Utah DD Council North Star

June 2009

From the Executive Director's Desk

— Claire Mantonya

The economy is impacting many of us personally and of special concern are the cuts in funding of disability supports. The Council is providing leadership and responding to our economic crisis with some creative and targeted projects. Over the summer, we will focus upon revitalizing a new grass roots advocacy effort across the state. We want you to become involved and commit to recruiting family and friends from your community to participate as well!

The Council has the ability now, as a result of the framework set forth in H.B. 340, to seek monies for the Respite Care Assistance Fund, and the Council will continue to support leadership development within the disability community.

These hard economic times will require that all of our community members step up and think of creative ways to solve issues facing us together. Currently I am working closely with the Utah Coalition of Caregiver Support (UCCS) as they are experimenting with the idea of time banking. Time banking is a concept of bartering services – a more formalized way to track and exchange services using the internet. My dream is to have the Council pilot a time bank to see if this concept can help families and individuals meet some of their needs. Go to www.timebanks.org so you can see more information. The UCCS is experimenting with time banking just among the agencies within the coalition. The coalition thinks this is a great concept that can involve many parts of the community that provide care giving.

Annual Award Nominations Open

It is time for the 2009 Advocacy Awards! Please consider nominating deserving individuals from the community to be recognized by the Council during their annual meeting on September 8th. This is our opportunity to honor people in the following categories: Self-Advocate of the Year, Employer of the Year, Volunteer of the Year, Child Advocate of the Year, Legislator of the Year, Parent of the Year, Adult Sibling of the Year, Media Representative of the Year. Nomination forms are available on the website at www.utahddc.org or you can contact the office (bemartin@utah.gov) to request a copy of the form. 800-333-8824 or 801-533-3965.

Nominations should be turned in by July 31st by regular mail, email or fax:

Utah DD Council
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Salt Lake City, UT 84101
clairemantony@utah.gov
Fax: 801-533-3968

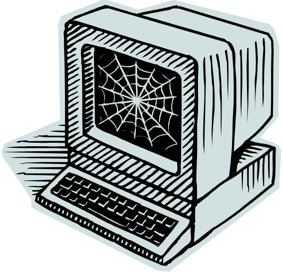
H.B. 340 Signed into Law

Governor Huntsman signed the Respite Care Assistance Fund into law on April 30th with Rep. Jack Draxler (House District 1, Logan) the sponsor of the bill looking on. Sen. Lyle Hillyard (Senate District 25, Logan) was the Senate sponsor. The idea for the bill originated when Andrew Riggle met with Rep. Draxler at his home in North Logan last summer. Andrew talked to him about the needs of so many families who are waiting for services, and Rep. Draxler decided to help be creative about respite.

Many Council members were involved in the passing of the bill, including testimony provided by Jennifer Kuhn, Andrew, Kris Fawson, and Claire Mantonya. The Council voted to house the administration of the Fund. A special committee appointed by Chair Kelly Holt has produced a draft of policies to manage the bill and the full Council will be voting on these policies in September.

Congratulations for all the hard work. Utah now has a mechanism in place through state law to house private and public donations that can be used to provide lifespan respite for people who do not qualify for state and federal programs.

Check out the Council's new look on the Web!



We have launched a newly designed website thanks to the hard work of our state technology person, Terry Davis, and the attention to details from Bonnie Martineau. Go to www.utahddc.org and see for yourself. Bonnie has the capability now to make changes from her computer, so we can update the site as needed without time lags or additional technical support charges!

Disability Policy Seminar in D.C.

Council members Jennifer Kuhn, Dr. Bryce Fifield, and Claire Mantonya attended the annual Disability Policy Seminar in Washington, D.C. at the end of April. This annual event brings together 500+ members of the developmental disability community to spend an intense two-days learning about the issues facing the disability community on the federal level. Participants get to hear directly from many Washington experts about the issues and bills as well as Advocacy 101. The Utah delegation met with Utah's congressional delegation as well to talk to our elected officials about our concerns and issues.

Some of the main issues that were presented during the seminar were The Community Choice Act and The DD Act.

Fact sheets that explain background information can be found on the web at http://utahddc.org/legislation/index.html. Claire and Jennifer will be glad to provide further information for people who are interested in learning more.

