



Utah Children's Care  
Coordination Network

## December 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 Tomoko and Nicole, Huntsman Cancer Institute, who are working with adolescent 13-18 cancer patients whose treatment affects fertility, often with time constraints. Insurance currently doesn't cover the cost of preserving the sperm/eggs related to cancer treatment. HCI will be working with the Legislature this session, and has some foundation support. A speaker from the Alliance for Fertility Preservation is coming at the end of January.

Service Category: [Internet Information Services](#)

[Alliance for Fertility Preservation](#) A locator tool allows cancer patients and oncology professionals to search for fertility preservation services in their area, and to submit referrals or request appointments through a secure online system. [MHP 32720](#)

*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: [December 2018 UCCCN Resources of the Month](#)*

---

### Presentation: Transition to Adulthood - Medical Care -- Dusty Frisby, RN, Care Coordinator and Liz Wall, Parent Partner, Summit Pediatrics; Gina Money, Utah Family Voices

---

**Dusty** – Summit Pediatrics decided some years ago to focus on Transition as a Medical Home quality improvement project. They developed some letters to send out to patients, posted them in rooms, and invited providers out to lunch to get relationships established for that warm handoff. It worked to a degree. What they learned:

- The transition process can vary widely depending on the child, their condition, their readiness
- Dusty maintains two resource lists for transition: autism-specific and general special needs.
- Dusty uses two transition timelines (in slides, available on request) from infancy to adulthood, derived from an older [The ARC](#) template. They encourage independence across the age span, and outline what the services are.
- Overwhelmingly, finding an adult provider is the most difficult part of transition to adulthood. Parents say they need to know *when* they will need *what* services: DSPD, Early Intervention, SSI, etc.

- After age 18, young adults must be eligible for services (vs. being entitled), need to reapply for many services/systems. Need to learn to advocate for themselves!
- Is the young person going to college elsewhere? Look for internal medicine docs in that town
- Summit uses pre-visit phone calls and notes in their EMR to help families they serve prepare for the transition process; by age 16-17, they begin to address guardianship
- There are Transition workbooks, checklists. They work for some families, not as well for others, things still get missed. Try not to make assumptions about what the family needs.

#### Helpful Resources

- [Transition to Adult Life](#), Utah Parent Center webpage
- [Finding Adult Health Care](#), MHP Family content section, Navigating Transitions
- [Got Transition.org](#)

**Liz Wall** --Liz is a Parent Partner at Summit Pediatrics and participates in the Summit Peds Family Council as the parent of Lottie, age 17, who has Down Syndrome. Their family is experiencing transition first hand - it's not just one transition; it's many and they happen over time, fast and slow. Transitions are also the milestones Lottie is not reaching (e.g., not driving at age 16) – need to keep that in mind, too. In her role as Parent partner, she has found that some parents want all the information ahead of time, others are in emotional overload. Dusty and Liz will even help families with some of the (very daunting) paperwork, like applying for adult DSPD.

**Gina** – In a phrase, “Transition sucks!” Systems are silo-ed; finding adult provider and specialists is very tough; accompanied by mourning the rites-of-passage kids are missing. Although *medical* transition is the topic today, it's actually the young person's whole life, with the goal being as much independence as possible. If the youth can indicate “yes/no”; they can make decisions, have agency, and help direct their care.

- Finding adult providers is very challenging. Some pediatricians network with adult providers which helps greatly.
  - Adult providers will need a good history, good summary of the young person's medical situation. Often, kids are scary on paper but are actually pretty stable – be sure to try to convey that.
  - Parents need to interview the new primary care office ([see video](#)).
  - Arrange to have medications filled for several months around the time the young person turns 18 to avoid being stuck without a new provider.
  - Same-day visits is not always possible for adults, 2 weeks out, leaves families with the ER and Instacare.
  - Medical care may cut-off at age 18, particularly specialty care (examples: Spina Bifida and CF Clinics)
- Need guardianship, Releases of Information, FERPA (for education records) waivers signed ahead of time.
  - Alternatives to guardianship: Supported Decision Making (see below)
  - Voc Rehab requires release of information if young adult is self-determining.
  - Benefits Counseling very helpful thru DWS services. Check ABLE accounts—individual has control, \$15,000 per year (relatives can contribute). Changes effective 2019.
  - Disability Law Center's Client Assistance Program (CAP)
  - Graduation should be postponed to access education services until age 22
  - Section 8 for subsidized housing.
- Got Transition link, [2018 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care](#)
- [Transition from School to Adult Life](#), a notebook, Utah Family Voices
- [Utah's Transition Action Guide: for Students with Disabilities and Team Members](#), CSHCN, UDOH contains a Transition Action Worksheet. Team members include: youth, parents, educators, vocational rehabilitation counselors, case managers DCFS, DSPD support coordinators, college disability resource center counselors.

[National Resource Center for Supported Decision-Making](#) -- Works to ensure that input is obtained from all relevant stakeholder groups including older adults, people with intellectual and developmental disabilities (I/DD), family members, advocates, professionals and providers. Resources library includes: Guardianship and Alternatives, Education and Transition Planning [MHP 29409](#)

- Handbook [My Voice Counts](#) – Supported Decision-Making, Utah Parent Center

## Other:

Our next meeting is **Wednesday, January 17th, 2019** at the USU Taylorsville site.

Here is our [UCCCN YouTube Channel Playlist](#) of archived meeting recordings and the link to the [December meeting recording](#).

And please *Save the Date* for our Spring 2019 Learning Session on **March 20th, 2019** on the topic **“Legal Issues and Services for Families with Children and Youth with Special Health Care Needs.”**

Wishing you the happiest of holidays!

Mindy and Tay

Mindy Tueller, MS  
Manager, [Medical Home Portal](#)  
Facilitator, [Utah Children’s Care Coordination Network](#)  
Department of Pediatrics  
University of Utah  
[mindy.tueller@utah.edu](mailto:mindy.tueller@utah.edu)  
801-213-3920

Tay Haines  
Portal Services and Resources Coordinator  
Medical Home Portal  
Department of Pediatrics  
University of Utah  
[tay.haines@utah.edu](mailto:tay.haines@utah.edu)  
801-587-1464

Medical Home Portal | UCCCN | 801-213-3920 | [mindy.tueller@utah.edu](mailto:mindy.tueller@utah.edu) | [Medical Home Portal](#)

STAY CONNECTED

