

# **March 23, 2018 Utah Children's Care Coordination Network (UCCCN) Learning Session Summary**

The audio recording and slides from the meeting can be found here: <https://www.youtube.com/watch?v=5XInxdjIXKk>.

## **For Clinicians, Care Coordinators, and other Professionals**

### **First listen, then communicate:**

- Information, but not too much and at the right time; every family is unique in how they take in information
- Recognize limitations on how much can be absorbed/remembered, especially in stressful times, often at the beginning of the journey, at missed milestones, events, or new transitions
- With empathy, validating families and recognizing the myriad roles of parents/guardians
- Keep it simple, but not simplistic
- Offer resources and a little (new) education every time
- Keep trying ... maybe now is a better time than before for that information
- Show your human side. Establish relationships with families
- Make sure that information is shared with all relevant providers and the family
- Allow families a variety of ways to communicate with you

### **Include parents in the process:**

- Consider adding a parent partner to your practice
- Consider establishing a parent advisory committee
- Try to connecting with an existing parent group OR create one if it doesn't yet exist
- Always refer to/connect the family to the Utah Parent Center/Utah Family Voices for current events, workshops, empowerment and support

## **For Families/Parents**

- You are the consumer ... you can and should state your needs, including that you are getting too much information, not enough coordination, that you'd like to talk to other parents who've experienced something similar, etc.
- Ask if your insurance has care management. Ask what your benefits are.
- Ask if your specialist has care coordination. Ask them to send visit notes to your Primary Care Provider (aka PCP, pediatrician, family doc)
- Ask if your providers use an Electronic Health Record (EHR) system with a patient portal so you can see visits, labs, tests, and other medical information about your child.
- Remember that you are the expert on your child and have unique knowledge and experience to share with healthcare professionals and systems

## **To All: Keep Advocating!**

### **Clinicians/care coordinators/other professionals, for your patients and their families**

- Network with other practices/colleagues to collaborate, share ideas, approaches, tools, resources
- You can be a change agent in your practice or organization!

### **Families, for your children and yourselves**

- Figure out a system for remembering and sharing important information ... a journal, a record book or binder
- Identify and engage your team – care coordinator(s), care manager(s), clinicians, advocates
- Find your sounding board, your forum, network

### **All**

- Be patient with each other, and remember that we are all in this together for the same reasons: to improve outcomes for these kiddos and their families.

**Major, longer-term challenges that need focus, ideas, innovation, and work:**

- Effective ways to share (the most important) information across clinicians, other providers of care, and families
- Electronic compatibility across systems to support information sharing
- Many more mental health providers, ideally integrated into primary care and specialty care practices
- More programs like the Comprehensive Care Clinic and the Prader-Willi Syndrome Clinic that provide comprehensive care for children with complex/uncommon problems
- Many more providers of adult care who willing and able to take on the care of young adults with “pediatric” conditions (and effective ways to transition care to them)