

Volunteer Connections

JANUARY 2014

Dear Volunteers,

I have been busy finalizing our annual volunteer report. This is a wonderful time for me to review all of the many activities our dedicated volunteers have been involved in. I want to personally thank each of you who consistently do your reporting. It makes a big difference in our ability to maintain and grow the funding sources for our volunteer programs. Thank you for all your dedication and continued efforts to serve others. Here are some of our annual volunteer totals for 2013.

- Total Volunteer Hours from both the CRV and IEP Coach Program: 1,851 hrs.
- Total # Impacted from CRV and IEP Coach Programs: 2,552 people
- Total Hours Spent in IEP Mtgs on behalf of Parents: 126 hours
- Total Hours Spent on IEP Consultations: 200 hrs
- Total Hours Spent on Other Activities/Training: 789 hours

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

Rebecca Turley
Volunteer Programs Coordinator
(801)272-1051 / rebeccat@utahparentcenter.org

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/Volunteer_reporting

What's Your Story?

The Utah Parent Center is looking for success stories from families who have been helped by the UPC. We will be using the stories and pictures we collect on our website, in marketing materials, and in training publications and resources.

- Did you call the Center for problem-solving help, resources, support, information, training, or materials?
- Did you attend one of our many workshops or the Family Links Conference?
- How did it help you? What did you learn that made a difference?

Send us a short paragraph telling your story and how the caring, competent staff of the Center helped you and your family.

Be sure to include a picture (or two!) that we can use when sharing your story. You could also video record yourself briefly explaining how the UPC helped you. Please e-mail your story, pictures and a completed media release form to cassandra@utahparentcenter.org. **Media Release Form:** [Image/Media Release Form](#)

VOLUNTEER SPOTLIGHT

It is my pleasure to spotlight Nikki Nelson, a Network Leader from the Washington County Family to Family Network. Nikki has been a resident of Washington County since 1990. She has an amazing husband, Andrew, whom she has been married to for 15 years and has 3 children, all boys. The oldest is 13 years old and he is getting ready to start 8th grade. She also has identical twin boys who are 5 years old. The twins were born in October of 2007, 11 weeks before they were due. They had what is known as a twin to twin transfusion causing them to be born early, at only 29 weeks. This caused great stress to the twins and resulted in one of the twins being diagnosed with Cerebral Palsy (CP) at about 12 months. He currently uses a wheelchair but loves to get on the ground to play with his cars. Slowly he is learning to talk and communicate. He eats regular food, loves to laugh, play with his brothers, listen to music, go for car rides, shop, ride the bus, swim, and just have a great time.



Nikki is currently a stay at home mom, with a small professional photography business on the side. She has a Bachelor's of Science in Business Administration and worked in the Human Resources field for 7 years before deciding to stay at home. During her college years she served on the Student Executive Council as the Organizations President working with the clubs on campus. She organized and helped all the clubs complete service projects throughout the community. Nikki has also served as a VISTA (Volunteers In Service To America) Volunteer for Dixie State College. This role included teaching a service class once a week to students. In addition, Nikki has served on the Bloomington Elementary PTA for 2 years and spent one year as the yearbook designer and coordinator. She also served one year on the Tonaquint Intermediate School PTA as the Reflections chair.

Having a child with special needs has introduced Nikki to a whole new world she didn't know existed. It has provided her with great opportunities to meet amazing people whom she wouldn't have met otherwise. Although raising a child with special needs is the hardest thing Nikki has ever done, it has truly been the most rewarding!

As a Family to Family Network Leader Nikki understands the value a support group can have on families in her community. Nikki states, "Sometimes there is a very "alone" feeling that comes from being a parent of a child with special needs. A support system is crucial to help dissipate that feeling. Somehow the word needs to get out there that support systems do exist and that there are so many resources available." Nikki loves volunteering and serving families and I am so happy to have her involved with the Utah Parent Center and the Family to Family Network.

