Dear Volunteers,

As your Volunteer Coordinator, it is heartwarming for me to hear the many ways you help and serve struggling parents in your communities. Thank you for your time and effort! Recently, I've had several parents call me about respite care options. As you know many parents need short-term temporary relief or respite in order to sustain their health and wellbeing. I've included in this newsletter a section on respite and caregiver resources. Please pass these resources on to the parents you serve.

**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.

**Reporting Link:** [http://www.surveymonkey.com/s/volunteerreporting](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!

**HOT OFF THE PRESS – A must read for ALL volunteers!**

Special monograph edition of the Utah Special Educator: Supporting ALL Students through MTSS: Multi-Tiered System of Supports

The March 2013 special issue of the Utah Special Educator journal is dedicated to all things MTSS, the most comprehensive and promising set of strategies for narrowing the achievement gap. This issue is supersized, 148 pages of killer articles to match Utah's increased focus on and demand for improved student outcomes. Please contact me if you are interested in a hard copy of this valuable resource.

**Journal PDF Link:** [http://essentialeducator.org/?page_id=112](http://essentialeducator.org/?page_id=112)
IEP COACH CORNER – Respite and Caregiver Resources
Parenting a child with special needs can be physically, emotionally and financially draining. Even though parents take great joy in providing care to their loved ones, many parents need short-term temporary relief or respite in order to sustain their health and wellbeing, reduce stress levels and maintain a healthy relationship with their spouse. In addition, respite has been shown to avoid or delay out-of-home placements, and reduce the likelihood of abuse and neglect. The following resources offer support to caregivers and assist families looking for respite care:

UPC’s Caregiver E-Journal
Read this publication to become better informed about achieving well-being, managing as a family, and resources available to caregivers.

Link to E-Journal: www.utahparentcenter.org/publications/e-journals/


Utah Caregiver Alliance
The Utah Caregiver Alliance is a nonprofit formed by and for families with loved ones with disabilities. The main functions of the Alliance are to help families who have children with disabilities:
- Find Care
- Provide Care
- Share Services
For now the registry is FREE. To connect with the registry call 866-404-9080 or go to http://caregiveralliance.com Help build the registry by spreading the word!

Care About Childcare, is a new statewide resource that helps parents find quality, licensed child-care services in Utah. The website, CareAboutChildcare.utah.gov is the first of its kind in Utah. It provides parents with options they can select in a child-care service and matches them with corresponding state-licensed centers and family/home providers. Parents who have children with disabilities can select the "special needs" option and the site will connect parents with providers who are happy to care for children with disabilities. This is a resource for children ages 12 and under.

The Utah Afterschool Network is a non-profit association established in 2005 by a statewide consortium of over 100 afterschool practitioners, youth advocates and leaders of state agencies. The Network is committed to funding and sustaining quality school-based/school-linked afterschool programming. "Afterschool" is an umbrella term for programs that improve outcomes for young people grades K-12 and occur during non-school hours (i.e. before school, after school, weekends, and summers). Find an afterschool program near you by going to http://childcare.jobs.utah.gov
Respite Care Resources Continued:

Care.Com - [www.Care.com](http://www.Care.com) provides a place for families and care providers to easily connect, share caregiving experiences, and get advice. The company addresses the unique lifecycle of care needs that each family may go through — including child care, [special needs care](http://www.Care.com), tutoring, senior care, pet care, housekeeping and more. The service enables families to find and select the best care possible based on detailed profiles, background checks, and references for hundreds of thousands of mom-reviewed providers who are seeking to share their services.

Hopeful Beginnings - [http://hopefulbeginnings.net/outpatient-services/respite/](http://hopefulbeginnings.net/outpatient-services/respite/), Serving the Salt Lake valley and surrounding communities, Hopeful Beginnings provides unskilled respite services that can be delivered weekly or as needed by the family under the direction of the treatment team and the individual’s treatment plan. All respite providers are infant and child CPR/First Aid certified, have reliable transportation, submit to a background check, and have regular training and supervision. For more information please call (801) 979-1351 or e-mail hopefulbeginnings@gmail.com.

Division of Services for People with Disabilities
For families receiving funding through DSPD, respite is care provided by a trained person that temporarily relieves parents or caregivers from the day-to-day care they provide to the individual with disabilities. It can be provided in the family’s home, in the home of the respite provider or in a specialized facility, depending on the needs and preferences of the family or individual. For information about services offered through DSPD and their eligibility criteria call (800) 837-6811 or go to [www.dspd.utah.gov](http://www.dspd.utah.gov).

