#### **COUNCIL VISION**

A world where all people have what they need to get what they want from life.





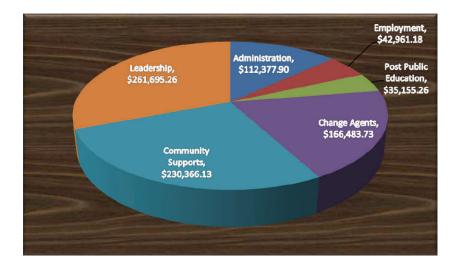


# **Utah Developmental Disabilities Council**

# **2013-2014 OVERVIEW**

The 2012-2016 5-Year Strategic Plan goals are listed below. This is the third year of work on these goals.

- (1) Support the development of opportunities for people with disabilities to pursue a range of post–public school education experiences.
- (2) Support the development of networks of self-advocates and advocates becoming effective change agents.
- (3) Support self-advocates and advocates in leadership opportunities.
- (4) Support the evolution of community resources and supports that empower people with developmental disabilities to lead independent lives in the community
- (5) Support the development of opportunities for people with disabilities to get and keep jobs.



# A MESSAGE FROM THE CHAIR

As you can see from our Annual Report, the Utah Developmental Disabilities Council has had many impressive accomplishments over the past year! We made great strides toward fulfilling our 5-Year Plan Goals in the areas of "Community Supports," "Employment & Education," and "Leadership." Our efforts have made impacts from Logan, at the top of the state, to Montezuma Creek, on the Navajo Reservation! Our projects have increased



educational and leadership opportunities for people with disabilities locally and nationally. We have also increased outreach to parents, siblings and other family members of individuals with disabilities as well as partnered with disability-related agencies and organizations and with legislators to increase the quality and availability of supports to families.

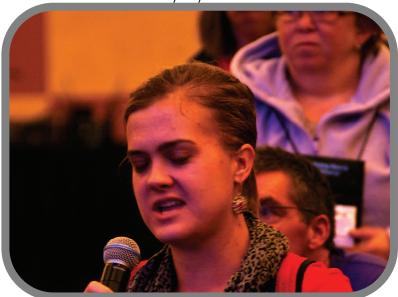
I am grateful for the incredible education I have received from serving on the Council. Rubbing shoulders with our accomplished citizen members and our outstanding professionals is a unique and rewarding experience that I have not found anywhere else. I especially want to acknowledge our wonderful staff, led by Claire Mantonya, our Executive Director, and including Troy Justesen (Director of Public Policy), Frank Long (Fiscal Analyst) and Libby Oseguera (Administrative Assistant). These talented and dedicated people help make our Council efforts impressive!

Thank you to our exceptional Council members for allowing me to learn from you and to participate in making Utah a better place for all Utahns!



#### **ABOUT THE COUNCIL**

Pictured: Council Member Kayci Lynam



#### **COUNCIL MISSION**

The Mission of the Utah Developmental
Disabilities Council is to be the State's leading
source of critical innovative and progressive
information, advocacy, leadership and
collaboration to enhance the lives of individuals
with developmental disabilities.

# **POST PUBLIC EDUCATION**

Post-secondary educational opportunities are finally becoming a reality for individuals with intellectual and developmental disabilities (IDD) in Utah! Utah State University, Utah's first 'Think College' campus kicked off the "Aggies Elevated" program in the fall of 2014 with a cohort of 8 students living on campus with their peers while attending college classes. In addition, the Utah Colleges of Applied **Technology** (UCAT) are opening new doors to students with IDD. Students with IDD will be able to attend more disability-friendly classes in the near future, which should help them to move into better paying careers. In 2014, the Legislature appropriated \$100,000 to the UCAT system to eliminate barriers and increase access for students with IDD. The Council worked with Representative Becky Edwards, Chair of the Economic Development and Workforce Services Committee, who led the way for creating better access for students with IDD into the UCAT system. The Council worked closely with UCAT administrators to develop an open Request for Proposals (RFP) to permit all Colleges of Applied Technology campuses around the state to apply to use those funds. Six separate campuses applied. Council staff and a former Council member participated in the development and selection of the grant awardees. The UCAT campus in Cedar City, the South West College of Applied Technology, received an award of \$100,000 in December 2014. Council staff will provide technical assistance as the campus begins to develop better ways to recruit and matriculate students with disabilities. The Council will

monitor the project and we look forward to seeing successful outcomes which will model the way for additional UCAT campuses to provide a better post-secondary education experience to more students with IDD.



