



From the Executive Director's Desk

— Claire Mantonya

WHY GRASSROOTS ORGANIZING?

The Grassroots Advocacy Partnership (GAP) is new project of the Utah Developmental Disabilities Council in partnership with many agencies that serve individuals with disabilities in Utah, including the Legislative Coalition for People with Disabilities (LCPD). The focus is to build coalitions and ignite and renew the energy of advocacy in this rocky economic climate. We have a legacy to honor the many people who have worked hard on behalf of the disability community before us, and *now it is our time for action.* Because of the combined resources of the partnership (especially the knowledge and experience of the agency partners), we will be able to approach our elected officials, policymakers, and community leaders with increased strength and knowledge to provide them with valuable information about the issues that are our highest priority.

The GAP is inclusive of the needs of all disability issues that impact families.

The GAP's efforts will enhance the LCPD's efforts by providing them with local networks of people who are passionate about the needs and rights of individuals with disabilities, and who are trained to respond to the pertinent issues in an effective manner. We want to work toward a year round, sustainable network of committed advocates for our disability community.

Our strength will come from:

- the unity of our message.
- the depth and breadth of our network of contacts.
- the connections we make on every level - local, regional, state, and federal. These connections will help us solve issues close to home, and also those that affect everyone on a more global level.

Advocacy can be hard and scary—especially at the legislative level. We encourage people to “sign up” and be as active as possible.

Sometimes it takes a few years of advocating experiences to become comfortable talking about the issues. Take the first step now and get involved. The GAP needs your energy and commitment today! Go to the Council's website to get connected. www.utahddc.org





Council News

**New Council Members and Reappointments for the
October 2009 – September 2012 term**

The Nominating Committee interviewed eight applicants for three openings on the Council. These applicants will fulfill the positions that are required by law – family members and self-advocates. The following people were appointed by Governor Herbert for the openings to the Utah Developmental Disabilities Council:

New Council Members:

Kristen Hone – Self-advocate from Salt Lake City

Kristen received her Associates Degree from Salt Lake Community College in May. She has severe cerebral palsy and has required total care from birth. She receives supports through the Division of Services for People with Disabilities and participates in a sheltered workshop.

Nevah Stevenson – Family member from Draper

Nevah has a 15 year old son with intellectual disabilities and seizure disorders. She is currently a stay-at-home mother with a working background in media and advertising sales. She has a B.S. from Boston University.

Deborah Bowman – Family member from North Salt Lake

Deborah has a 24 year old daughter with multiple disabilities. She works part-time at the Utah Parent Center and has been involved in many volunteer activities within the disability community as an advocate. She holds a B.S. from the University of Utah.

Reappointments to serve a second term:

Council members re-appointed by Governor Herbert to serve a second three-year term of office are **Sherri Dial** from Santa Clara (family member); **Amy Weyrich** from Salt Lake (family member); and **Jane Tuttle** from West Valley City (family member). Thank you to members completing their service - **Quinton Busk** from Richfield (self-advocate, and **Mandee Buckley** from Salt Lake (family member). Thank you to liaison members completing their service to the Council: **Kris Fawson**, Legislative Coalition for People with Disabilities, **Helen Post**, Utah Parent Center, and **Christene Jones**, Utah Association of Community Services.

New Agency Liaison Council Members

Bill Young: Utah Statewide Independent Living Council: Voting member.

Robert Bucciare: Neurobehavior Home Program at the U. of U.

Jennie Gibson: Utah Parent Center

Suzanne Smith: Utah Down Syndrome Society

Jeanie Pettit: West Jordan Care Center

Congratulations to all new and re-appointed Council members!

Utah Developmental Disabilities Council 2009 Advocacy Award Winners



Bill Wise

Bill Wise – Self-Advocate of the Year

Bill of West Jordan lives with and “watches over” 80 other residents with disabilities. He has overcome some personal issues to be able to ride Flextrans on his own. He is responsible, a team player, and is always will to help others in his community. He loves to learn at the library.

Becky Rambo – Educator of the Year

Becky has helped South Valley School with their People First meetings. She is the Transition Coordinator and she teaches people to speak up for themselves. Becky is a great mentor as two of her former students are now active and vital Council members – Eder Soriano and Eric Stoker!



Becky Rambo



Jan Baker Ferré

Jan Baker Ferré – Volunteer of the Year

Jan has been very effective advocate for the needs of people with disabilities for many years. She is constantly at the Capitol during the critical times and she keeps current with how legislation may impact people’s lives. She has devoted her life to equal treatment and opportunities for people with disabilities. Her volunteer work has benefited the lives of countless Utah families.

Ben and Penney Tucker – Parents of the Year

Ben and Penney Tucker of Bluffdale are parents of five children, three with developmental disabilities, two of who were adopted. They have a very forgiving and positive attitude toward others and life in general. They are active with Special Olympics and one daughter wants to be a Special Education teacher while the other one wants to be a doctor specializing in Down syndrome.



Penney and Ben Tucker



Qwyn Kuhn

Qwyn Kuhn – Child Sibling of the Year

Qwyn, age 5, of Salt Lake City was nominated by her two older siblings with disabilities. Her brother Wladimir said “Qwyn will jump on the tramp with me. She shares everything, all her stuff with me. She lets me help her when she needs help. She makes me laugh. She is a good friend.” Her sister Emily said, “Qwyn forgave me when I break her Leapster. She forgave me when I rip her Hannah Montana pitcher. She forgave me cause I eat her candy.” Qwyn is a great sister even at such a young age!

