## e-Connections

November 30, 2012

Salt Lake City, UT 84101

Phone: 801-272-105 Toll-Free in Utah: 1-800-468-1160 Spanish: 801-272-106

#### PROJECT SPOTLIGHT:

#### UTAH FAMILY VOICES - KEEPING FAMILIES AT THE CENTER OF CHILDREN'S HEALTH CARE

The national Family Voices organization aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.



The local Family Voices affiliate, Utah Family Voices works in partnership with the Utah Parent Center and Utah Bureau of Children with Special Health Care needs to assist families of children with special health care needs and/or disabilities and the professionals who work with them. Utah Family Voices is staffed by parents of children with special health care needs who have experience and expertise in navigating the maze of services and programs.

Utah Family Voices staff provides assistance in:

- Finding the <u>right</u> primary care physician (medical home).
- Finding private and/or public insurance and funding.
- Accessing early and ongoing evaluation and screening.
- Referring and making connections with up-to-date community based services and resources.
- Helping families build their leadership to effectively advocate for their children and potentially others.
- Assisting in the transition from child to adult health care and services.

#### CONTACT UTAH FAMILY VOICES

Phone: 801.272.1068 or Toll-Free in Utah: 1.800.468.1160

Spanish Line: 801.272.1067

Email: <u>utahfamilyvoices@juno.com</u>

Facebook: Click here to join UFV on Facebook

Blog: utahfamilyvoices.blogspot.com

#### Meet the Utah Family Voices Staff:



Christine, Jodi, Gina (director), Tina

#### GOT FAMILY-CENTERED CARE?

Quality of care improves when health care providers listen to families. When families and health care providers work together, this is called family centered care. We are doing research to develop a way to measure whether health care providers are delivering family-centered care. You can help by taking an online version of a family-centered care assessment tool to test how well it works. This online survey will take 15 - 20 minutes to complete and will:

- Ask some questions about you and your child. (Nothing that will identify you or your child personally.)
- Ask about how your health care provider works with you and your child. (Your provider also won't be identified.)

NOTE: Your participation is completely voluntary. Taking this survey (or choosing not to) will not affect services that you get from Family Voices or any other agency. Click here to participate. Or visit: http://www.surveymonkey.com/s/FCCA-F-1a



#### ARE YOU READY TO IMAGINE THE POSSIBILITIES OF ACCOUNTABLE CARE IN UTAH?

Attend the Utah Health Policy Project's Better Care Conference on Friday, December 14, 2012 from 9:00-4:00 at the Episcopal Church Center of Utah – Wasatch Retreat and Conference Center, Salt Lake City. A \$20 donation is requested to attend.

The purpose of the Better Care Conference & Summit is to set the vision for accountable care--which will lead to better care for all Utahns. Accountable care changes the way we compensate medical providers. Right now, we pay for each test and procedure, whether the patient benefits or not. That gives the provider a strong incentive to order more tests and perform more procedures than may be necessary. Accountable care pays the provider to make patients well and keep them healthy. This is better for patients—and for taxpayers.

#### Additional goals of the conference:

- Highlight better care opportunities within health reform at the state and federal levels
- Understand what better care looks like for different populations
- Look at wellness incentives—what works and what doesn't

#### Target Audiences:

- Health care providers and stakeholders
- Patient advocates and health care consumers
- Policymakers and public health officials
- Academics, researchers, and students
- General public and members of the media

More information available at: <a href="http://www.healthpolicyproject.org">http://www.healthpolicyproject.org</a>
Or on Facebook at <a href="https://www.facebook.com/utahhealthpolicyproject">www.facebook.com/utahhealthpolicyproject</a>

Space is limited. Register for the event here: <a href="http://bettercareuhpp.eventbrite.com">http://bettercareuhpp.eventbrite.com</a>

#### **NEW!** ONLINE SCREENING TOOL FOR AUTISM

Check out the new M-CHAT.org - The online Modified Checklist for Autism in Toddlers.

M-Chat is a tool that identifies children who may need a more thorough development evaluation. It has 23 yes/no questions that are designed to assess risk for autism and can be completed within minutes. It is important to note that M-CHAT is NOT a diagnosis but a positive result means that you should contact your child's physician so that your child can be more fully examined.

