

VISIONS & VALUES

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COUNCIL MEMBERS:

Theresa Wilding, Chair, Terreton
 Rick Betzer, Vice Chair, Shelley
 Kristyn Herbert, Cons. Rep., Boise
 Jim Baugh, Boise
 Mary Bostick, Boise
 Tanya Brindle, Boise
 Dona Butler, Nampa
 Donna Denney, Midvale
 Debbie DePaola, Lava Hot Springs
 Paige Fincher, Boise
 Julie Fodor, Moscow
 Tygh Hales, Boise
 Bob Jackson, Eagle
 Mary Johnson, Grangeville
 Kim Kane, Boise
 Liz Ricciardi, Coeur d'Alene
 David Rogers, Boise
 Roger Shanahan, Hansen
 Mike Smith, Moscow
 James Steed, Pocatello
 DIRK KEMPTHORNE,
 GOVERNOR
 Marilyn B. Sword,
 Executive Director

"Be Determined" Bus Tour a Success!



The small towns of Terreton and Mud Lake came out en masse in support of their hometown girl and rally organizer Theresa Wilding.

For two weeks in June, two school buses traveled the state and carried the message of "**Be Determined**" to 36 Idaho communities. Council members and staff plus self-advocates and others started in Preston and Bonners Ferry and traveled a total of 1600 miles, holding rallies in 34 communities before ending up in Boise for a grand finale at the Capitol on June 24. An estimated 750 people attended at

least one of the rallies.

The rallies received considerable media attention as the tours wound through the state. Seven television stations and 6 different newspapers featured stories about bus tour rallies. In some communities, the story made the front page and featured a personal profile about someone in the community. Council

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Leaders to Watch - Meet Levi Robinson



One of the highlights of the bus tour in June, was the chance to meet new people and make new friends. One of the new friends that we made

was Levi Robinson, an enthusiastic and well spoken young man from Blackfoot. He attended the rally with his folks, Shirley and Almy.

Levi is a determined 14 year-old

who has no problem speaking his mind and sharing his dreams. He enjoys school, especially science, computers and technology. "I plan to go into the computer industry. I'd like to start a computer company for the disabled." An excellent student, Levi plans to continue his education, earn six PhD's. and perhaps work for NASA.

Levi found the discussion at the self-determination rally very interesting. He has very specific ideas about how the service system could

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COUNCIL PROJECTS



Steps To Statewide Self-Advocacy

The five teams that currently make up the Idaho Self-Advocate Leadership Network (SALN) met in Boise in July. The teams worked on steps that would get them closer to their goal of becoming a statewide self-advocacy organization. Here are the results of their work:

➤ Created a mission statement: **“To advance equality though growth, education, and advocacy by providing opportunities so that individuals with disabilities may achieve their greatest unique potential.”**

➤ Developed a plan to map out steps to become a statewide organization.

➤ Agreed on the following education topics for teams of SALN to provide in presentations

to other people with disabilities:

1. How to be a self-advocate
2. Self-Determination
3. Self-directed support waiver option
4. People First Language
5. Transition-age students (18-21 year-olds) with a focus on real work for real pay & self-determination values
6. Sexual abuse/assault victim education
7. Project Vote

The five teams in Regions 1, 2, 5, 6, and 7 are excited to welcome their new teams being recruited now in Regions 3 (Nampa-Caldwell-Emmett area) and 4 (Boise-Mountain Home-McCall area). Training for these teams is scheduled to begin in November and run through July, 2006.

Council Announces Grant Funds Available

This fall, the Council is issuing several requests for proposals making funding available for a variety of projects:

Universally Accessible Playground - up to \$10,000 is available for one community in Idaho (outside of Ada County) to help with the development of a playground that is accessible to all. Proposals will be due on October 30.

Transportation Demonstration – demonstrate a model of a transportation voucher system for individuals with disabilities in one rural community in Idaho. The Community Inclusion Driver model may be used as a guide for this demonstration. RFP in development; proposals will be due in November.

Cost/Benefit Analysis of Segregated Work Settings – research and analyze the cost to Idaho to provide segregated work services to Idahoans with disabilities and the long and short-term benefit to those individuals. RFP in development; proposals will be due in early December.

Council Webpage Redesign – redesign the Council’s webpage using Frontpage software and meeting 508 accessibility requirements. RFQ will be released mid October; bids will be accepted until November 18.

Questions regarding any of the above should be directed to the Council at 1-800-544-2433 or 208-334-2178.

Legislative Information Day

The Council and the Idaho Self-Advocate Leadership Network will sponsor a Legislative Information Day at the Capitol Rotunda Tuesday February 28th from 7:30-3:30. A continental breakfast will be provided. Self-Advocates (adults with Developmental Disabilities who speak up about issues that impact their life or the lives of others with disabilities) will be talking with Legislators about issues preventing people with disabilities from participating in their home communities in meaningful ways. Please mark your calendars and join us.