IEP COACH CORNER:

IEP Coaches please review the following changes to the Utah Special Education Rules. It is important to stay up to date on all the new changes and revisions to the Rules so you can be knowledgeable and effective in helping parents prepare for IEP meetings.

Utah Special Education Rules Updates

In December, 2013, an updated version of the Utah State Board of Education Special Education Rules were released and reprinted due to the number of revisions that have occurred since it was printed in 2007. These updates have been available on the USOE website and have already been implemented in the schools. The new edition now has everything incorporated in one place. The rules can be accessed on the Utah State Office of Education website under the Special Education Department at <http://www.schools.utah.gov/sars/Laws,-State-Rules-and-Policies/Rules-and-Regulations.aspx>.

As always, Utah Parent Center staff are available to assist parents with questions about special education. We may be reached at 801-272-1051 or toll free at 1-800-468-1160. Below is a summary of the substantive changes that are included (most recent changes in bold):

- I.E.(7) Definition of consent was revised to add revocation of consent.
- **II. J.(10) SLD Eligibility using the Discrepancy Method was revised.**
- III.T.(3-4) Revocation of consent was included.
- IV.I.(1) Pro Se representation in due process was included.
- VIII.C. State monitoring and enforcement was revised.
- VIII.E.(3) State use of targets and reporting was revised.
- VIII.G.(6) Public attention was revised.
- VIII.J. Provision of technical assistance was revised.
- **VIII.L.(5) Medicaid consent was revised.**
- VIII.P.((6) Subgrants to LEAs for eligible students ages 3 through 21; Base payment calculations; Reallocation of funds were revised.
- VIII.Q.(5) Subgrants to LEAs for Section 619 for eligible students ages 3 through 5 and Reallocation of LEA funds were revised.

The IRS Offers Help to Parents of Children with Special Needs

Parents of children with special needs have unique financial concerns - their children often need special care that is expensive. The government grants these families many special tax deductions that they are often unaware of. Please review the following article for a listing of credits and deductions that could provide some financial relief.

http://www.nesca-news.com/2013/04/the-irs-offers-help-to-parents-of.html?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+NescaNewsNotes+%28NESCA+News+%26+Notes%29



Moving Your Son or Daughter Towards Independence

By Robyn Chidester, Utah Parent Center Parent Consultant

For most of your child's life you have been advocating for your child and making decisions for him or her. As children age parents need to help them advocate for themselves to the best of their ability. When youth turn 18, regardless of their disability, they are recognized as adults. This is sometimes a hard time for a parent as a child becomes an adult and is becoming more independent. First remember that at age 18 unless you have guardianship, your young adult is recognized as an adult and is the client when using services of adult agencies. It is the youth that now signs the IEP and has meetings individually with the Vocational Rehabilitation counselor, medical professional and other agencies. If your son or daughter wants you included he or she can sign a release form for you to become involved but may choose to not involve you, and that is his/her right. Our goal is to teach independence to our sons and daughters and to see how well they can function on their own. For involved parents, independence is not always easy. It is hard to let go and turn the process over to our youth. Don't wait until the last moment and assume your son or daughter can run his or her own meetings.

It is important to start the transition process by the time your child is an adolescent. Youth will need to advocate for themselves to the best of their ability. Teaching self-advocacy is not a single conversation, but rather a process that will evolve over time. It is important to teach self-advocacy skills and to practice those skills. Learning self-advocacy is a key step in becoming an adult. It means the individual with a disability can take responsibility for him or herself and can describe his or her strengths, disability, needs and wishes. Helping youth to develop a sense of self will aid in the transition process and will develop a skill that will benefit an individual throughout his or her life. By the age of 16 your son or daughter should participate in his or her own IEP meetings and practice self-advocacy skills. You need to note that part of self-advocacy may involve knowing what to disclose about one's disability. This is called self-disclosure. It is important that an adolescent with disabilities be told he or she has a disability. Self-disclosure is simply to open up, to reveal to tell, or to intentionally release personal information about one's self for a specific purpose. A great place to practice self-advocacy is in the Individualized Education Program (IEP) meetings. Self-advocacy begins with the individual learning about his/her disability, and strengths and weaknesses. A great resource is the Job Accommodation Network (JAN). JAN provides a short summary of different disabilities and a list of accommodations that might be helpful in the workplace or school. Once a youth understands his or her disability, practice having the youth introduce him or herself, give a synopsis of his or her disability, and his or her interests, strengths, and desires for the future.