#### The online checklist:

An AAP recommended developmental screening tools for children between 16 and 48 months of age.

Access to M-CHAT.org available at no charge.

M-CHAT takes about 15 minutes to complete.

Results can be printed and discussed with pediatricians during the well-child care visits.

M-CHAT can be used anonymously, or securely saved for later review.

If you have questions about the M-CHAT or other autism screenings, please contact Utah Family Voices at 801.272.1068.

UTAH PARENT CENTER AND DAVIS SCHOOL DISTRICT TRANSITION MINI-CONFERENCE Register today at <a href="http://conta.cc/W9LXmA">http://conta.cc/W9LXmA</a>

# **REGISTER NOW!**

## Get Your Teen with Special Needs Ready for Transition in 2013!

Davis School District Transition to Adult Life Mini-Conference
January 28 - 29, 2013 9:00 - 4:00 PM

Davis District Administration Building

45 East State Street, Farmington, Utah 84025

Register online at: <a href="http://conta.cc/W9LXmA">http://conta.cc/W9LXmA</a>
Pre-Registration is Required. Space is limited so plan to attend now!

For more information, contact Roz Welch Davis District Parent Consultant or the Utah Parent Center's main office:

> Davis: Roz Welch 801-402-5120 Utah Parent Center Main Office: 801-272-1051

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#### MONDAY, JANUARY 28

### FROM NO WHERE TO KNOW WHERE: TRANSITION TO ADULT LIFE

As families of children and young adults with disabilities, we have learned many things — but most of us admit that we have much more to learn.

#### Topics include:

Utah Parent

Center

- Developing the IEP and Transition Plan
- Laws impacting transition
- Person-Centered Planning
- Guardianship
- Transition options for Students with Significant Disabilities
- Districts' Transition Programs

#### TUESDAY, JANUARY 29

#### Getting and Keeping That First Job

This workshop will offer information about preparing for employment for your youth or young adult with disabilities.

#### The Journey to Adulthood

Come learn about what to know to help your child learn about puberty and sexuality.

#### Skills for Teaching Effective Self-Advocacy

We will discuss how you can help your child become a self-advocate.

#### Panel of Transition Experts -

Including DSPD, SSI, USOR, Choose to Work, Independent Living Center, Utah Benefits Planning Assistance and Outreach

#### Also Announcing!

Come to the FREE Davis Transition Fair at the DATC on January 10, 2013! 5:30 - 8:00 PM

Davis Applied Technology College - 550 East 300 South, Kaysville



#### PARENT WORKSHOPS IN GREEN RIVER, UTAH BEING HELD ON DECEMBER 5, 2012

The Utah Parent Center is pleased to present a <u>free</u> parent workshop for parents of children with disabilities or special needs On Wednesday, December 5, 2012 from 6:30 – 8:30 pm at Green River High School. The workshop titled, Parents as Partners in the IEP Process and Positive Behavior Supports, will be held concurrently in both English and Spanish. <u>Click here for printable flyer.</u>

Have you ever asked yourself:

- How can I give suggestions to the school about my child's program?
- What can I do if I don't agree with the school?
- Where can I go for help with my child's IEP?
- What are positive behavioral supports and interventions?
- What is a functional behavior assessment?

Parents are important members of the IEP team. They can and want to be effective partners with other members of the team in developing and delivering special education programs for their student with disabilities. However, they often lack information. This workshop will help parents understand their role, rights and responsibilities in the IEP process. They will learn how to effectively prepare for, participate in and follow-up on IEP meetings held on behalf of their student. In addition, participants will be introduced to a new way of thinking about their child's behaviors and about the need to advocate for behavioral interventions and supports. This portion of the workshop will introduce and provide an overview of the concepts of functional assessment and positive behavior interventions and supports. Information will be presented by trainers who are parents of children with disabilities.

There is no cost to attend. Pre-registration is requested. To register for this event, please contact Shlisa Hughes at 435.749.1657 or by email at <a href="mailto:shlisahughes@yahoo.com">shlisahughes@yahoo.com</a>

#### CLASES DE PADRES EN GREEN RIVER, UTAH ON MIERCOLES, 05 DE DICIEMBRE 2012.

El Centro de Padres de Utah le invita como padre o madre de niños con una necesidad especial a que participen del entrenamiento. Clases de padres en Los Padres Como Parte En El Proceso del IEP y Intervención de la Conducta Positiva Miércoles, 05 de diciembre 2012, 6:30 – 8:30 p.m. at Green River High School. Click here for printable flyer.

