



Volunteer Connections

Dear Volunteers,

This month my daughter Sarah celebrates her 18th birthday. She will be a young adult with significant disabilities so it is important to consider her future needs moving forward. Although she will be attending her graduation ceremony she will not be receiving a diploma. Instead she will continue her education in a post-secondary program offered through her school district. I am currently going through the formal process of legal guardianship so I can continue to make the necessary 'life' decisions for her benefit. Navigating the adult service world is also a priority. As volunteers, I know many of you have also gone down this path. For those of you working with parents who have children with disabilities reaching adulthood, I would like to share some of my favorite transition resources.



Please see pages 2 and 3 to view these resources.

VOLUNTEER REPORTING:

Please take the opportunity to report any volunteer activities you've been involved in. The link below will provide you with 6 different types of activities you can report on such as:

- Direct support to families.
- Conferences and trainings.
- Helping parents with IEP related support.
- Serving on committee's that promote systems change for families who have children with disabilities.
- Outreach promotion of UPC services and events.
- Sharing your family story with educators or participating on a parent panel.

If you have participated in any of these activities, select "yes" when your activity appears on the survey. You will then be asked: When did you participate in the activity? How much of your time was involved? and How many people were served?

Reporting Link: <http://www.surveymonkey.com/s/volunteerreporting>

VOLUNTEER APPRECIATION GIFTS:

ALL volunteers who have provided service and have fully completed the reporting survey will receive an appreciation gift! This is our way of thanking you for your time and dedication in serving parents who have children with disabilities and telling us about it! Each gift will include its own message of appreciation. Please take the time to do your reporting so we can recognize your good works!

IEP COACH CORNER – Transition to Adulthood Publication and Resource List

From No Where to Know Where: Transition to Adult Life

The Utah Parent Center is pleased to present this information and training modules which are part of a four-part series of training on topics related to transition of young adults with disabilities to adult life and adult services. One overview module about transition is also available in Spanish. It will be helpful for you to download a copy of the Utah Parent Center handbook for parents entitled “From NO Where to KNOW Where: Transition to Adult Life”. You can also obtain a free DVD with the transition training modules and a free copy of the parent handbook by calling the Utah Parent Center at (801) 272-1051 or (800) 468-1160.

Transition Training Modules: <http://www.utahparentcenter.org/training/videos/>

Transition to Adult Life Information Sheets

The following link will provide you with info sheets which will help you and your child with a disability or special needs prepare for the transition from school to adult life.

Info Sheets: <http://www.utahparentcenter.org/publications/infosheets/transadultinfosheets/>

Transition Ideas for those with Significant Disabilities

If you are assisting the parent of a youth with significant disabilities and need suggestions on how to create a successful transition plan, you will appreciate the following link which includes transition ideas and a list of adult service agencies.

PDF Version: <http://www.utahparentcenter.org/wp-content/uploads/2013/03/Transition-Ideas-for-those-with-Significant-Disabilities.pdf>

Utah’s State Services Resource List – Recently Updated

A description of each adult service agency including contact information is provided.

PDF Version: <http://www.utahparentcenter.org/wp-content/uploads/2011/09/Updated-Utah-State-Resources-Guide-January-2012.pdf>

Legal Solutions for Families with Disabilities – New Webinar

This 25 minutes video presented by Lisa Thornton, provides parents and families with children with disabilities an overview of planning and legal needs for parents including: Special Needs Trusts, Guardianship, Medicare/Medicaid, Social Security, Letter of Intent and Life Care Plans.

View this webinar at: <http://www.utahparentcenter.org/training/webinars/>

Guardianship Associates of Utah- <http://guardianshiputah.org/> or (801) 533-0203

Guardianship Associates of Utah (GAU) is a non-profit organization. GAU provides direct Guardianship, Conservator and Trust services to individuals who have been deemed by a court of law to be incapacitated, incompetent or legally disabled. GAU contracts directly with the Office of Public Guardian in the State of Utah to provide services to individuals. GAU also provide private pay guardianship and conservator services for a fee.