#### **CHANGE AGENTS**

It took several years, but **Utah People First** finally achieved its goal of official IRS approval for their non-profit 501(c)(3) status! Utah People First held a successful Quality of Life Conference at the Park City National Ability Center in August. Forty-five attendees experienced a series of activities and workshops on Friday, overnight and all day Saturday.

The People First Board of Directors held two silent auction fund raisers in 2014: one during the Division of Services for People with Disabilities (DSPD) Annual Provider Conference and the second during the Council's Annual Awards Luncheon. The proceeds from these fundraisers go directly toward the People First organization.

The Grassroots Advocacy Partnership (GAP) along with Council members focused on educating policy makers about several important legislative priorities. Council members talked with the Legislature about the importance and impact of funding the waiting list for DSPD services. The Council also worked closely with Representative Becky Edwards and the Worker's Compensation Board to require that Medicaid Waiver self-administered model (SAS) families have worker's compensation insurance for their direct care support staff. This protects both the family's assets and the workers. DSPD families using the SAS model currently hire their own direct support staff using funding from the Community Supports Waiver. These families were exempted by state law from having to purchase worker's compensation insurance for their direct care staff. This exemption was created by the legislature over 18 years ago when SAS was first piloted. The original budgets were too small to provide enough money for families to both pay worker's compensation insurance premiums and pay for staff. The decision to ask the Legislature to reinstate the worker's compensation insurance requirement received mixed emotions from the disability community. But through a focused effort to educate families, disability advocacy groups, legislators and the Worker's Compensation Fund Board, the bill to remove the exemption was passed. This law goes into effect in July, 2015. It will remove the exemption from worker's compensation

#### **ABOUT THE COUNCIL**



#### 2013-2014 Council Members

Alice Hirai	Jennifer Kuhn	Richard Harward
Adina Zahradnikova	Jennifer Morgan	Rita Bouillon
Brian Wood	Kayci Lynam	Robyn Chidester
Bryan Dial	Kelie Babcock	Russell Thelin
Bryce Fifield, PhD.	Kimberly Belliston	Tonya Hales
Cheryl Hansen	Kristen Hone	Tracy Johnson
Christine Timothy	Lenny Jones	Tracy Justesen
Deborah Bowman	Linda Hansen	Vicki Clayson
Dustin Erekson	Lori Packard	Rep. Paul Ray
Eric Stoker	Nels Holmgren	Sen. Patricia Jones
Ginny Rouse	Nevah Stevenson	

Paul Smith

James McFadden

#### **EMPLOYMENT**

The Council partnered with the DSPD with an award of \$10,000 for their customized employment project with Cary Griffin of Griffin-Hammis Associates. The project provides capacity building within the provider system by teaching job coaches to understand creative ways to support people in customized employment jobs. There is concern about the amount of staff turnover due to low wages. This project is helping providers to broaden their perspective about how and where to support people in getting jobs, and how to make those jobs better fit a person's skills and talents.

The Council adopted Wisconsin's "Take Your Legislator to Work" program that we learned about during the annual NACDD Conference in DC. We promoted the project in collaboration with both the DSPD and the Utah Parent Center to help us identify individuals working in the community who would be willing to invite their own legislators to come to work with them for the day. We had three successful 'matches.' A young man with Down syndrome who works in the equipment room at the University of Utah's sports complex, had both his Representative and Senator come to work with him. We were able to get a story covering this young man and his work highlighting the visits by his legislators on the front page of the Salt Lake Tribune. In Price, former Council Chairperson, Kelly Holt, invited her Senator, David Hinkins, to come to work with her at the local college where she works as a custodian. The Council received



great publicity for this project and we plan to use and build upon it annually. The Wisconsin DD Council's staff was very gracious to share their materials, which helped us tremendously in our effort to get this project underway in such a short time period.

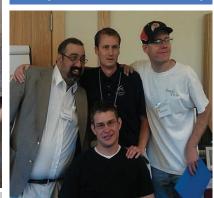
Pictured: Kelly Holt and Senator Hinkins during his visit to Kelly at her job.