Se ha preguntado usted alguna vez:

- · ¿Que es un IEP? ¿Qué es la intervención de la conducta positiva?
- · ¿Cómo puedo sugerir algo en la escuela acerca del programa de educación especial (IEP) de mi hijo/a?
- ¿A dónde puedo ir por ayuda con el IEP de mi hijo/a?
- Estas y muchas otras preguntas se pueden contestar.
- ¿Esta usted cuidando, o tiene usted un niño con desordenes de conducta?

Este taller le ayudará a los padres a entender su papel, derechos y responsabilidades en el proceso del IEP. Este taller es para todo aquel que esté interesado en la educación especial y el proceso del IEP de su hijo/a, como también obtendrá información en algunos tópicos incluyendo evaluaciones, transiciones, procedimientos de conducta y la Sección 504. Este taller también es para los padres que tienen hijos con problemas de conducta y no saben que hacer con ellos. ¿Sabía usted que a través de la escuela usted puede recibir ayuda? Si usted tiene un hijo con necesidades especiales, usted puede venir a este taller a capacitarse. ¿Porque? Porque si usted tiene un hijo/a con necesidades especiales, usted también tiene la necesidad de saber como poder ayudar a su hijo/a a través de la escuela. Muchos niños tienen comportamientos inapropiados que son parte de alguna necesidad. Necesitamos aprender sobre estas conductas como: donde, cuando, y cual es el propósito de estos comportamientos. Venga y aprenda algunas de las herramientas para poder manejar estas conductas. Herramientas Positivas serán compartidas en este taller. Situación, Comportamiento y Resultados serán tocados. Venga, lo necesitamos.

Este taller es GRATIS. Se requiere que se registre! Para más información o para registrarse llame al 1.800.468.1160.

#### **ORGANIZATION HIGHLIGHT:**

#### DISABILITY LAW CENTER

The Utah Parent Center is pleased to highlight the Disability Law Center. The Disability Law Center is Utah's Protection and Advocacy Agency for people with disabilities across the state. Since 1979, the Disability Law Center (DLC) has helped thousands of Utahns with disabilities and their families. The DLC has broad statutory powers to safeguard the human and civil rights of persons with disabilities. We provide self-advocacy assistance, legal services, disability rights education, and public policy advocacy on behalf of the more than 400,000 Utah residents with disabilities. Our services are available statewide and without regard for ability to pay. You are invited to view this 3 minute informative organizational introduction on the Utah Parent Center's website. Click below to view now.



#### DISABILITY LAW CENTER RULING: CONLEY VS. UTAH DEPARTMENT OF HEALTH

On September 27th, 2012, the Disability Law Center received a favorable decision in Conley v. Utah Department of Health. The decision will allow a large group of Utahns with disabilities to access speech augmentative communication devices (SACDs), thereby improving their functional independence and quality of life.

The Utah Court of Appeals ruled that the Department of Health's Division of Medicaid and Health Financing's categorical denial of SACDs to individuals over the age of 22 is a violation of the comparability of services provision of federal Medicaid law.

Plaintiff Nicholas Conley has cerebral palsy. While in school, the district provided Mr. Conley with a SACD. After leaving the school system at age 22, he lost access to the device. Now Nicholas is unable to communicate his most basic wants and needs orally, nor can he any longer communicate meaningfully with friends and family members.

Plaintiff Patty Olguin lives in a nursing home. She has multiple sclerosis and dysarthria. Dysarthria is a speech disorder that renders her unable to communicate orally. It is difficult for Ms. Olguin to direct her medical treatment or tell the staff about pain or other medical problems she is having. Patty's inability to communicate freely also significantly decreases her ability to enjoy life in the community.

The legal question is whether the Department can fund SACDs for children, but not adults. The court held that the distinction in policy between adults and children is irrational and an abuse of discretion. This decision affects not only an adult's eligibility to receive Medicaid-funded speech devices, but potentially many other services and devices that are currently only available to children. We have just found out that the Division of Medicaid and Health Financing will not appeal the decision!



