

**Subject:** August 16, 2017 Resources of the Month

Dear UCCCN members,

Here are your August 2017 resources of the month.

## **Brainstorming**

**Case #1** – from Cindy Hally, Wasatch Peds, Bountiful— child patient is typical, mother has complex medical needs, father is looking for childcare financial support, as mom can no longer care for several children.

[SSI, Supplemental Security Income](#) for mom

[Social Security Administration](#) – Salt Lake City. Delivers Social Security services, SSI, Supplemental Security Income [medicalhomeportal.org/services/provider/10699](https://medicalhomeportal.org/services/provider/10699)

[Day Care Assistance](#)

[South Davis Service Organization](#) Web-based resources for family and child safety and support:

Childcare: Department of Workforce Services (tied to income) - Payment to Provider Program, and Find Childcare Near You at Care.com [medicalhomeportal.org/services/provider/21166](https://medicalhomeportal.org/services/provider/21166)

[Head Start / Early Head Start](#)

[Utah Clicks – Applications](#) Utah Clicks website helps you complete and submit paperwork for several state programs: Early Head Start, Head Start, Baby Watch, Baby Your Baby, CSHCN. [medicalhomeportal.org/services/provider/10142](https://medicalhomeportal.org/services/provider/10142)

**Case #2** - from Eric Christensen, Integrated Services Program regarding telehealth services, UDOH is unable to help kids living out of state for reasons of licensure.

[Utah Telehealth Network](#) links patients to healthcare providers in Utah, nationally and globally. It also links hospitals, clinics and health departments from Logan to Montezuma Creek and from Vernal to St. George. [medicalhomeportal.org/services/provider/27753](https://medicalhomeportal.org/services/provider/27753)

**Case #3** – An update from Heather Carlson, CSHCN Integrated Services: Single mom with three adopted special needs children, ages 16, 20, 21, in mobile home trailer, all with severe medical problems. None of children have SSI, only 1 has Medicaid, mom has no equipment. She has a great family practice doctor who lacks support staff for care coordination. Gina and Christine Evans of Utah Family Voices have been helping tremendously over the last month-plus, meeting with a court liaison. Mom is now a little hopeful. Mom has not had anyone helping her to apply for vital services such as DSPD or SSI. The Integrated Services Program in Ogden has an office in the same building as DCFS and Fostering Healthy Children: fortuitous connections are happening.

**New Resource** - from Jill Conner, Shriners, shared a new resource, **SpineScreen**, a free app for parents to assess kids for scoliosis, developed by the orthopedic specialists at Shriners Hospitals for Children. Download from the App Store or Google Play (android or iPhone). Referral line 800 314-4283.

[medicalhomeportal.org/services/provider/27754](https://medicalhomeportal.org/services/provider/27754)

*Disclaimer: These resources come 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.*

*You can find a custom list of these service providers that can be copied, printed or emailed here: [August 2017 UCCCN Resources](#)*

## **Announcements**

- Eric Christensen - Lynne Nilson has dedicated a portion of the MHC block grant for 3 years to support UCCCN and Medical Home Portal (MHP). Eric's advocacy was key to making this happen.
- Chuck Norlin, MHP is awaiting word on 3 years funding from a HITECH proposal that will support implementing the Pediatric Patient Summary as an "app" into EHRs and integrating the Medical Home Portal; this will make it accessible within pediatricians' workflow, initially to be implemented for Epic and iCentra.
- Chuck, MHP survey to identify adult providers for CSHCN resulted in 2: [Westridge Health Center \(medicalhomeportal.org/services/provider/13452\)](#) and [CopperView Medical Center \(9800 S Bangerter\) \(medicalhomeportal.org/services/provider/27052\)](#) (Med-Peds). We will send this survey out a second time.
- Chuck presented some preliminary findings from the survey of care coordinators – please click this link to the [Pediatric Care Coordination Questionnaire](#) if you haven't yet completed this 10-15 minute survey. Your responses will help us to see how things have changed since 2015 when we first asked UCCCN members to fill it out, and to determine topics and areas to focus on. It is very helpful to us if identify yourself at the end—care coordinator, care manager, hospital, etc.

## **Presentation**

### **Stephanie Roach, Utah Parent Center, "Answers to Your IEP & 504 Questions"**

Stephanie also coordinates a state-wide Family to Family Network that is supported by the Division of Services for People with Disabilities (DSPD). It provides support for families on the waitlist for DSPD, funding for which is dependent on the State Legislature. Stephanie provided the following information:

What can medical professionals do in addition to writing recommendation letters for testing?

- Doctor's notes written to the school are great suggestions, schools have to consider them
- Be specific – use data to back up requests
- Help parents understand your recommendations
- Teach parents to advocate for their child
- Attend meeting if possible (in person or by phone)

How can care coordinators help parents to advocate?

- Make sure parent understands their child's medical or mental health condition
- Help them think about the accommodations they would like
- Teach them communication and advocacy skills
- Role play
- Parents can be overwhelmed and may need to hear things several times before they truly understand.

Communication/Advocacy skills:

- Write down what they are requesting so it is articulated clearly
- Provide data to back up their request—what has worked for you, what have you observed?
- Seek first to understand, then to be understood
- Validate stated feelings
- Ask questions to make sure you understand their perspective
- Use “I” statements instead of “you” statements. Focus on YOUR thoughts and feelings instead of what you think the other person is thinking and feeling
- Difference between being aggressive and assertive
- Teach them that it’s ok to advocate. It’s their job. It’s ok to let schools know what they would like and if they disagree.
- Help them understand that ultimately, the decision is up to the school, but there are ways to appeal the decision.

What are ways physicians’ offices can better communicate with schools to better assist children collaboratively?

- See if parent will sign release of information
- If you encounter resistance, be persistent but kind; use your best communication and negotiation skills
- Acknowledge effort by schools

We’ve had patients who have been denied accommodations after testing. Is there a way to remedy this?

- Ask the school how they intend to ensure equal access when not providing the accommodation
- Parents can appeal decision
- Help parents gather data for appeal
- Look at other accommodations that may be helpful

Additional

- Figure out what is at the root of the parent’s concern
- Help them articulate their concerns
- Empathy – acknowledge the difficulty, the feelings of overwhelm can shut a parent down and make it difficult to advocate. Help them work through their own stress.
- Discuss a time frame during meeting, 4 weeks, 6 weeks for instructional; if behavioral, 2 weeks.
- Chuck: taking someone with you—someone from Utah Parent Center, maybe doctor—most relevant--one person recording, second person to keep you on task.

Stephanie had two handouts: ‘Effective Communication and Advocacy Skills for Parents,’ and ‘Accommodations for Students Under Section 504.’ These will be made available in electronic form.

## **Other**

Our next meeting will be September 20th at the Utah Parent Center. You can find the August 2017 and all archived meeting recordings at the [UCCCN YouTube Channel Playlist](#).

Thanks to you,

Tay

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