#### **CHANGE AGENTS**

insurance for the FY15 budget year and beyond. The GAP provided continuing education within the disability community to teach citizens about the importance of being involved in the legislative process. Individual GAP organizers took on the responsibility of educating state legislators by creating "teams" that contacted and informed their own, local legislators. Throughout the year GAP leaders networked within their own communities to grow membership and locate citizens who are willing to visit their legislators and share their stories, along with the Council's talking points. GAP members met

with 87 individual public policy makers in 2014. They also met multiple times with several legislators and held multiple "Meet Your Elected Officials" meetings across the state.











#### **LEADERSHIP**



One of the Council's goals is to create and support leadership within the disability community. This is ongoing and has proved to be successful with many state and nationally recognized leaders.

Council Vice-Chair, Eric Stoker, was recognized both locally and nationally for his many contributions and accomplishments. He was asked to utilize his excellent emceeing skills at the annual Family Links Conference as well as during the Annual Council Advocacy Awards Luncheon. He was selected for the

National Association of Councils on Developmental Disabilities (NACDD) Champions of Equal Opportunity Award during NACDD's national conference in Washington, D.C. in July.

In addition Eric appeared on two separate local TV spots on the Salt Lake City ABC affiliate channel which were broadcast throughout Utah. During February he was featured along with our Council Chair, Deborah Bowman, and Executive Director, Claire Mantonya, to speak about disability awareness. In September, Eric and Claire appeared again on the same program where Eric's many accomplishments such as holding 3 part-time jobs and his many hours of volunteer work were highlighted.

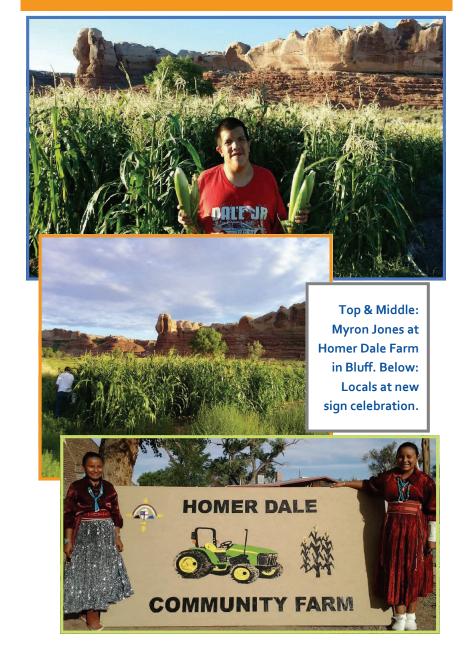
**Newly elected Council Vice-Chair, Kayci Lynam,** attended Council Chair training provided by NACDD in Washington DC in July. Kayci was also named to the Utah Transportation Authority's Disability Consumer Advisory Team this year.

Several former Council members are now part of the leadership of our sister agencies. James O'Neill from Park City serves on the Disability Law Center Board. Kelly Holt, from Price, is the current Chair of the Utah State Consumer Advisory Committee and Tom Brownlee from St. George, is also a member of that Committee. The Council staff plays a key role in developing Utah self-advocate leaders and helps ensure that when Council members complete their terms of service,

#### **COMMUNITY RESOURCES**

The Council provided funds to hire a community builder in the 4-Corner's area to support the Asset Based Community Development (ABCD) Navajo Project. Elsie Dee, a former Council member, is charged with coordinating with the Navajo Episcopal Mission in Bluff and ensuring that the community garden/farm project is all inclusive. Mike Green from Denver is providing technical assistance for this ABCD project with the major emphasis to engage youth and elders in learning about traditional Navajo gardening/farming techniques. The project is building community connections and there is potential to generate income opportunities in the future. The Aneth Chapter Court system is using the garden for community service hours. Twelve participants provided community service hours in 2014 as well as the Court judge. Transitions, the local DSPD day program, provided support so that people with disabilities could engage in the garden. A seed gathering/exchange was developed last fall and was used as a way to increase awareness of the garden and to create opportunities to share Navajo traditions at many scheduled community bazaars and events in the Four Corners area. The Idaho DD Council staff visited the project so they could learn about ABCD work. This project is building community and naturally including people with IDD, in this remote, poverty stricken rural area. Emphasis on fresh healthy foods and Navajo traditions are at center stage. We are very excited that so much progress has occurred just the first year of this 3-year project. The Council doesn't have a formal housing goal, but Council staff continues to participate in the ongoing Utah Home Choice Loan Committee. The Committee deliberates monthly on a variety of applications for home ownership loans that are supplemented with a partial low interest loan from the Olene Walker Trust Fund. The committee deliberates by evaluating an application form that describes the family, their need for the loan based on disability and financial qualification. In 2014, applications from 24 families were considered and 23 approved for home loans. This assistance helped individuals and families with children with disabilities get housing that would accommodate their disabilities.