COUNCIL VISION:

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

COUNCIL PROJECTS

Idaho Panel Wows Audience!

"The best presentation at the summit!" "You guys were great!" These were two of many positive comments heard after the workshop session by members of the Idaho Self Advocate Leadership Network at the Alliance for Full Participation Summit in Washington, DC on September 22-23. SALN representatives James Steed, Tracy Martin, and John Russell were joined by support staff Felicia Funk-Heideman in providing information regarding

self-determination, Idaho style. The group stressed the key factors of partnership between the DD Council and the Division of Medicaid, the involvement of self-advocates at every step of the way, and the importance of the Independence Plus grant in providing needed funds for system planning and design. The workshop was facilitated by Council Chair Theresa Wilding and was attended by over 105



participants. Representing Idaho at this historic summit of 2200 advocates and self-advocates from across the U.S. were **Julie Fodor, Rick Betzer, Erick Yeary, Marilyn Sword, Tanya Brindle, Kathleen Butler, Kelly Hall and Shannon Dunstan.**

Information Sought for DD Council's New Five Year Plan

Enclosed with this issue of *Visions and Values* is a survey for you to complete and return. The survey is also available on the Council website at www.state.id.us/icdd/. Your responses will provide the Council with information that will contribute to the development of the Council's next Five Year Strategic Plan (2007-2011). Information from the survey will assist the Council in gaining an understanding of the most important issues confronting people with developmental disabilities in Idaho. We will also gather information through discussion groups across Idaho. If you belong to a group that could include this in one of their meetings or are interested in hosting a discussion, please contact the Council office.

Bus Tour *(continued from pg. 1)*

member and rally team organizer Mike Smith was one such person who was featured in a front-page story in the Moscow-Pullman Daily News.

Thirty elected officials, representing all levels of government, attended rallies, often taking part in the program. Among them were Secretary of State **Ben Yursa**, State Senators **Kate Kelly, Gary Schroeder, Denton Darrington, and Brent Hill** and Representatives **Kathie Garrett, Donna Pence, Mike Mitchell, Pete Neilsen, and Larry Bradford**. At the Boise rally, Mayor **Dave Bieter** welcomed a

crowd of nearly 200.

The rallies were intended to share information about the concept of people with developmental disabilities having choice, control and responsibility in their lives. It also gave the Council the opportunity to share information about the upcoming Self Determination option in the Home and Community Based waiver for individuals with developmental disabilities. According to Medicaid officials at the Department of Health and Welfare, this waiver option is tentatively scheduled to roll out, starting in Boise, Moscow and Pocatello, sometime after January 1, 2006.



Final rally at the Capitol with members of the Idaho Self Advocate Leadership Network



“My Voice, My Choice” Idaho’s Self-Directed Services Program

“My Voice, My Choice” is the name that has been chosen for Idaho’s new Self-Directed Services Program. The program will be implemented in three areas of the state at the beginning of 2006: Moscow, Boise and Pocatello. These areas were chosen based on several factors including (but not limited to): interest by individuals who use Medicaid waiver services, supportive service providers and available community resources. Starting the program in only three areas allows for more focused efforts in training staff, individuals, service providers and community members to help ensure a more successful outcome for individuals choosing the option.

As the “My Voice, My Choice” program reaches the final stages of development, several activities are taking place. The Division of Medicaid held a negotiated rules meeting on August 10th in Boise for public input on the rules that will govern the self-directed services option. A large group of stakeholders including self-advocates, parents, providers, Department of Health and Welfare staff and advocacy organizations spent the morning discussing the proposed rules and related issues.

The rules will be implemented as “Temporary Rules” during the initial phases of the self-directed waiver option. This will allow for changes, as needed, to ensure a quality program for individuals who

enroll in the option, and meet the needs of Medicaid to administer the program.

Also, a communication plan to provide information to stakeholders and build public awareness is in the works. Rinda Mitchell at the Division of Medicaid heads up the Self-Determination Communication Team that has been tasked with developing a plan that will coordinate communication efforts around the state. Included in the plan are public awareness materials, partnership meetings with DHW staff and providers, informational orientation meetings with individuals with disabilities, parents and community members and more detailed trainings for staff, providers and individuals choosing the new option.

The first informational meetings will be held in Moscow, Boise and Pocatello in November. Contact Rinda Mitchell at Medicaid or Tracy Warren at the DD Council office for details about the meetings. The communication workgroup will be finalizing a plan for the development of training materials and will seek input into that process.