#### FILM SCREENING: "INVISIBLE DISABILITIES: THE PROBLEMS OF PERCEPTION"

"Invisible Disabilities: The Problems of Perception" will have its premier screening on Friday, November 30 at the Salt Lake City Library, Main Auditorium, 210 East 400 South, Salt Lake City. Contact information: 801-524-8200

This moving 20-minute documentary examines the challenges adults with special needs in our communities face when their disabilities, at first glance, can be hidden on "invisible". The screening will be followed by a panel discussion featuring Temple Grandin, Ph.D., author of *Thinking in Pictures*, Chief Chris Burbank, Salt Lake City Police; and William M. McMahon, M.D., U of U School of Medicine. The panel will be moderated by Betsy Burton. The DVD and selected books, including those of Temple Grandin will be available for purchase at the event.

#### INFANT HEAD SHAPE DEFORMITIES AND CORRECTION ONLINE INTERACTIVE TRAINING

The Utah Assistive Technology Program (UATP) will present a free online interactive training, Infant Head Shape Deformities and Correction Through Use of Cranial Remolding Orthoses, on Wednesday, December 5, 2012 from 3:00-4:30 p.m. This free training, presented by Dallin Chambers, certified Orthotist at Northwest Orthotics and Prosthetics, will cover head reshaping through the use of a cranial remolding orthosis. The following aspects will be discussed: head shape deformities, necessary measurements – how to obtain them and what they mean to you as the practitioner or parent - contraindications, scanning process, overall treatment from initial evaluation to final appointment, insurance companies that cover them and their requirements.

In order to participate, you will need a computer with high-speed Internet access. If you are interested in participating please RSVP by Monday, December 3, to Storee Powell via email storee.powell@usu.edu, or call 435-797-7412. Participant instructions will be emailed to you. If you are a screen reader user please contact Sachin Pavithran at 435-797-6572 or sachin.pavithran@usu.edu, no later than Monday, December 3 to make arrangements to participate via phone. If you need any other accommodations in order to participate in the training please let Sachin know by this date also.

#### CAMP K - KOSTOPULOS DREAM FOUNDATION DECEMBER ACTIVITIES

The Kostopulos Dream Foundation is dedicated to improving the quality of life for people with disabilities through recreation, education and growth experiences.

Teen Quest is an exciting program for teens ages 13-17 with special needs. This program provides teenagers with an opportunity, at least once a week, to socialize with their peers, while addressing their individual needs. Activities occur on Friday evenings and include dances, movie nights, sporting events, snowshoeing/skiing, horseback riding, arts and crafts, and more. The program is designed to assists teens in developing self-efficacy, leisure skills, independence, and interpersonal relationships as they learn about themselves, others, and the world around them. Download the December activities calendar.

Adult Social Club allows adults with special needs, ages 18 and up, to expand their social circles, while learning how to use community resources. These weekly activities typically occur on Tuesday evenings and include a variety of events such as movies, live theater performances, nature hikes, concerts, dinner, dances, special events, canoeing, horseback riding, mini-retreats and exercise classes. The program is designed to assist adults in developing self-efficacy, leisure skills, independence, and interpersonal relationships. <a href="Download the December activities calendar here">Download the December activities calendar here</a>.

#### LEGISLATIVE COALITION FOR PEOPLE WITH DISABILITIES DECEMBER MEETING

The LCPD will be holding their next meeting on Thursday, December 6, 2012 from 12:30 -2:00 pm at the Utah State Division of Services for the Blind and Visually Impaired at 250 North 1950 West, in Salt Lake City. For more information about the LCPD and their calendar of events, visit <a href="https://www.lcpdut.org">www.lcpdut.org</a>

#### Assistive Technology in Action Part 2 – Meet Elle

The Family Center on Technology and Disability (FCTD) and PACER Center are pleased to announce the release of our second video in the assistive technology awareness series, AT in Action. In this video, you'll meet Elle, a young woman with cerebral palsy who, with the help of AT, is able to communicate with family, friends, and teachers. We invite you to view and share this video with your colleagues and the families you serve. Click below to view now.