Some additional preparation would be to discuss the format and purpose of the meeting. Why is it important to your youth? Who will be present at the meeting and what are their roles? Will vocational rehabilitation or other agencies be present? What are the agencies mission and role? Could the youth help write the agenda with the special education teacher or an agenda of their own with the parent? Teach your youth to ask for explanations if he/she does not understand something. At the end of the meeting review what the team has decided. No matter what type of schooling, employment or community life option that your adolescent chooses, self-advocacy will play an important role in getting there.

For further information on transition planning see the UPC Handbook "From 'No' Where to 'Know' Where – Transition to Adult Life <http://www.utahparentcenter.org/publications/handbooks> . Also check out the Events Calendar for Transition Workshops at <http://utahparentcenter.org/upcoming-events>

If you need individual information call the Utah Parent Center and talk to a Parent Consultant at 801-272-1051.

For more help:

The 411 on Disability Disclosure: A Workbook for Youth with Disabilities
<http://www.ncwd-youth.info/411-on-disability-disclosure>

Job Accommodation Network (JAN)
<http://www.askjan.org/links/atoz.htm>

Tips for Teens: Use Your IEP Meetings to Learn How to Advocate for Yourself
<http://www.pacer.org/parent/php/php-c149.pdf>

New Multi-Agency Transition to Adulthood Resources

The following series of information sheets have just been added to the Utah Parent Center website. They will provide information to help parents and young adults understand the transition process from school to adult life and services. For the full listing of transition related information sheets go to:

<http://www.utahparentcenter.org/publications/infosheets/transadultinfosheets/#sthash.gtkJ4CTN.dpuf>

- [Career Guidance and Exploration in Action](#)
- [Considering Guardianship](#)
- [Disclosure on the Job](#)
- [Entitlement versus Eligibility: The Big Shift](#)
- [Family Roles in the Transition from School to Work](#)
- [Help Your Young Adult Learn About Accessing Accommodations](#)
- [Helping Your Child Prepare for the Age of Majority](#)
- [Helping Youth Develop Soft Skills for Job Success](#)
- [How Families Can Build Soft Skills at Home](#)
- [Preparation is Key to Gaining Accommodations for ACT or SAT](#)
- [Transition Planning and the IEP](#)
- [Rights and Responsibilities Under the Americans with Disabilities Act](#)
- [Vocational Rehabilitation Can Help Students in High School](#)
- [What is Self-Determination?](#)

Transition to Adult Life Video Modules

The Transition to Adult Life video is available both English and Spanish versions. The video is broken up into four modules as listed below. The module in Spanish is an overview.

[MODULE 1 : Changing Roles and Responsibilities; Parents and Youth Planning for the Future](#)

[MODULE 2 : IEP Requirements and Developing the School Transition Plan](#)

[MODULE 3 : Understanding and Accessing Adult Services](#)

[MODULE 4 : Other Transition Concerns—Medical Care, Financial Planning, and Employment](#)

[SPANISH : De 'NO' saber a donde...A 'SABER' a donde La transición de los Individuos con Incapacidades a la vida Adulta](#)



Join the Utah Parent Center on Facebook to get up-to-date information from the Center and information about activities in your area!