Council Members Expertise Recognized by ADD

The Administration on Developmental Disabilities has tapped into the expertise of the Utah Council to conduct their Monitoring and Technical Assistance Review and Support - the infamous MTARS. **Claire Mantonya** served on the federal team that reviewed the North Dakota DD Council in May. **Tom Brownlee** will be helping with the Protection and Advocacy review in Rhode Island this summer, and **Kelly Holt** will be working with the Nevada DD Council this fall.

NEXT FULL COUNCIL MEETING:

September 8, 2009
Location: to be announced

This is our annual meeting so make sure to save the date!

Grassroots Organizing Partnership

The Council approved $30,000 for an in-house managed project to revitalize grass roots advocacy efforts for the disability community. Marsha Honoré-Jones will manage this effort with the guidance of a cross disability committee appointed by Chair Kelly Holt. Kris Fawson, Andrew Riggle, Eder Soriano, Helen Post, Bill Young, and Claire Mantonya have met and a plan has been determined to move quickly over the summer months to identify, recruit, and train local organizers across the state who will have an outline of specific responsibilities to conduct in local legislative districts. The goal will be to educate and mobilize interested citizens so they can participate in the democratic process within their communities and let decision makers know the importance of supporting individuals with disabilities and their families so people may live in their communities and participate in community life. Training activities and local kick-off events will be held throughout Utah over the next several months.

If you are interested in becoming part of this grass roots effort, please contact Marsha Honoré-Jones at the office by phone or email: mhonore@utah.gov . We need everyone to become involved especially as money to fund disability supports has declined.

What I Learned in Washington D.C.

By Jennifer Kuhn

I was given the opportunity to attend the 2009 Disability Policy Seminar in Washington DC this April. I was overwhelmed not only with our country's history and a sense of pride, but by what "we the people" can do to assist our state representatives to understand the needs so they will support funding that will increase the quality of lives for people with disabilities and their families.

The first thing I learned right away is that their offices are spread out over a distance. So, no matter how many or what kind of Dr. Scholl shoe inserts you wear, your feet with still hurt!

Secondly, I knew that I would not be able to meet all of my state representatives in person and that some meetings would take place with their staff. I was nervous. I didn't know if they would even look at the "fact sheet" I gave them or even pass along my concerns and ideas to my representative. I am happy to report that our Utah state representative's staff do care and they do pass along our information. Although not every visit was a productive one, I was given the opportunity to practice "biting my tongue" while thinking, "don't bite the hand that feeds you". I found that some of my representatives lack the knowledge of what we, the "disability community," need and require from them. I realized that I could not expect them to know what my family needs or wants are without making it known.

Thirdly, I learned right away that asking them questions not only kept their attention but increased or expanded their interest. I would ask "What do you know about ____?," "Where do you stand on ____?" "Do you care about ____?" By asking questions, I was able to learn where they stood on certain bills and issues and then I knew which topics I needed to follow up on with more information for them or education for me!

Fourth I learned that it really helps to go prepared. Try to research or call before a visit. Find out where your representative stands on a specific topic. Take your "fact sheet," have the sheet be no more then one page front and back, and keep the information simple and short.

For example my family's "fact sheet" has our family photo at the top. Below that I listed our names, ages and diagnosed disabilities. Below that I listed the bill that would be going before my legislator or the topic I wanted them to learn about and then I simply stated why we need that specific service or funding. If we were already using that service, I would explain how it has increased the quality of life for my child or our family. If applicable, I would expand on how a service can prevent a need for an increase of more services in later years or maybe even decrease the need for services with the end result being an increase in the quality of life for that person or family, and an increase in their activity and contribution back to their community thus saving our state money. And if I had ideas, examples or experiences that supported that service or bill, I would share them.

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What surprised me the most was that our representatives wanted to hear from me! In our group meetings with our congressional delegation there were four other professionals (two with PhD's) but, when the meeting with our representatives started, they asked to hear from me, not the professionals! They wanted to learn about my daily struggles and how they can help my family. I actually felt like they were asking for instructions.

We need to remember that we are all on the same team. We all want to increase the independence and quality of life for others. We all want to save our state money and use as little services as possible. If we go into a meeting or write a fact sheet/letter with a positive attitude our message will be more effective.

Finally we need to remember that we are educating and changing the perspective of elected officials about families and people with developmental disabilities. Change takes time, information, energy, patience and the ability to "think outside the box." Let's face it, some of us just don't transition well.

A week after returning home I was once again surprised to learn that I didn't change their mind on the issues that went before them. They actually voted the opposite of what I requested. I had to remind myself, that I need to continue to educate, follow up and build a relationship with them.