Transition to Adulthood Publication and Resource List – Continued...

Frequently Asked Questions about Postsecondary Education Options for Young Adults with Significant Disabilities, written by Bob Moran, Scott Kupferman and Jeff Sheen from Utah State University.

Read this article online at:

<http://essentiaeducator.org/?p=13696>



Employment Resources:

Utah State Office of Rehabilitation/Vocational Rehabilitation: www.usor.utah.gov

Work Ability Utah: Benefits Planning, Work Incentives, Transition www.workabilityutah.org

Division of Services for People with Disabilities: Supported employment, www.dspd.utah.gov

Parent Support:

Utah Parent Center – www.utahparentcenter.org , (801) 272-1051

Family to Family Support Group Network – www.utahfamilytofamilynetwork.org

Utah Family Voices Health Information Center - <http://www.utahfamilyvoices.org>

Autism Council of Utah – www.autismcouncilofutah.org

PEERS (Programs for Establishing and Enhancing Relational Skills) Enrolling Now!

PEERS involves matching typical teens with a teen or young adult with high functioning autism to create opportunities for career exploration, and work-related social skills and career skills development and can lead to meaningful employment and life-long careers. PEERS gives teens the opportunity to develop appropriate socialization skills with peers and coworkers, gain hands-on employment experience in a variety of jobs and community settings, create a resume and obtain references, and apply for volunteer or employment positions. This program is offered through Easter Seals Goodwill . For more information contact Jacquelynn Bradley at (801) 244-3177 or by email at: jacquelynnb@esgw.org

Scenic View, a Center for Learning and Living

At Scenic View Academy individuals with learning disabilities, Aspergers or an Autism Spectrum Disorder, 21 years of age or older, will receive the necessary attention from qualified staff to help them learn skills to get a successful job, maintain their own apartment, and pay for their own living expenses. Staff at Scenic View will help participants learn how to interact with others in social situations, manage their money well, and feel more comfortable in their community. Scenic View is a private program located at 5455 N. River Run Dr. in Provo. For more information call (801) 226-2550 or go to their website at www.svacademy.org . Financial aid packages are available.

VOLUNTEER SPOTLIGHT

It is my pleasure to introduce Kimberly Schneider as our Volunteer of the Month. Kimberly has 3 children with disabilities. Nathan, 14 yrs old, has learning disabilities, ADHD and social anxiety. Cody, 11 yrs old, has Ullrich Congenital Muscular Dystrophy and asthma due to his weak lung muscles. Alexys, 7, was recently diagnosed with Celiac Disease and ADD. Kimberly has been an IEP Coach for the Utah Parent Center for the last 5 years. When asked why she enjoys



helping parents through the IEP process Kimberly states, “I love being able to give these parents moral support and to let them know it is ok to fight for their child.” Kimberly is also a Surrogate Parent for several nearby charter schools. Currently, Kimberly interns with the Regional Treatment Center in Ogden as a Group Therapy Facilitator and is a Parent Partner with Northern Utah Pediatrics through a project with Utah Family Voices. Kimberley states “I do all of these things to help others know the importance of using their voice and standing up for what they believe. Whether it is for their child or themselves, we all need accommodations every once in awhile and there is no reason not to ask for it. I also do this to help educate others who may not be completely informed of all the resources available to them.”

...My biggest goal is for them to succeed and reach their full potential in life...”

Kimberly and her family are very active in fundraising and helping the Muscular Dystrophy Association. This organization has helped both her family and son Cody diagnosed with Muscular Dystrophy. Giving back to the community is very important to Kimberly. In the future she would like to run a large fundraiser to support the projects of the Muscular Dystrophy Association.

