



Utah Children's Care
Coordination Network

November 2018 Resources of the Month

UCCCN Website

Medical Home Portal

Dear UCCCN members and interested parties,

Here are your resources of the month:

Brainstorming:

Case #1: from Walt Torres, CSHCN – a new resource, for medical non-emergency travel: for LDS Hospital and all Intermountain facilities, through the social work department. Both Uber Health and Lyft Business Healthcare offer the service to healthcare organizations for their patients with transportation needs.

Service Category: [Non-emergency Medical Transportation](#)

- [Uber Health](#) - Patients may receive scheduled Uber rides for non-emergency medical travel through their (participating) medical providers. For providers, Uber Health is a HIPAA compliant transportation platform for healthcare organizations. Providers can also use Uber Health to help get crucial staff to work. [MHP 32601](#)
- [Lyft Business / Healthcare](#) - Patients may receive Lyft rides for non-emergency medical travel through their (participating) medical providers. Healthcare organizations may subscribe to schedule rides for patients, especially those without easy access to transportation. [MHP 32602](#)

Case #2: from Gina, UFV -- A family that chooses to have their child return to a public school district or charter after attending a private school with the Carson Smith Scholarship may not have all the protections and services in place from a former IEP upon returning to the public school system. The child may need to be reevaluated for special education services even though the child was on a Special Needs scholarship, as determined recently by Utah State Board of Education.

Gina also clarified Home/Hospital support. A child regardless of having an IEP can receive home/hospital instruction for a temporary disability or illness. The child usually receives 1-2 hours of instruction. Whereas a child with an IEP may receive specialized instruction in the home if the IEP team has determined that the particular placement is in the best interest of the child's individualized educational needs. See the "Back to School" section in the Portal's [Hospital to Home/Community](#) page.

Case #3: from Gabi, UPIQ – Congratulations to Busy Bee Pediatrics, Bountiful! They have been certified a Patient-Centered Medical Home by NCQA. Benefits: NCQA designation, QI is streamlined, behavioral health integrated, and the practice may see payer reimbursement down the road. It is an expensive process, takes about 12 months on average to complete. University Pediatric and South Main clinics are currently in the middle of the process. Insurers such as SelectHealth may also certify.

Service Category: [Medical Quality Improvement Organizations](#)

- [National Committee for Quality Assurance \(NCQA\)](#) To improve health care quality, NCQA

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: [November 2018 UCCCN Resources](#)

Presentation: Hospice, Palliative Care & Goal Planning, Rainbow Kids, Beth Nordfors, RN

Emphasis for this presentation is on *goal planning* for families.

Hospice is near the end of life, 6 mos or less (Medicare rule). Provides care in the home. Families hear the word hospice and feel they are giving up on my child. Help reframe: best care, best place, at the best time.

Relationships with families, look for opportunities to talk about the hard topics. This is a form of palliative care. Palliative care is appropriate at any age, any state, as soon as child is diagnosed with a life-threatening condition; can accompany curative treatment. Hospice is a branch on the palliative care “tree.” Best quality of life for the child for as long as possible, based on the child’s and family’s goals.

Rainbow Kids Palliative Care (RKPC) (AKA One Intermountain Pediatrics Palliative Care)

- Also named Supportive Oncology for Adolescents and Pediatrics (**SOAP**) team
- Rainbow Kids supports practices - can be their eyes and ears
- They’ve been around for more than 10 years
- Ages they serve are prenatal to 39 yrs
- More and more families are choosing for their child to die at home; they know they have the choice

Family’s Goals ... often simple things

- Be in the home, or in the hospital
- Procedures, medications can affect goals
- For example, Elisabeth wanted to be comfortable, able to go school, play with her siblings

Families are often confused, feel like the train is out of control. The aim of RKPC is to put the family in charge.

“Code status”: respiratory issues, or, heart not beating. Full code is do everything possible (chest compressions, IV, intubation), or DNAR, or something in between. Pain and discomfort accompanies some of the code interventions, the quality of life afterwards, and other decisions if the full code is successful.

When should you bring it up?

- Changes, unexpected or otherwise
- Parents’ questioning, asking for your opinion
- “Are you worried? Tell me what your worries are.”

Why should you bring it up?

- EMS has to attempt resuscitation - legally bound unless the Utah POLST is in place
- Physician Order for Life Sustaining Treatment (POLST) (providers are NPs, PAs, MDs/DOs) all ages
- Can feel like a brick wall; families need our help
- Advanced Directives for adults only ([Utah Advance Care Planning documents](#))

From [FiveWishes.org](#):

- [Five Wishes: Individuals & Families](#) 18 & older, a legal document in 40 states (not Utah), helpful and free guidance

- [Five Wishes: Pediatrics, Adolescents, and Young Adults](#) - not a legal document, helpful and free guidance
- [Voicing My Choices](#) – for young adults (\$5)

POLST - goes across all ages. Transferable between all health care facilities, to help direct health care in the community. For younger than 17, the POLST has to be signed by 2 licensed providers. **Not** a do-it-yourself form. California, Colorado, Idaho all honor Utah POLST forms. * If a child arrives in ED with POLST, it will be honored unless the child's guardian is present to override. An individual is allowed to amend or revoke a POLST at any time upon request. Youth 18 and older who aren't competent to make their own decisions need a guardian. Still need a POLST. The POLST form can be found here:

https://health.utah.gov/hflcra/forms/POLST/POLSTStatic_Revised2-16.pdf

Write in goals, for example "comfort." Doesn't have to be technical terminology. **Fill it out to have the most empowerment: DNR and comfort measures only.** A relief for parents because they always still have choices for **more** care/treatment. Doing less is not possible.

Angie: do families worry about what their care providers think? Beth: yes, they don't want to disappoint their providers. Need to bring it up. "What are you most worried about?" We will support whatever you put on the POLST; important for them to know what the POLST can do for them (and what it can't).

Use motivational interviewing techniques when talking with families. "We know the decisions you make for your child are made out of love." Help let families know they are not being judged. "We will support you, whatever your wishes are." "What are you hearing from the specialists/doctors about prognosis?" "It doesn't mean you are giving up hope, but that you are hoping for something different ... time, comfort, etc. What are your greatest hopes for your child?"

Ask about spiritual beliefs. The acronym FICA can be useful.

- **F - Faith and Belief**
- **I – Importance**
- **C – Community**
- **A - Address in Care**

For additional training opportunities, see the **Utah Certificate of Palliative Care Education (UCoPE)**: <https://continue.utah.edu/proed/palliativecare>

Gina Money, Parent

Gina's first child was intubated, ventilated, trached, on life support at home. They just didn't know enough at that time about his condition. Gina's third child started showing signs of the same rare genetic disorder. End of life forms felt to Gina like she was giving up on her children. She was lucky enough to have a medical home: they had home health, visits from the primary care clinician. Her third child was able to voice the pain he was in. Gina was supported in the choices she made - her children were not the same. Her PCP gave her permission to change her mind at any time (to do more). As you work with these families, remember the siblings, as well. Include their desires in goal planning, too.

Other:

Our next meeting is **Wednesday, December 19th, Transition to Adult Medical Care** and a holiday party!

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

Take care,

Mindy and Tay

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