# **COMMUNITY RESOURCES**



#### **LEADERSHIP**

other leadership opportunities are available to them within their home communities.

**Bryon Murray** from Roosevelt is a self-advocate who served 6 years previously on the Council. He was both Vice-Chair and Chair and completed two years serving as the President of the National Self-Advocates Becoming Empowered (SABE) organization this year. The Council provided continuous support to Bryon as President of SABE throughout his two-year term of office. The Council is very proud of the way Bryon represented Utah at the national level. In partnership with a former Council member, Tom Brownlee, a four session self-advocacy training class was completed through the Next Step Leadership Project. Tom took the initiative and created a selfadvocacy training class which he taught to other self-advocates at Ability First, the Provo Independent Living Center. Feedback showed that the training was well received and many individuals reported that they enjoyed the activities. We are excited that this activity supports the inclusion of people with IDD by recognizing that they can be leaders and to be included within the Independent Living programs. The Council's Director of Public Policy, Dr. Troy Justesen, was invited to testify on June 24, 2014, before the Senate's Health, Education, Labor and Pensions (HELP) Committee. Dr. Justesen

provided testimony about the critical need for continued implementation of the Americans with Disabilities Act (ADA) and with the Olmstead decision. Dr. Justesen has over 20 years of experience with disability issues, health care, education, and implementation of government programs.

Dr. Troy Justesen (bottom left) and the others called to testify in front of the HELP Committee in Washington D.C.



### **COMMUNITY RESOURCES**

The Council provides critical support opportunities that allow self-advocates and families to be involved in state disability/health work groups. Many state agencies request that the Council provide names of citizens whom they can involve with their particular work groups. A major DSPD/Health Department work group was established by the 2014 Legislature to study and make recommendations regarding the complex system of background checks throughout the Department of Human Services. Council Chairperson, Deborah Bowman, served on that work group throughout the year as well as People First Chairperson, Kelly Holt.

Former Council member, **Tamera Dalton**, was asked to serve on a work group addressing the problems created by low direct care support staff wages. These are examples of how citizens concerned about people with developmental disabilities are included in established work groups. In addition, citizen input continues through the re-establishment of the DSPD Policy Advisory Board that the Council was critical in establishing two years ago.

With some support from the Council, the Utah Caregiver Alliance



(UCA) developed a free respite registry, www.hiremycare.org, which is online and operational. UCA is a member the Utah Coalition for Caregiver Support (UCCS). UCCS obtained federal Lifespan Respite Funds and UCA worked to provide respite to families who are not receiving formal DD services. Through the efforts of the UCA, fifty three (53) individuals received up to \$900 dollars of respite from monies provided by the UCCS. In March 2014, UCA was alerted that unused Respite money would be returned to the original funders at the end of April. UCA quickly

asked for and received those funds that then provided respite for an additional 16 individuals by June of 2014.

# **COMMUNITY RESOURCES**

The Council's Disability Safety Training project is a multi-agency collaborative partnership among the Utah State, the Disability Law Center, Human Capabilities, the Utah Coalition Against Sexual Assault and the Utah Domestic Violence Council. All of these agencies are committed to educating people with developmental disabilities, providers, first responders and families; improving access to services; and reducing abuse and violence against individuals with developmental disabilities. The training is now available online at http:// ucasa.org and on DVD for group homes. Training was developed, reviewed, revised, delivered and evaluated to first responders, including law enforcement. Training was provided to a total of 50 officers in Tooele, Summit and other counties. Other law enforcement

Pancake Breakfast Attendees

training was provided for Sandy and West Jordan officers in July. The Council's goal to connect and develop an adult sibling network is in the works.

Bryan Dial, a Council member and an adult sibling from St. George, attended the Adult Sib Breakfast at the Disability Policy Seminar in D.C. People First collaborated with sibs for a fundraising event called

Honor Our Brothers and

Sisters." Amy Notwell and Claire Mantonya held two adult sib breakout sessions during the annual Family Links Conference and 8 sibs attended. Utah Sibs now have a Facebook page (Utah Sibling Leadership Network) and hope to be more successful this coming year. Utah members are participating in phone conferences with the National Sibling Leadership Network.



Pictured Right: Kelly Holt