New Postings on the Utah State Office of Education Transition Page

<http://www.schools.utah.gov/sars/Transition.aspx>

- Updated Graduation Guidelines
<http://www.schools.utah.gov/sars/DOCS/resources/graduation111813.aspx>
- REL West: Summary of research/resources on the assessment of students with disabilities transitioning to postsecondary education or careers
<http://www.schools.utah.gov/sars/Transition/assessment-info.aspx>
- REL West: Summary of research/resources on life skills courses for students with disabilities
<http://www.schools.utah.gov/sars/Transition/information.aspx>
- Adult Education Policy and Procedure: Adult Education Students with Disabilities
<http://www.schools.utah.gov/sars/Transition/board-rules.aspx>

New Vocational Rehabilitation Transition Webpage

After months of preparation, the VR transition webpage is now live. It is now listed under the “Divisions” button, then under “Division of Rehabilitation Services”, but will have its own button on the horizontal menu bar at www.usor.utah.gov. The page may be directly accessed at <http://www.usor.utah.gov/division-menu/division-of-rehabilitation-services/transition>. The website provides:

- Transition Resources including the VR application
- Vocational Rehabilitation Introductory Video for teens and adults
- Transition Counselor Finder - This leads to a map of Utah – click on your county to find your school district or charter school. Currently, all charter schools are listed with the districts in which they are physically located; this will be changed in the future.

We Need Your Tips and Success Stories about Meeting the Needs of Adults with Disabilities

The Utah Parent Center recognizes that it is often difficult to meet the needs of adults with disabilities across the lifespan. Services may not exist or families may not know what services are available. Families may need to find creative solutions to meet some needs.

We are in the process of developing materials including videos and fact sheets for our web page that will be a resource and inspiration to families whose adults with disabilities need supports.

If you have a story or a tip about how you or someone else came up with solutions, we would like to know about it. Please help make a difference and pass your wisdom on to other families. Tips and success stories are needed on such topics as:

Success Stories—Innovative ways of Meeting Unmet Needs

- ❖ Innovative Ideas for Employment
- ❖ Any other areas where adults with disabilities may need support.
 - Adult Services Programs including Community Living, Post-secondary Education, Recreation, and Respite Care
- ❖ Tips from Experienced Parents about what worked!

The logo for "What's Your Story?" features the words "What's" and "Story?" in a large, bold, blue font, with "Your" in a smaller, grey font centered between them.

Please include with the story:

Your name and contact information, the age of the person you are writing about and what disability/disabilities the person you are writing about has.

Please send stories and tips to Ashlie Baker at ashlie@utahparentcenter.org or call 801-272-1051.

UPCOMING CONFERENCES & TRAININGS

Save the Date!

2014 Family Links Conference

Friday, February 28 and Saturday, March 1, 2014

Location: Murray High School



The Family Links Planning Committee is currently working on finalizing this year's conference agenda. What we can tell you is: This year's conference will feature a Friday Dinner and Keynote presentation by Matt Townsend of the Townsend Relationship Center who will be energizing and involving participants with his unique approach to building and maintaining successful personal and family relationships. Those who have seen him present or have heard him on KSL News Radio know that Matt has the perfect mix of cutting edge research in communication and human relationships combined with the skill of a top-notch humorist. This blend ensures that audiences are entertained as well as enlightened and leave with practical information that can be immediately applied to their life.

The conference will continue on Saturday with a keynote presentation by Judith Snow. She is a powerful, energetic and joyful speaker, her passion is matched only by her commitment. Her entire life is dedicated to making a difference for people all over the world. For almost 30 years, Judith has pioneered education and training programs that have resulted in changing the lives of thousands of people labeled 'disabled'. Her vision is to create a world in which everyone is included and contributing to their communities. In addition, the conference will be hosting more than 29 breakout session, an exhibitor, prize drawings and more!

Watch for more information to come or visit <https://www.facebook.com/FamilyLinksEvents> to get up-to-date information about the conference. Or visit www.utahfamilylinks.org to view the full program.

Transition to Adult Life Mini-Conference

Monday, January 27

From No Where to KNOW Where

Developing the IEP and Transition Plan- The transition to adult life can leave you feeling you are "NO Where" - totally lost! Get to "KNOW Where" by learning about planning for transition to adulthood. We will go into detail about the process the IEP team follows to help students have a successful transition.