When asked what drives her passion for the volunteer work she does, Kimberly states, “My kids drive most of my passion. My biggest goal is for them to succeed and reach their full potential in life. I want to be a role model for them so they know what they deserve in life and know how to stand up for their rights as individuals. I am also driven by the knowledge and belief that individuals with disabilities have the right to use their voice, receive help and accommodations, and to live a functional and happy life.”

UPCOMING CONFERENCES AND TRAININGS

Utah Down Syndrome Foundation's 1st Annual Conference, "Limitless Possibilities", will be held on Saturday, **April 20th from 8:00 AM – 5:30 PM at the Doty Education Center at Intermountain Medical Center in Murray**. The Keynote Speaker will be Jim Faber, President of the National Down Syndrome Congress. For a workshop schedule and to register early go to: <http://udsf.org/conference2013/>

1st Annual Utah Multi-Tiered System of Supports & Effective Practices Conference is scheduled for June 12th & 13th at the Davis Conference Center in Layton, UT. This conference is designed to educate both parents and professionals on how to implement School-Wide Positive Behavior Interventions and Supports (SW-PBIS). Topics include: MTSS, RTI, PBIS, Numeracy, Behavior, Assessment, Transition, Pre-School, Significant Disabilities, Tier 2 & 3 interventions, Progress Monitoring, Autism, and Bullying Prevention. For more information go to <http://www.updc.org/umtss/>

US Autism & Asperger Association World Conference & Expo will be on August 15-18 at the Sheraton Salt Lake City Hotel and Conference Center. Over 40 of the world's most respected experts will discuss new treatment regimes and effective therapies. Keynote Speakers will include Temple Grandin, PHD who is one of the most accomplished and well known adults with autism in the world and Martha Herbert, MD, PHD who is an Assistant Professor of Neurology at Harvard Medical School and a Pediatric Neurologist at the Massachusetts General Hospital in Boston. For more information, go to www.usautism.org or call (801)816-1234.

Latest E-Connections, for more resources and events including a schedule of upcoming UPC workshops: <http://www.utahparentcenter.org/publications/electronic/e-connections/>

ONGOING VOLUNTEER OPPORTUNITIES

Please contact me at rebeccat@utahparentcenter.org or call at (801) 272-1051 if you are interested in participating in any of the following volunteer opportunities. I would love to hear from you!

Seeking new Family to Family Support Group Leaders and/or Co-Leaders for our Salt Lake Network

New Network Leaders should be receiving services, on the waiting list, or in the process of determining eligibility with the Division of Services for People with Disabilities. This allows Leaders to be a resource for individuals and families using these services as well as for other organizations. A Co-Leader or other Network Officer is not required to meet these criteria. New Leaders will receive ongoing support from the Utah Parent Center and existing Network Leaders.

Utah Parent Center Volunteer Connections: March 2013

Parent Panel Requests: The Utah Parent Center is asked several times a year to speak to students at the college level going into both general and special education. Our current parent panel requests come from the University of Utah and Westminster College. Volunteers who participate on the panel share information about their child with a disability and provide insights about their child's educational experience to future educators. It provides parents with a great opportunity to share what has worked well with their children and offer advice and tips on what needs to work better. The students benefit greatly from the 'parent perspective.'

IEP Coach Training: The Utah Parent Center has an ongoing need for parent volunteers who have been trained to help parents successfully go through the IEP process. If any volunteers are interested in receiving this training or know of someone who would make a good IEP Coach, please let me know. New volunteers will need to take our New Volunteer Training as a prerequisite to the IEP Coach Training and will need to fill out a New Volunteer Application. All IEP Coaches need to support parents by attending a minimum of 3 IEP meetings per year to remain active. For more information about this training program please review the following information piece: http://www.utahparentcenter.org/wp-content/uploads/2013/02/IEP-Coach-Opportunity-Program_2012.pdf



LOVE UT GIVE UT FUNDRAISING EVENT FOR THE UPC-SEEKING YOUR PARTICIPATION

The Utah Parent Center needs your help! The Center is participating in the Love Utah Give Utah online fundraising opportunity on March 22, 2013. On that day the Community Foundation of Utah will lead a state wide effort to bring together Utahns for 24-hours of unprecedented giving.