A report to state legislators will be provided by the Division of Medicaid and the temporary rules will be reviewed during the next session.

High School Redesign

The Idaho State Board of Education is proposing new rules that could change Idaho high school and middle school curriculum and graduation requirements for all students. The desired outcome is a more rigorous, academically focused curriculum intended to better prepare Idaho students for college and careers after high school. Some of the changes seem positive: Post-school readiness plans to be developed for every student and elective classes that are career focused will be required. Other changes cause some concern: a student will have to maintain a cumulative “C” average and complete pre-algebra before entering 9th grade with no alternative means to meet those requirements included in the rules. To read an overview of the proposed changes and information about the possible affect for students with disabilities, visit the Council website.

Tools for Life: Transition & Technology Conference

Get ready for the second annual “Tools for Life” Fair in Boise Feb 27-28, 2006. The focus is preparing and supporting individuals with disabilities as they transition from school to life. For more information contact Sue House, IATP/Center on Disabilities and Human Development at sueh@uidaho.edu.

STATE NEWS

Youth Leadership Summit

Young Self Advocates Tell It Like It Is

Graduates of past Idaho Youth Leadership Forums and other young people from around the state came to Boise in early August for a summit to discuss leadership development programs and issues important to youth with

disabilities in Idaho. For two days the young leaders shared with each other their successes and challenges. They not only identified ways to be more effective leaders in their communities, but also discussed the barriers

faced by young people with disabilities in our state. On day three the youth were joined by a variety of agency and organizational representatives to collaborate in a future plan for youth leadership development in Idaho.



Tom Ball, YLF Graduate

The desired outcome from the summit will be a communication network for young people with disabilities in Idaho, focused development of youth leadership programs in regional areas, and a continued connection with youth enabling them to join forces and work on the issues that they say are important.

Levi Robinson *(cont. from pg. 1)*

be more effective for people with disabilities. He feels that "Medicaid has too much code and rules." Shirley, Levi's mom, said that juggling all the paperwork and bureaucracy to get the simplest things done is often exhausting. "It is frustrating for kids like Levi when they know that people are just putting them off. Levi knows what he needs and yet they just keep saying that you have to wait."

Levi and his family also face barriers in getting needed medical

equipment and specialty care. "The doctors up here (in Idaho) just say 'Go to Salt Lake.' So I have to sit in the car for 3-4 hours and then sit and wait to see a doctor and then get back in the car to come home."

Levi keeps up on the issues and is politically active. He is on his school debate team and feels that our government thinks that people with disabilities don't count. "I had input on the state government. I talked to my representative about the recent Idaho ADA law. I helped make that happen. It would certainly

help if people were more like me and speak out when they see what needs to be changed."

Levi's political goals go beyond student council. "I plan on being President of the U.S. one day," to which Levi's father jokingly replied, "If that happens, I'll move to France." Levi says that when he takes office he will make sure this country is run the way it should be. He would make sure that people get the medical care they need. We need to keep an eye on Levi Robinson, an up and coming leader in our state.

More State News on DD Council Website at www.state.id.us/icdd/

- Idaho Special Education Manual Updated to Reflect Changes to IDEA
- High School Redesign: What This Might Mean for Students With Disabilities
- New Rules Proposed for Assisted Living and Certified Family Homes

NATIONAL NEWS

Drugs, Duals, and Doughnuts: No Wonder They Call It “Part - D”

by Jim Baugh, Executive Director, Co-Ad

The implementation of The Medicare Modernization Act (MMA) will add a new “Part D” to the types of Medicare coverage. Part D is the new coverage for prescription drugs for Medicare participants. While everyone agrees that Medicare participants need affordable access to prescription drugs, not everyone will be happy with the program as it rolls out this year. Most people on Medicare will be very happy to finally have some coverage for the ever rising cost of needed prescription medication. Most will also be overwhelmed with the array of new choices they will face. There will likely be over thirty (30) drug plans to choose from in Idaho, each with a different drug formulary, different premiums, and co-pays.

There are some shortcomings to this coverage. The companies offering plans under Part D do not have to cover all drugs. Each will have a list of the drugs they cover and some of them can require special authorizations by the company, some classes of drugs are not covered at all. A very commonly prescribed class of drugs which is not covered, is benzodiazepines, which includes a whole list of drugs like Valium, Ativan, Xanax and Klonopin which are prescribed as muscle relaxers, anti-anxiety agents, mood stabilizers, sleep aids and sometimes as secondary anti-seizure medications. There is also a huge gap in the coverage which some have called the “doughnut hole.” This gap will require some people to pay for a huge part of their annual drug costs.