#### DIVISION OF SERVICES FOR PEOPLE WITH DISABILITIES ANNUAL REPORT NOW AVAILABLE Director's Message: Paul T. Smith, Director, DSPD

The dedicated team at the Division of Services for People with Disabilities is pleased to present the 2011 fiscal year report. This report is designed to illustrate how many people utilize the services provided by the Division, describe the services being used, and highlight the historical and current need for these services.

The past fiscal year has brought many changes, challenges, and opportunities for improvement for the Division of Services for People with Disabilities. During this year we implemented budget cuts enacted during the last legislative session, reduced staff and changed management, and began focusing on collaboration, accountability, and improvement of the critical services we provide to the people of Utah.

Despite budget challenges, the Division has kept its mission in the forefront: to promote opportunities and provide supports for persons with disabilities to lead self-determined lives. The DSPD team is excited about the focus on employment for people with disabilities and is grateful to be one of the agencies working on the 'Employment First' initiative passed by the Legislature last session. The Division received an ongoing appropriation this year to re-ignite its 'Supported Employment' program, and we are dedicated to ensuring its success.

The Division employees consider it an honor to work for the people of Utah and I am impressed every day by their hard work and dedication. I hope that you find this annual report a useful tool in understanding how services are delivered to people with disabilities in Utah.

To read the complete report: <a href="http://www.dspd.utah.gov/reports-pdf/">http://www.dspd.utah.gov/reports-pdf/</a>DSPD%202011%20Annual%20Report.pdf



#### **UPCOMING UTAH PARENT CENTER WORKSHOPS AND TRAININGS**

#### GREEN RIVER

#### Parents as Partners in the IEP Process and Positive Behavioral Supports

December 5, 2012 6:30-8:30 pm Green River High School
This workshop will help parents understand their role, rights and responsibilities in the IEP process. They will
learn how to effectively prepare for, participate in and follow-up on IEP meetings held on behalf of their
student. In addition, participants will be introduced to a new way of thinking about their child's behaviors and
about the need to advocate for behavioral interventions and supports. This portion of the workshop will
introduce and provide an overview of the concepts of functional assessment and positive behavior
interventions and supports. Click here to download printable flyer.

#### Los Padres Como Parte en el Proceso Del IEP y Intervención de la Conducta Positiva

05 de diciembre 2012 6:30-8:30 pm Green River High School Este taller ayudará a los padres a entender su papel, derechos y responsabilidades en el proceso del IEP. Este taller es para todo aquel que esté interesado en la educación especial y el proceso del IEP de su hijo/a, como también obtendrá información en algunos tópicos incluyendo evaluaciones, transiciones, procedimientos de conducta y la Sección 504. Este taller también es para los padres que tienen hijos con problemas de conducta y no saben que hacer con ellos. Aplaste aquí para bajer el anuncio.

#### **DAVIS COUNTY**

#### Get Your Teen with Special Needs Ready for Transition in 2013!

January 28-29, 2013 9:00 am – 4:00 pm Davis District Administration Building From No Where to Know Where: Transition to Adult Life -As families of children and young adults with disabilities, we have learned many things – but most of us admit that we have much more to learn. Topics will include: Getting and Keeping the First Job, The Journey to Adulthood, Skills for Teaching Effective Self-Advocacy, a Panel of Transition Experts, and much more. Click here for a printable flyer. This event is offered at no charge! Space is limited. Click here to register today!

#### Parents as Partners in the IEP Process Workshop

February 12, 2013 6:30-8:30 pm Davis Professional Development Ctr This workshop will help parents understand their role, rights and responsibilities in the IEP process. They will learn how to effectively prepare for, participate in and follow-up on IEP meetings held on behalf of their student. If you have guestions, please contact Roz Welch at 801.402.5120. Click here to register for this event.

#### SALT LAKE COUNTY

#### Transition to Adult Life Workshop

February 12, 2013 1:00-2:30 p.m. Granite Education Center This free workshop will offer information about transitioning to life after school. It will help parents understand the transition to adult life, prepare to participate in plan development and implementation as well as focus on issues and changing roles during this exciting, challenging time. If you have questions, please contact Michelle Murphey at 385.646.4190. Click here to register for this event.

Continued on following page.