Utah State Developmental Center Respite – Now Open
The USDC will provide limited residential based respite services for individual adults 18 years or older with Intellectual disabilities. Respite guests must be currently receiving DSPD services, qualify for Medicaid enrollment and have respite approved services in their Person Centered Support Plan. USDC Respite Services will provide the following services:
- Basic Care
- Meals
- Housekeeping Services
- Linen Services

USDC will function in a cooperative effort to help providers, families and caretakers meet their respite care needs by providing a temporary, safe and home like atmosphere. For more information about this respite program go to [http://usdc.utah.gov/respite.html](http://usdc.utah.gov/respite.html).
UPCOMING CONFERENCES AND TRAININGS

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.

Dual Diagnosis Conference – Monday September 23 from 9-4 PM at the Utah Parent Center
The Utah Parent Center is excited to bring you an in-depth training on the topic of Dual Diagnosis. Dual Diagnosis is when a person with a developmental or intellectual disability also has a mental health need (anxiety, depression, OCD and other mental illness diagnoses). The information provided at this training is also intended for parents who have children who are at risk for getting Dual Diagnosis.

Experts in the field will help parents do the following:
- Understand Dual Diagnosis and its challenges
- Analyze what your child’s behaviors could be telling you
- Determine other medical causes to rule out
- Look at medication uses and side effects with a medical professional
- Learn from other families who will share their experiences about working with professionals and how a dual diagnosis impacts a family.

Registration information will be available soon. For questions and/or information about travel stipends, please contact the Utah Parent Center at 801-272-1051.

2nd Annual UVU Conference on ADHD, Co-Sponsored by CHADD of Utah will be held on September 27, 2013 at the Student Center at Utah Valley University. This year’s keynote address will be given by Dr. Edward Hallowell, one of the world’s leading experts in ADHD. The conference is designed for students, parents, teachers, administrators, and professionals who are interested in learning about ADHD, treatments, education and family life, available services, and practical resources. Breakout sessions will be instructed by a multidisciplinary group of experts who will share their research and best practices. For more information go to: http://www.uvu.edu/uc/adhd/

Save the Date! Family Summit – November 8th & 9th. The Summit will include parent leaders from several organizations including our Utah Parent Center volunteers. This conference will teach participants the leadership skills needed to be effective parent leaders and advocates in their communities. More information to come!

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

**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: www.utahparentcenter.org/wp-content/uploads/2013/08/IEP-Coach-Opportunity-Program_2012.pdf

**Seeking Table Captains for UPC’s 30 Year Celebration Breakfast on Tuesday, September 10, 2013 at the Marriott Hotel.** The breakfast begins at 8:00 AM and ends at 9:00 AM. This fundraising event will increase awareness of the Utah Parent Center and its mission to help families who have children with special needs and will help raise funds to support the Center’s programs that help children and families. As a Captain you will be responsible to invite 9 people to join you at a table to enjoy a free full breakfast and a program to learn more about the work of the Utah Parent Center. Your family, friends, clients, neighbors and work colleagues make excellent potential guests. During the program, guests will be asked to consider a contribution, although a gift is not required and there is no minimum level. The UPC’s job will be to inspire your guests to make a donation. Please contact me at (801) 272-1051 if you are interested in participating!
SPECIAL INTEREST: DISABILITY ISSUES IN THE NEWS

Gabe’s Care Map: Cristin Lind, Mom, Illustrates What It Takes To Raise One Boy With Special Needs:
www.huffingtonpost.com/2013/01/18/gabes-care-map-special-needs-children-caregivers_n_2469564.html

With Fewer Kids Learning Braille, Schools Told To Step Up
Amid concerns that many with visual impairments are not learning to read Braille, federal officials are reminding schools that they have a legal obligation to teach the tactile writing system. www.disabilityscoop.com/2013/06/21/with-braille-schools/18205/

Poll Finds Disability Caregivers On The Rise
In a poll of over 3,000 individuals nationwide, the Pew Research Center found that 8 percent of adults in the United States had provided unpaid care to a child with a health challenge or disability in the previous year. That’s up from 5 percent in 2010. www.disabilityscoop.com/2013/06/24/poll-caregivers-rise/18215/

BOOK OF THE MONTH – Available for loan from our Lending Library
The Survival Guide for Teenagers with LD by Rhoda Cummings, ED.E. and Gary Fisher, PH.D. This book has been written especially for teenagers with LD looking for answers about succeeding in school and preparing for life as an adult. This step-by-step-handbook of school skills and life skills will help you:
- Learn how to take charge of your education (it’s not too late)
- Find out what it takes to live on your own (it’s not too soon)
- Discover why LD can’t stop you from being your best-now and in the future

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 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

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
(801)272-1051 / rebeccat@utahparentcenter.org