

Subject: May 2018 Resources of the Month

Dear UCCCN members,

Here are your May 2018 resources of the month.

Brainstorming:

Case #1 -- from Heather Carlson: a success, 6 yr old boy with type 1 diabetes struggling with school – it's been a year of frustration for parent and child. 504/medical was problematic also. Heather and Celina of Utah Parent Center (UPC) attended IEP with principal and speech pathologist and district nurse; first hour an exhaustive unburdening of frustrations and validating all sides; second hour resolved many issues. Heather and Celina met with nurse afterwards, educated her on resources; she will share these in monthly parent newsletters. When the nurse was at other schools, responsibilities fell to teacher. Now the school will train a person in office and the child will have an aide.

Greg Hawkes: training needed for James Mason Center groups that include diabetic kids for everyone's safety. Heather, ISP, has emergency sheets for schools; parent or an older child can do classroom education. The specialist physician should provide a quarterly or annual medical summary for diabetic patient to share with school (or alternative, like James Mason). Primary Children's has an information page on diabetes for parents.

[Diabetes Clinics](#) Services Category

[Diabetes Clinic and Education Center](#), Primary Children's Hospital. Diabetes Clinic and diabetes self-management education program provide ongoing comprehensive interdisciplinary education and specialized care to children and adolescents with diabetes type 1 or type 2, and their families. [MHP 29353](#)

[CSHCN Administration & Programs](#) Services Category

[Integrated Services Program \(ISP\)](#), Bureau of Maternal and Child Health, Utah Department of Health. Assists families of children and youth who have special health care needs with coordinated care planning, education and resources, in order for them to make informed decisions. This may include primary and special health care, behavioral health, developmental and educational programs, financial support resources and social services that meet their special needs from infancy through the transition to adulthood. [MHP 23910](#)

[Parent / Family Education](#) Services Category

[Utah Parent Center \(UPC\)](#) The Utah Parent Center offers a variety of services through projects and programs, providing mostly FREE information, training and peer support to families of individuals with disabilities and the professionals who serve them. Projects include: Parent Training and Information (PTI) Project; Utah Family Voices – Family to Family Health Information Center; School District Consultants; Family to Family Network; Autism Information Resources; Volunteer Programs (funded by the U.S. Department of Education's Office of Special Education Programs). [MHP 10727](#)

[Utah Family Voices \(UFV\)](#) Staffed by parents of children with special health care needs, UFV offers statewide assistance in a variety of ways: providing emotional and peer support through direct contact by phone, email and/or in person to families, assisting with navigation of credible information and referrals so families can access the appropriate public and private resources and services, presenting customized trainings and workshops for families and professionals on a variety of topics; and providing information and training to professional partners and health care providers on family-centered care and family involvement. [MHP 10171](#)

Case #2: from Jade Porter, University Health care manager: success getting a teenager to a first-time PC appointment, and already having a care plan, with daily management and specialists. Take-home message – insurance care managers may have the same goals as medical home care coordinators and may know (some of) the issues even before they do. Insurance care managers are great resources – use them!

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 printed, emailed, and more, here: [UCCCN Resources May 2018](#)

Presenter: Meeting families where they are - Dusty Frisby & Liz Wall, Summit Pediatrics, Heather Carlson & Toni Estrada, UDoH Integrated Services Program & Christine Evans, Utah Family Voices

Christine recounted a case that was very difficult - single mom with a chaotic household, 3 kids with significant disabilities, major distrust of the medical system. Christine was able to listen, having utilized the same services, and a child with a similar condition. She was able to see the situation from the perspective of the mom. Heather: recognized immediately that she wasn't going to be able to do it all and would need Utah Family Voices. Trust was established which

allowed the mom to be persuaded to take steps needed: SSI, DSPD, etc. Email thread that kept everyone in the loop, frequent meetings that are now as needed. Assigned tasks, updates. Only one person was in contact with mom so as not to overwhelm her.

Dusty and Liz share a private office that is outside of the main practice for privacy. Recounted a case of a baby (unplanned) with many medical difficulties, mom is still recovering from the birth, mom is overwhelmed with what needs to happen. Liz (and Dusty) were able to go to the house (mom couldn't come to the clinic) and help mom with the required application paperwork. DSPD application is enormous. Liz can help cut through the red tape, give direct phone numbers. Differences between services in different states can be huge too – Liz has experience with that. But Liz reiterates the need for one point person for families to count on, and that's Dusty. A great partnership.

Heather - suggests that practices help families get a Care Notebook put together. That's really helpful for communication with the medical home team or care coordinator and specialists, others on the care team.

Question: when do you refer to UFV or ISP or both? Who pays for them?

Eric: Summit Pediatrics model is ideal, with a parent partner and care coordinator. If you don't have that in your practice, use ISP for the care coordination piece, and UFV for the parent side ... refer to both, every time (per Gina). ISP is funded through the Maternal Child Health block grant. Anyone can refer to ISP (family, primary care, etc.) via a phone call, or email. How long does it usually take, what kind of contact? ISP support could be provided in person, could be by phone, email. Whatever the family needs. UFV is partially funded through the MCH block grant, and other federal grants. They mostly use phone to connect with families. UFV staff have to do a lot of recurring training on Medicaid, other services.

Toni - try to be a neutral partner so that all the people/organizations involved can feel like they are supported. Understanding the family where they are culturally (Spanish speaking) is very important.

Families also need to be validated as they face becoming a part of the social services support system (Medicaid, SSI, etc.) which may be very difficult for them. Wasn't part of their plan. Watch for cues, acknowledge their "grief."

Presenter: Working within your practice to improve care coordination - Jeremy Egusquiza, South Main Clinic Office Manager

Jeremy: South Main is really good at putting out fires, not so good at stopping them before they begin. Current focus is on Population Health Management. First step: registries for general patients that provide the most important info at a glance, regularly updated. Reminders for care, wellness checks, etc. Also a separate risk registry. Notifications of high risk behavior (high utilizers, etc.). Soon/ future: South Main will be following patients through the referral process. Don't want to lose track of patients when they aren't in front of them, "screaming" at

them. They've worked with their IT folks to leverage everything they can from their EHR. Jeremy is happy to answer any questions. Jeremy.egusquiza@hsc.utah.edu

Other:

An AAP news article published on May 14th, "Primary care teams discover benefits of improving family communication"

<http://www.aappublications.org/news/2018/05/14/familyengagement051418> Information about a Quality Improvement project that Summit Pediatrics participated in. Very relevant to today's meeting's topics. If you can't access the article and would like a copy, please request from Mindy.

Our next meeting is **June 20th**, 2018 at [the USU Salt Lake Distance Education Regional Campus](#) and other USU distance sites.

You can find the archived recording here: <https://youtu.be/d3DphTk7bN0> (all but the last 5 minutes) and <https://youtu.be/bOMvdlWwhM> (the last 5 minutes)

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