#### **SALT LAKE COUNTY** (Continued)

#### Preparing Your Child for the Transition to Middle and High Schools

February 12, 2013

6:30 - 8:30 pm

Canyons Technical Education Center

The transition from elementary to middle school and from middle to high school is bound to create some anxiety for students and parents. Join us for an evening where we will discuss what can be done to help ease the transition and prepare your child for success. Information about timelines and expectations will be addressed. Additionally, a representative from the Canyons Special Education department will be there to provide information about the grade reconfiguration and what it means for your child with disabilities. If you have questions, please call Lynda Hansen at 801.826.8192. Click here to register for this event.

#### Parents as Partners in the IEP Process Workshop

February 13, 2013

6:30-8:30 p.m.

**Utah Parent Center Office** 

This workshop will help parents understand their role, rights and responsibilities in the IEP process. They will learn how to effectively prepare for, participate in and follow-up on IEP meetings held on behalf of their student. If you have questions, please call Amy Weyrich at 801.856.1264. Click here to register for this event.

#### Section 504: Services for Students in Public Schools

Feburary 20, 2013

6:30-8:30 p.m.

Utah Parent Center Office

It is important for parents of students with disabilities and special needs to have information and an understanding of Section 504 of the Rehabilitation Act. Understanding the provisions of this important law can help parents be effective partners in working with schools to meet the educational needs of their student with disabilities. This also applies and can be particularly helpful for those students with disabilities who do not qualify for special education services. If you have questions, please call Amy Weyrich at 801.856.1264. Click here to register for this event.

#### Get Your Teen with Special Needs Ready for Transition in 2013!

March 12-13, 2013

9:00 am - 4:00 pm

Canyons District Administration Bldg.

From No Where to Know Where: Transition to Adult Life -As families of children and young adults with disabilities, we have learned many things – but most of us admit that we have much more to learn. Topics will include: Getting and Keeping the First Job, The Journey to Adulthood, Skills for Teaching Effective Self-Advocacy, a Panel of Transition Experts, and much more. Click here to download printable flyer. The cost for this event is \$15 which includes lunch and materials for both days. Click here to register for this event.

#### UTAH COUNTY - STATEWIDE EVENT

#### 2013 Family Links Conference – 'When Go To Your Room Isn't Quite Far Enough'

March 8-9, 2013

9:00 am -4:00 p.m.

Vivent Technology, Provo

This two-day series, presented by Jo Mascorro, M.Ed., will provide strategies to assist teaching children ownership and management of their behavior. How many times do I have to tell you? Sound familiar? Welcome to the world of parenting! This presentation series will provide participants with an array of strategies to assist in teaching children accountability for their behavior.

Early bird registration cost: \$20 - After January 31, 2013 cost will be \$30.

Save the dates for this event. Registration coming soon!



#### Utah Parent Center Information Disclaimer

Utah Parent Center ● Celebrating OVER 28 years of service!!!

Projects of the Utah Parent Center:

Utah Family Voices - Family to Family Health Information Center

Autism Information Resources at the Utah Parent Center

Family to Family Network – Serving families eligible for services from DSPD and more!

Phone: (801)272.1051 • Toll Free Utah: (800)468.1160 • Fax: (801)272.8907 Email: <a href="mailto:info@utahparentcenter.org">info@utahparentcenter.org</a> • Website: <a href="mailto:www.utahparentcenter.org">www.utahparentcenter.org</a>

Our Mission: To help parents help their children with disabilities to live included, productive lives as members of the community. We accomplish this through the provision of information, training, and peer support.

The Utah Parent Center is a non-profit organization federally funded by the Office of Special Education Programs under grant #H328M020032. The Utah Parent Center (UPC) does not represent or endorse any particular point of view, unless expressly stated. Every effort is made to provide accurate and complete information. The content of this message is provided as an informational resource ONLY. For items from other individuals or organizations, we encourage readers to contact the original source with questions or concerns. Only approved items will be posted. The UPC is not responsible for content contained on, distributed through, or linked, downloaded, or accessed through this message. This newsletter is NOT a discussion group and you will only receive official email newsletters from the Utah Parent Center. We do not trade nor sell the email addresses of our subscribers. Permission to forward and reprint the information herein is granted with complete attribution. Please forward this information to your friends and colleagues that may be interested in subscribing to this newsletter. You have received this message because you are on the Utah Parent Center listserv. To be removed, please contact the Utah Parent Center at info@utahparentcenter.org