A month later I actually got an e-mail from Senator Hatch's office in Washington DC. One of the bills that I e-mailed them about was going before them and they were requesting more information about that bill and my personal thoughts on it.

Later I went to a meeting where my state senator was attending. She actually came up to me and my family and talked to us. After picking my jaw up off the floor, I asked her how she knew who we were. She said that she had received our "fact sheet," with our family photo in the mail.

So overall I learned that it is vital for me stand up not only for my children with developmental disabilities, but for those families who can't. I now take other families' fact sheets with me when I attend meetings or I will mail a few together. I will forward action alerts or information about topics or bills to other voters. If we could all do this imagine what would happen!

*May I suggest to follow up with a thank you note to your representative with in two weeks of your visit, or communication.
*Fact sheet information obtained by "10 Minute Advocate" by; Utah Legislative Coalition for People with Disabilities, 801-463-1592, www.lcpdutah.org
*Action Alert
*Cap Wiz

HERE IS AN EXAMPLE OF JENNIFER'S FACT SHEET

Kuhn Family Fact Sheet*

Paul & Jennifer Kuhn
Wladimir age 11 Traumatic Brian Injury
Emily age 9 Traumatic Brain Injury, Epileptic & Legally Blind
Qwyn age 5 too much energy

ABLE ACT S. 493 H.R. 1205

This bill will allow families of children with disabilities to save money for their future needs without the risk of losing benefits of eligibility that they may need assistance with like employment training, assistive technology, housing and other services.

As a parent of two children with developmental disabilities I would gladly save money for their future needs. By allowing me to do this, we could not only increase the quality of life for my children, but increase their involvement and contribution to their community and state, while decreasing their need for public assistance therefore saving our state and government tons of money.

HATE CRIMES H.R. 1913

The current law does not provide federal involvement in cases where crimes are motivated by bias against the victim's real or perceived disability.

As a parent of two disabled children if I knew that my state and government was assisting me in the protection of not only my children's safety but, a law that would provide a consequence to those who purposely single them out, I would feel more comfortable promoting and supporting community involvement for my children.

This will allow my community and state to benefit from my children's abilities, and lead to more self-reliance and networking with community support. This will result in less public assistance, thus saving our state and government money.

MEDICAID AND COMMUNITY CHOICE ACT S. 683 HR 1670

I ask that you assist in changing Medicaid so that people with intellectual and developmental disabilities can have a choice of where to live in their community, rather than an institution.

My children with disabilities can live in their community with minimal assistance. By allowing them the choice of where to live, it increases their involvement and productivity in their community thus leading to a better quality of life for all and saving the taxpayers money.

EMPLOYMENT

Please increase funding for employment programs, such as: transition services and expanding resources to vocational rehabilitation to "think outside the box" for employment.

Like many others, my children with disabilities will be able to work and want to be able to assist in meeting their own financial needs. In fact both my children have their own small business. Wladimir, age 11, is the CEO of "Magnificent Magnets" and Emily, age 9, collects, shreds and recycles paper for others.

My children are learning at an early age that they can "work" and that having a disability does not mean staying home and collecting a monthly check from the government.

If you could increase the opportunities for employment for people like my children, they can contribute to their own needs, thus saving taxpayer money.

D.D. ACT

We ask that you support an increase in funding for the DD Act programs. These programs offer advocacy, support and participation of individuals with disabilities in all facets of their community life.

My local Utah DD Council presented "Thinking outside the Box"; ways to assist your loved one in employment. My family got the idea and motivation to teach our children they can contribute to their own needs from a community family support meeting resulting from this training.

We started early, our son Wladimir, age 11, is the CEO of "Magnificent Magnets" and Emily age 9 collects, shreds, and recycles paper for other family members.

By funding the D.D. Act, you will be putting a prevention plan in place. The funding of these organizations teaches and motivates individuals and families to "think outside the box", thus decreasing the burden on taxpayers..

UTAH DD COUNCIL CALENDAR FOR 2009

(Please check the UDDC website frequently for updated information)

June 9:	Executive Committee Meeting: 11:00 AM - 1:00 PM
June 30	State People First Meeting: 10:00 AM - 3:00 PM
September 8	Full Council Meeting - Annual Meeting and Advocacy Awards

information Access Utah Network ®

Call us with your disability questions!

800.333.8824 www.accessut.org

Go to http://www.ustream.tv/accesut7

for live and archived Access Utah Now broadcasts!

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