Tuesday, January 28

Plan for the Future

This workshop will help parents to understand vocational rehabilitation programs and services including how VR can be involved in the IEP; supported employment provided by the Division of Services for People with Disabilities; and how to access college/university support services.

Conferences will both take place at The Utah Parent Center 230 West 200 South, Suite 1101, SLC, UT, 84101 from 8:30 AM- 3:30 PM. Lunch will be on your own. Register online at <http://conta.cc/1bVWJHA> or call [801-272-1051](tel:801-272-1051).

Have a child with a Learning Disability and/or Special Needs?

Nebo School District and the Learning Disabilities Association of Utah (LDAU) are hosting a free special one-day conference JUST FOR PARENTS of children with special needs presented by the Utah State Office of Education and the Utah Parent Center. This conference will be presented in two sessions. You can attend either session or both.

- Date: Wednesday January 29, 2014
- Location: Nebo School District – 350 South Main, Spanish Fork
- Topics include: Identification of a Specific Learning Disability, Review of the eligibility process, Understanding the process for receiving services under IDEA, Transition for students K-12, What is the difference between an IEP and 504?, How to advocate for your student

For more information and to register e-mail Gaylia Tanner at gayliat@live.com.

Conference Flyer: <http://origin.library.constantcontact.com/download/get/file/1102821897786-414/LDAU-Nebo+District+Event+1-29-14.pdf>

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

Dual Diagnosis e-Journal Now Available

What is Dual Diagnosis? Developmental Disabilities plus Mental Health Needs

Any person with disabilities is at higher risk for having mental health diagnoses for a number of reasons. In this journal you will find information about some of these reasons and also about medical issues that may cause behaviors that cause us to suspect there are mental health concerns. You will become more aware of some of the signs to look for. You will also find some stories of families who have dealt with the challenge of dual diagnosis and some tips from families about things that have been helpful to them. Lastly, you will find information on some resources and places to go for more information.

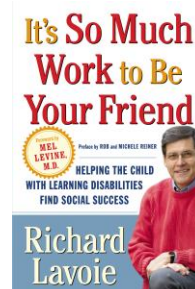
The Utah Parent Center has recently published an e-journal on Dual Diagnosis. This e-journal is part of a series published by the Utah Parent Center (UPC). This material has been prepared to provide information and resources to both parents and professionals.

We hope the information in this issue is helpful to you and your son or daughter who might have mental health challenges in addition to a disability. An electronic copy of this and previous journals along with supporting information is available on or through the UPC's website at: www.utahparentcenter.org/publications/e-journals

I want to give special recognition to Julia Pearce, Family to Family Network Leader from Salt Lake City, for her contribution to the Dual Diagnosis e-Journal. Great job!

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

It's So Much Work to Be Your Friend by Richard Lavoie – A successful social life is immeasurably important to a child's happiness, health, and development, but until now, no book has provided practical, expert advice on helping children with learning disabilities achieve social success. For more than 30 years, Richard Lavoie has lived with and taught children with learning disabilities. In this book Rick offers techniques and practical strategies that can help children ages six to seventeen overcome shyness and low self-esteem, use appropriate body language to convey emotion, focus attention and avoid disruptive behavior, enjoy playdates and making friends and employ strategies for counteracting bullying and harassment. **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.**



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 Statewide

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 (DSPD). This allows Leaders to be a resource for individuals and families using these services as well as for other organizations. Networks may have Leaders or other officers who do not meet the criteria related to DSPD. New Leaders will receive ongoing support from the Utah Parent Center and existing Network Leaders. Please contact me for more information.

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: [IEP Coach Opportunity Program](#)

SPECIAL INTEREST: DISABILITY ISSUES IN THE NEWS

Check out 7 of the most popular and controversial news topics that happened in the special needs community for the year 2013. <http://www.friendshipcircle.org/blog/2013/12/31/the-seven-most-talked-about-special-needs-news-stories-of-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:

- Family Photos – Showcase your family including your child with a disability.
- 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](#)