Terry & Annette McNair – Adult Siblings of the Year

When Annette’s parents passed away, Terry and Annette stepped up to support their brother with a disability, Dave, in many ways. They are paying the tuition at PARC so that Dave can attend since he doesn’t have any public funding sources. They support the Special Needs Mutual that Dave attends. Terry has gone to the legislature to help lobby for the needs of people with disabilities. They represent the many wonderful adult siblings that step up when their parents are no longer able to care for their adult child with a disability.



Terry McNair



Sen. Jack Draxler

Rep. Jack Draxler – Legislator of the Year

Rep. Draxler from North Logan showed great courage and insight as he sponsored the Respite Care Assistance Fund bill this past legislative session. He was able to understand in a very compassionate and sensitive way the needs of caregivers whose family members have disabilities, and his work will help many Utahns across the lifespan through the years to come.

Pat Parkinson – Media Representative of the Year

Pat Parkinson, a reporter for the Park City Record, wrote a feature piece during the 2009 Legislative Session about the advocacy work of James O’Neill. Pat was on the hill and he recognized James from Park City, so he interviewed him and then wrote a great article showing how regular citizens are working to have their voices heard on the Hill.



Pat Parkinson



*Ed Fox and Marsha Milburn of
C-A-L Ranch Stores*

C-A-L Ranch Store of West Jordan
Employer of the Year

The management of the Cal Ranch store on 7800 West and 2200 West has provided on the job training opportunities for students with disabilities from South Valley School. Marsha Milburn and Ed Fox are representing C-A-L Ranch today as they work most closely with the students. They make the students feel appreciated and a valued part of the store employee team.

Congratulations to all winners and nominees!

NEXT FULL COUNCIL MEETING:

November 10, 2009

**Location: UDDC Conference
Room**

**Make sure you come so you can
meet the new Council Members!**

Loud and Clear: Voices from the Disability Community 2009 Film and Lecture Series

This film and lecture series presents fresh and unique stories about people living with disabilities. These films are presented in partnership with the Disability Law Center and the SLC Film Center. All screenings start at 7:00p.m. at the Utah Museum of Fine Arts – Dumke Auditorium at 410 Campus Center Drive Salt Lake City, UT. **Free, accessible parking** is located near the auditorium. Each film will be followed by a post-screening discussion. All films will be captioned, have audio commentary and sign language interpreters will be available for the discussions. For additional accommodations, please contact Ashley Campbell at (801) 363-1347 (Voice/TDD) or at acampbell@disabilitylawcenter.org

September 23, 2009

Opening Reception 5:30pm-7pm

Film & Discussion 7pm – 10pm

Film: INCLUDING SAMUEL

Director: Dan Habib

INCLUDING SAMUEL chronicles the Habib family's efforts to include their son with cerebral palsy in every facet of their lives and explores cultural and systemic barriers to inclusion. Post film discussion on the benefits and challenges of providing inclusive services for people with disabilities.

October 21, 2009

Film & Discussion 7pm – 10pm

Film: BLINDSIGHT

Director: Lucy Walker , Rated PG

BLINDSIGHT follows the gripping true-life adventure of six blind Tibetan teenagers on a climbing expedition up the formidable 23,000-foot Lhakpa Ri, at the doorstep of Mount Everest. Post-film discussion with Erik Weihenmayer, who was featured in the movie and is the only blind man in history to reach the summit of Mount Everest.

November 19, 2009

Film & Discussion 7pm – 10pm

Film: BODY AND SOUL: Diana and Kathy

Director: Alice Elliot

BODY AND SOUL: DIANA AND KATHY is an intimate portrait of two women with disabilities who are determined to live independent, non-institutionalized lives. Post film discussion on independence and self-determination issues in the disability community.

December 16, 2009

Film & Discussion 7pm – 10pm

Film: SO MUCH, SO FAST

Directors: Steven Ascher and Jeanne Jordan

SO MUCH SO FAST documents 5 years in the life of Stephen Heywood who, at 29, discovers he had the paralyzing neurodegenerative disease Amyotrophic lateral sclerosis (Lou Gehrig's disease). Determined to live as well as possible, Stephen gets married, has a son and rebuilds two houses. His and his wife Wendy's observations of the world and his disease explore the fragility of life. The film also tracks his family's response to the drug companies that ignore his disease because there is not enough profit in curing it, and his brother's creation of the ALS Therapy Development Foundation research facility to find a cure for Stephen's disease in time.

UTAH DD COUNCIL CALENDAR FOR 2009/2010

(Please check the UDDC website frequently for updated information www.utahddc.org)

October

- 8 [Access Utah Broadcast: The Housing Authority of SL County 11:30 a.m.](#)
- 13 Executive Committee Meeting, 11:00 a.m. to 1:00 p.m.
- 22 [Access Utah Broadcast: Utah Nonprofit Housing Corp \(UNPHC\) 11:30 a.m.](#)
- 28-29 National DD Conference in New Mexico

November

- 10 Full Council Meeting - 10:00 a.m. to 2:00 p.m.

December

- 8 Executive Committee Meeting, 11:00 a.m. to 1:00 p.m.



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!