assure continued provision of HCBS to those individuals who choose to transition from institutions; and,
- 4) Ensure that procedures are in place to provide quality assurance and continuous quality improvement of HCBS.

A statewide meeting of stakeholders was held on November 19 to gather input on what to include in Idaho's proposal. Once the proposal is submitted, a decision is expected within 60 days. The Council was one of several organizations supporting this effort.

## EDITORIALS



**James Steed**  
Acting Council Chair

### IT'S ALL ABOUT WE

In my soon to be 50 years of being on this big green and blue globe, I have realized that as a person approaches 50 they become the caretaker of their own art museum. In this museum there are paintings depicting significant events in a person's life. In my museum I have 3 separate and distinct rooms. The first room in my museum has events that have changed the world such as Neil Armstrong's walk on the moon.

The second room in my museum contains the tragedies that have changed the world. September 11, 2001 has a large water color in that room. The third room in my museum contains the events that have personally impacted me and the people I care about. I added a big painting to the third room on October 21, 2010.

On October 21, 2010 Idahoans with developmental disabilities came from across the state to attend Idaho's first Self-Advocacy Conference "Self-Advocacy: It's all About We." October 21-23, Idahoans with developmental disabilities broke through our cocoon of silence to become Self-Advocates who have a voice and choice of what goes on in our lives. Idaho Self-Advocates through fantastic and informative keynote speakers and breakout sessions came to the realization that one voice is great, but many voices become "**We**" and "**We**" is a force to be reckoned with when it comes to the home and community based services that assist us in living independently. I look around the third room of my museum and I see vacant spots on the wall because now that we are "**We**" the work has just begun.

I would to thank the people who made Idaho's first Self-Advocacy possible. Thanks to LIFE Inc. and LINC, Inc. for sponsoring the entertainment, the Center on Disability and Human Development for sponsoring the North Idaho bus, Disability Rights Idaho for not only explaining the importance of voting being our voice but also for decorating for the dance, the Idaho Self-Advocate Leadership Network for their assistance in planning the conference and all the breakout sessions the network did. Finally, I would be remiss if I did not thank one of the nation's best Developmental Disability Council staff: Marilyn, Christine, Tracy, Amanda, Ron, and Shane - thank you so much for assisting Idaho Self-Advocates. **Self-Advocacy...it's All about We!!**

### LISTENING AND LEARNING

There is nothing like going on the road and talking to people to cause you to adjust or readjust your thinking and perspective. In 2005, the Council embarked on a 10-day statewide bus tour to promote the concept of self-determination and help launch the self-directed waiver option for adults with developmental disabilities. We found that people were hungry for accurate information about this option and services in general. We put considerable resources into providing that information.

This fall, on a much smaller scale, we held public forums and focus groups to gather input and ideas from people across the state about issues they think the Council should be working on in our next five-year plan. This information supplements data we are receiving through a survey on the



**Marilyn Sword**  
Executive Director

Council's website. All of this data, collected and prioritized will be developed into goals that will guide the Council's work through 2016.

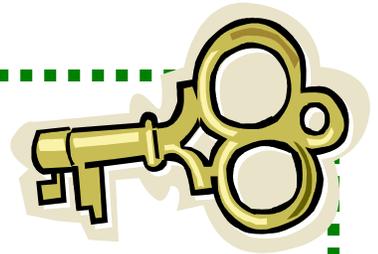
So what did we hear? Not surprisingly, people are worried about the cuts being made and how they will continue to be able to live in their communities. We heard concern about the lack of jobs and transportation to support people working, about how difficult it is to find good quality direct care staff without high turnover, about the lack of real inclusion of students with disabilities in some school districts, about how hard it is to access services and how cumbersome and inefficient the eligibility determination process is. We heard very specific suggestions such as eliminating the use of the Scales of Independent Behavior-Revised, the current tool used by the state to determine eligibility and set individual budgets.

But people were also quick to point out what was and is working in their communities. Integrated recreational programs, local support groups, the availability of services, a supportive business community. In nearly every location, parents applauded the Infant Toddler Program and Katie Beckett (the Home Care for Certain Disabled Children program that allows access to Medicaid coverage for children with significant disabilities whose families would not otherwise qualify for Medicaid). Many expressed appreciation for work the Council has done in self advocacy and support for the Idaho Self Advocate Leadership Network, person-centered planning, and Disability Mentoring Day.

But the one overarching comment that we heard in all locations was the need for accurate, timely, and easy to understand information about services and what was happening to them. People want information early enough to make adjustments as to how changes will affect their lives. And they want it in formats that are user-friendly, not complicated and full of jargon or so hard to find on a website that they give up. Clear, accessible information that people can use in their daily lives.

The people we spoke with are resilient, caring, surprisingly optimistic, and very community oriented. They are strong and creative. They are not looking for a handout but the support they need to be contributing and responsible citizens. They are more than willing to be partners in solving the current dilemmas that Idaho faces. We just need to keep listening and learning from what we hear.

## Do you know of a great resource or activity in your community?



We have a great way for you to share information about that resource with other families and individuals who might need it.

Please go to the IdahoHelp website and type the information into the submission box. It only takes a few minutes and you may be helping someone with a resource that can enhance their life.

**IdahoHelp – Web-based Community Resource Directory**

[www.idahohelp.info](http://www.idahohelp.info)

# CALENDAR OF EVENTS - WINTER/SPRING 2011

<b>DATE</b>	<b>JANUARY</b>
14	CDHD Community Advisory Board Meeting, U of I Boise Center
21	Interagency Council on Secondary Transition
25	Joint Meeting of Public Transportation Advisory Committee & Interagency Working Group on Public Transportation
25-26	State Independent Living Council Meeting, Boise
26-28	DD Council Meeting, Cambria Hotel, Elder Street, Boise
31	<a href="#">Deadline for Inclusion Awards Nominations</a>
<b>DATE</b>	<b>FEBRUARY</b>
2	Consortium of Idahoans with Disabilities (CID), IPUL
3-4	Early Childhood Coordination Council (EC <sup>3</sup> )
18	Special Education Advisory Panel (SEAP)
21	President's Day
<b>DATE</b>	<b>MARCH</b>
1	<a href="#">Deadline for DD Council Membership Applications</a>
2	Consortium of Idahoans with Disabilities (CID)
7-8	Tools for Life: Secondary Transition Conference, Idaho Falls
25	<a href="#">Deadline for Youth Leadership Forum Applications</a>
<b>DATE</b>	<b>APRIL</b>
5	Special Education Advisory Panel (SEAP)
6	Consortium of Idahoans with Disabilities (CID)
6-8	Title 1 Conference (Successful Educational Practices), Boise
19	Community Care Advisory Council
27-29	DD Council Meeting
<b>DATE</b>	<b>MAY</b>
4	Consortium of Idahoans with Disabilities (CID)
5-6	Early Childhood Coordination Council (EC <sup>3</sup> )
8	Mother's Day
15-16	Early Childhood Coordination Council (EC <sup>3</sup> )
30	Memorial Day
<b>DATE</b>	<b>JUNE</b>
1	Consortium of Idahoans with Disabilities (CID)
17	Interagency Council on Secondary Transition
19	Father's Day