Every donation made to the Utah Parent Center during Love UT Give UT will help qualify the Center for even more challenge grants and awards, making your donation impact the Center in more ways than one. If you cannot make a donation on March 22, 2013 you will be able to set up your donation in advance to go through on March 22nd. Love UT Give UT is about raising money from the community for the community. Please spread the word about this opportunity for the Utah Parent Center. Just Point. Click. Donate. Awesome! Visit us at: <http://loveutgiveut.razoo.com/story/Utah-Parent-Center>

SPECIAL INTEREST: DISABILITY ISSUES IN THE NEWS

A Night to Remember For Students with Disabilities in Layton

Two Layton, Utah high school girls ensured a night to remember for two classmates with disabilities. **Read more:** <http://www.disabilitycoop.com/2013/02/14/teens-dates-special-needs/17311/>

Feds Omit ABA Therapy from New Insurance Requirements

Despite a heavy lobbying effort, the Obama administration declined to include autism therapy in final rules this week defining what must be covered by insurers under health care reform.

Read more: <http://www.disabilitycoop.com/2013/02/22/feds-aba-insurance/17346/>

Documentary by local High School Students on Albinism is getting International Attention

Local Woods Cross High School sophomore Megan Palmer and her cousin Jenica Woolley made a short documentary on Albinism called, “Dancing Eyes”. The documentary has received international attention and has been nominated in 4 categories: Best Picture, Best International Picture, Best Story & Best Sound by the THIMUN Qatar Northwestern Film Festival. **The following article provides information about the project and includes a link to the actual documentary:** http://www.abc4.com/content/news/top_stories/story/Utah-teen-creates-film-on-albinism/LXlvrkeYtUy3YhuaH5Pc8w.csp

Beauty Queen with Autism Makes Miss America History

She didn't walk away with the crown, but Alexis Wineman knows she topped the American public's list for Miss America.

Read more: <http://www.disabilitycoop.com/2013/01/15/beauty-queen-autism-history/17078/>

BOOK OF THE MONTH – Available for loan from our Lending Library

The Power of Positive Parenting by Dr. Glenn Latham –As they have in the past, parents today are still asking: How can I deal with my child’s tantrums? How can I get my kids to do their chores promptly and without complaining? What can I do to help my family members live together more harmoniously? Dr. Latham’s practices in The Power of Positive Parenting are based on solid psychological principles because they have originated in research done over the past 60 years. This book is a wonderful tool for parents who want to understand how to foster appropriate behavior in children and at the same time maintain a happy and loving relationship. **If you are interested in borrowing a copy of this book please call the Utah Parent Center at (800) 468-1160. We would be happy to mail you a copy.**

***Call the Utah Parent Center for a full listing of books available in the Lending Library.**

Utah Parent Center Volunteer Connections: March 2013

CALL FOR PICTURES

The Utah Parent Center is looking for pictures of children or young adults with disabilities engaged in the following types of activities:

- Using assistive technology
- Participating in a community based activity.
- Showing off a talent.
- Working at a job site.
- Demonstrating a skill.
- Participating in a school based activity

The Utah Parent Center wishes to use these pictures in training and marketing materials which promote the Center's goals and objectives. All parents will be asked to fill out a media release authorizing the use of your pictures. Please e-mail all pictures and completed media release form to cassandra@utahparentcenter.org.

Media Release Form: [Image/Media Release Form](#)

Please send me information on any event or resource you feel would be valuable to other volunteers. Don't forget your reporting!!! Thank you everyone!

Sincerely,



Rebecca Turley
Volunteer Programs Coordinator
Parent Consultant and Trainer

Utah Parent Center, 230 West 200 South, Suite 1101, Salt Lake City, UT 84101
Phone: 801.272.1051 Email: rebeccat@utahparentcenter.org