Most people on Medicare who have better coverage through pension plans or private policies can just decide to stay out of Part D if they choose to do so. There will be no such choice for people who qualify for both Medicare and Medicaid. These people, called “dual eligible” or sometimes just “duals”, will be required to get their drug coverage

through Medicare Part D. This coverage must be chosen from certain plans which have no premiums, no deductible and no “doughnut hole”. If the person does not choose a plan, the government will choose one for them. They will, however, have co-pays of \$1.00 to \$3.00 for each prescription fill or refill. The plans may not cover all of the drugs the person has been getting under Medicaid, and the new coverage may affect some people’s eligibility for other programs like food stamps, or housing assistance. The drug plans will have to cover at least two drugs in each “class” but the companies decide what the “classes” of drugs will be. They are supposed to cover all or almost all drugs used to treat seizures, mental illness or AIDS (but not benzodiazepines or barbiturates...go figure). Some drugs which Medicaid has approved may have to be re-authorized and some people may be required to try cheaper drugs and fail before getting approval for a more expensive drug which works for them. There will be new appeals procedures to contest denials, but we don’t know what these will be like.

State Medicaid programs may help soften the blow for some people by stepping in and paying for coverage. But we don’t know yet what kind of help Idahoans will get. We do know that states will **not** be allowed to pay the \$1.00 to \$3.00 co-pay.

Once the confusion over plans and coverage is cleared up (no small task), some people will finally have some coverage for prescription drugs that they didn’t have before. It won’t be the best coverage but it will certainly be better than nothing. However, people who are already eligible for both Medicaid and Medicare will probably actually be worse off under this new program. In the new language of Part D, we can say “Duals don’t deal with the doughnut, but do dole out dough for drugs.”

More National News on DD Council Website at www.state.id.us/icdd/

■ **Idaho Carries Message to Alliance for Full Participation and Wows Audience**

■ **National SABE Conference May 2006**

EDITORIALS

Just Do It!

On September 22-23, 2005, 11 national organizations came together to hold a summit in Washington DC entitled *Alliance for Full Participation: Many Voices, One Vision*. The vision of the Alliance was "That people with developmental disabilities and their families realize the promise of integration, productivity, independence and quality of life choices." The conference was to create a social agenda and action plan for fulfilling its vision.

In response to the Summit, Self Advocates Becoming Empowered (SABE) developed the following message. It reflects the

feelings of many self-advocates throughout the nation:

Just do it!!!!

Many have listened, some have taken action and we thank you. But we have talked enough and waited too long!!!

We have told you what is important to us. Get rid of the infamous and hurtful "r" word, do not label us. We will not put up with the "r" word continuing as part of an organization's name, even as initials. If you are working with me and for me then do not disrespect me.

We have been prepared enough. ASK the people who are living in institutions. Would you trade places? Close institutions. Get us real jobs. Close sheltered workshops.

Give US the money to live OUR lives. Money follows the

person means it is OURS, not programs.

We have the right to make our own decisions. With or without the support from others. WE CAN RUN OUR LIVES.

Support our movement. IT IS OURS. You receive millions of dollars in our name. We want to control this money, as we are the EXPERTS.

You must change, we have changed, we are taking the power. Walk the Walk, Respect Us or We will go on without you!

I am pleased at the success of the Summit and I look forward to the continuing efforts of the organizations involved to move closer to the vision above. I hope that self advocates, families, and the organizations in Idaho can continue to work together to "**Just Do It!!!!**"



Marilyn Sword,
Executive Director

The Power of Helping

On August 28-29, 2005, Hurricane Katrina slammed into the Gulf Coast and destroyed the lives of thousands of our fellow citizens. Among those most impacted by this deadly storm were our brothers and sisters with disabilities in Louisiana, Mississippi and Alabama. Many of these individuals and their families were trapped, unable to evacuate and left to die. Warnings to get out were not accompanied by the means to do so. The richest country on earth was not able to provide the safety net

upon which these people depended.

And now with the effect of Rita, much remains to be done. If you would like to help with this enormous recovery effort, the following information can direct you to organizations that are working to provide relief for individuals with disabilities and their families who are victims of this disaster:

Katrina Relief Fund/The Arc: Go to www.thearc.org or send a check payable to the Katrina Relief Fund to: The Arc of the United States, 1010 Wayne Ave., #650, Silver Spring, MD 20901. Fund provides immediate

relief to Katrina survivors who are people with developmental disabilities and their families.

Families Helping Families/NACDD: At the Crossroads of Louisiana, 2840 Military Highway, Suite A, Pineville, LA 71360. Assists individuals with disabilities in Louisiana who have been impacted by Katrina.

UCP Hurricane Katrina Disaster Relief Fund: Call 1-800-872-5827 or log on to www.ucp.org/donate. Fund for supports and services for displaced people with disabilities and their families across the disaster area.

Thank you for your help.