

Dear UCCCN members,

Here is a meeting summary and your July 2017 resources of the month.

### **Announcements**

The Medical Home Portal recently sent requests to 3 Family Practice organizations asking their members to complete a survey to help youth with chronic conditions transitioning to find welcoming adult care practices: Utah Academy of Family Physicians, Utah Chapter of the ACP, and University Community Clinics. We hope to add to the Medical Home Portal Services Directory information on practices willing to see these young adults.

New Medical Home Portal content in the “For Families” section:

- [End of Life Issues](#)
- [Guardianship](#)
- [Understanding your Health Insurance](#)
- [Services for the Uninsured or Under-Insured](#)
- [Organizing Important Information](#)

### **Brainstorming**

Case #1 – from Nancy Cunningham – Nancy recently had a family with commercial primary insurance and Healthy U Medicaid as secondary. Without enough clear initial communication, the family got one shipment of diapers through the commercial insurance’s contracted company, but no more because it actually wasn’t covered by the primary insurer. For durable medical and therapies, frustration arises in clarifying what’s covered. Additionally, the family may need to first get a denial from primary insurance before Medicaid can pay as insurer of last resort. In speaking with insurance, ask first for a care manager, a manager, then provider relations to get the right communication exchange. Parents need to know specifically what to ask about what is covered, and to do it early to avoid having to pay out of pocket until the situation is resolved.

### **Updates/Reminders**

Eric Christensen from the Utah Department of Health, Integrated Services Program gave an update on the [UDAC \(University Developmental Assessment Clinics\)](#). UDAC’s clinical services are now fully under the University and the clinic’s location has moved to the Eccles Outpatient Services building across the street from Primary Children’s Hospital. Until clinic space is freed up, hours are limited, and the wait time for some specialties could be several months. The UDOH is exploring ways to help eligible rural families pay for travel costs to the Wasatch Front. The UDOH is also working on preliminary plans to re-establish traveling clinics at 3 rural locations six times a year each. More details will be shared as they become available. You may contact Eric at [echristensen@utah.gov](mailto:echristensen@utah.gov) with questions. [medicalhomeportal.org/services/provider/23877](http://medicalhomeportal.org/services/provider/23877)

Jill Conner mentioned that [Shriners Hospitals’ Special needs car seat clinic](#) is held the last Friday of each month. Expert staff. Call 801 536-3564. Open to older kids. Insurance often won’t cover costs for modified car seats and Shriners may be able to assist. [medicalhomeportal.org/services/provider/27005](http://medicalhomeportal.org/services/provider/27005)

**Presentation: Mental Healthcare Needs for Youth with Dual Diagnoses: Assistive Technology Can Play a Part**

**Paige Albrecht, Family Resource Facilitator, Utah Parent Center**

[NADD: National Association for People with Dual Diagnosis](#) website explains dual diagnosis which affects 30 – 35% of the ID/DD population. *Dual Diagnosis* is used for in other diagnosis's but for this population is it defined as a child or individual with Intellectual or Developmental Disability *and* mental health issues.

[medicalhomeportal.org/services/provider/22578](http://medicalhomeportal.org/services/provider/22578)

- Awareness, Acceptance, Access, Abilities
- Communication is a huge thing: what to do for kids who don't talk?
- Primary diagnosis can be an issue - the developmental disability may take the lead for which services are available, speak with your insurance care manager. Not dealing with an ongoing mental health issue may evolve into a medical issue.
- There are not enough providers who have the skills and the comfort level to provide mental health treatment to children with intellectual and developmental disabilities which makes access to appropriate therapy challenging; Utah's mental health system is considering bringing a training to the state to potentially build expertise and capacity.

**Julia Pearce, Assistive Technology (AT) Specialist, Utah Center for Assistive Technology, NADD Board Member**

- Assistive Technology should be looked at every year as part of the IEP review, ages 3 – 22.
- From The Individuals with Disabilities Education Act (IDEA), "AT is any device to increase, maintain, or improve a person's activities." Can take a device and change it 90% if that's what it takes to help the child. AT is both the device and the service.
- Picture symbols can be very helpful for some kids to help with their schedules
- Patient-centered care: when I do this ... it means .... Watch ["If you listen you will hear us"](#), a well-done project commissioned by Leicestershire and Leicester Learning Disability Partnership (on YouTube).
- [Utah Assistive Technology Teams \(UATT\)](#) There are 30 teams throughout the state that evaluate and provide assistance for AT to students ages 3 - 22 that are served on an IEP. IDEA states that the child should be evaluated annually for any assistive technology needs to access FAPE (Free and Appropriate Public Education) [medicalhomeportal.org/services/provider/24225](http://medicalhomeportal.org/services/provider/24225)
- [Utah Center for Assistive Technology \(UCAT\)](#) is a statewide resource offering free evaluations to all individual of all ages and disabilities. UCAT collaborates with other agencies that have specific expertise in serving individuals who are deaf and/or blind. Devices may be modified, designed and fabricated by staff or referred to most appropriate community resource. [medicalhomeportal.org/services/provider/10780](http://medicalhomeportal.org/services/provider/10780)

A list of these service providers in the Medical Home Portal may be found here, [July 2017 UCCCN Resources](#).

*Disclaimer: These resources come in part from our members as part of the meeting brainstorming session; please check with your providers to make sure they are appropriate for your patient/families.*

**Other**

Next meeting: August 16<sup>th</sup>: Back to School – Your questions on IEPs and 504s.

Please submit your questions about IEPs and 504s or any other education-related topics for children and youth with disabilities to [Tay.Haines@utah.edu](mailto:Tay.Haines@utah.edu) by **August 4<sup>th</sup>**. Stephanie Roach, Project Coordinator Family to Family Network/Utah Parent Center, will be addressing them in our August meeting.

Here is the [UCCCN YouTube Channel Playlist](#) of archived meeting recordings.

Thank you!

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