

UCCCN Resources Jan 2017

Subject: January 2017 Resources of the Month

Dear UCCCN members,

Thank you for your patience. Here are your January 2017 Resources of the Month.

Brainstorming, Case #1 – from Pat Rowe - transitioning a 22-year-old with CP into adult care, Complex care at Intermountain, SelectHealth with State Medicaid as secondary, lives in Farmington. At a loss to find a physician.

[CopperView Medical Center](http://medicalhomeportal.org/services/provider/27052) South Jordan. Pediatric and adult medical clinic with a number of Med-Peds physicians (Specialty Board Certified Internal Medicine and Pediatrics)
medicalhomeportal.org/services/provider/27052

[Farmington Health Center](http://medicalhomeportal.org/services/provider/24966), University of Utah Health Care. Primary care, urgent care, over 30 specialty services including Huntsman Cancer Institute and Moran Eye Center.
medicalhomeportal.org/services/provider/24966

Transition Issues Discussion

[Got Transition](#) website for health care transition quality improvement, with specific forms for specialists, since a young adult may be transitioning to multiple adult docs.

Provide a concise summary of the important relevant information on a patient for the adult care provider, so they won't be overwhelmed with the child's entire medical history.

Claudia mentioned Med/Peds docs (Internal Medicine/Pediatrics) with the U of U that can be referred to. We will be contacting them for inclusion in the Medical Home Portal Services Directory.

Summit Pediatrics conducted a survey to identify local physicians willing to take transition kids, and found one provider with whom they established a relationship, with very warm handoffs. Summit's Parent Family Council prioritized transition ages 5 – 18 and is doing its own research, with haphazard results. Not all families are ready to hear and act on information at the same point in the timeline of their child.

Consent forms and guardianship must be in place and guardianship started by the child's 18th birthday to enable the family to be included in health care discussions and decision-making. A conference focused on person-centered planning, "Celebration of Self-Determination," is scheduled for July. More information will be available on the Utah Parent Center website in the near future. Gina will send out a save the date flyer as soon as it is available.

From Gina and Utah Family Voices, [Utah Parent Center](#) provides transition training and workshops throughout the state, including Guardianship. The current and upcoming events are

on the Utah Parent Website under the events tab.
medicalhomeportal.org/services/provider/10727

Brainstorming, Case #2 - from Pat Rowe – There is a shortage of home health private duty nurses, trach vent trained “skilled nurses.” Commercial insurance typically doesn’t pay.

Care Coordination Agencies

[Pediatric Comprehensive Care](http://medicalhomeportal.org/services/provider/22626) Comprehensive Care Clinic is going to be adding an additional care coordinator and APC and social worker (will help with kids with trach vent). The clinic will be a connector service with families for inpatient/outpatient care across the continuum.

medicalhomeportal.org/services/provider/22626

[South Davis Community Hospital](http://medicalhomeportal.org/services/provider/11486) Long-term care facility which provides services for children with special health care needs. Inpatient services include home health, rehabilitation, hospice, and specialty pediatrics. medicalhomeportal.org/services/provider/11486

Home Health Private Duty Nursing Discussion

Dr. Fruin, CSHCN, UDOH together with Primary Children’s hospitalists and Family Voices has a discussion group going, “Medically Complex Child Coalition.” Subjects include the skilled nursing shortage, alternative licensing for aides, the long waitlist for the tech dependent waiver, commercial insurance not covering home care, minimal parent training. The intent is to do the research, gather support and have concrete ideas, then go to the Legislature next year.

Let Claudia know you are interested in the coalition – cfruin@utah.gov

Medically-Dependent Waiver is really only for trach vent kids because of critical needs and limited spots; the waiting list continues to grow. More children are living longer and need help; there are not enough private duty nurses to fill the needs, as well as funding increased reimbursement for the providers.

Some concerns from individual nurses:

- Private duty nurses don’t get enough medical support, hospice support or training.
- Hospice and Private Duty Nursing may not be possible concurrently if changes occur with health insurance.
- Pediatric nurses don’t often have the skills or desire to take care of those who are transitioning to adulthood.

Care coordinators are encouraged to reach out to insurance care managers.

- A creative problem-solving solution: extend 90 days of private duty nursing benefits by training family members who can take 3 days a week and nurses the other 4 days. So

long as it can be proved that providers have been trained and are competent, they can get paid.

- Respite means parents may leave the home while someone who is trained is providing the care.
- Due to the Nurse Practice Act, an RN (or LPN with oversight of an RN) are designated to be the only ones to provide the skilled care that many of these medically complex children need if Medicaid or other health insurance funds are paying for the care.
- Legislators have been meeting with families, advocates and providers who are involved and concerned.

Many families with you that are transitioning to adulthood either stay with their pediatrician or come back to the pediatrician because of the lack of adult providers with enough knowledge and interest in becoming the adult medical home. A suggestion is that there may be more success if the adult medical homes had a trained care coordinator to help the pediatrics office transition the care.

Advocacy

- Everyone has a voice to educate their own legislators on the needs of families of children with disabilities and complex health care needs. Give them stories, have families call their local representative because one voice really can make a difference.
- Check out [Legislative Coalition for People with Disabilities](http://legislativecoalitionforpeoplewithdisabilities.org) for more information.
medicalhomeportal.org/services/provider/10153
- A training date for UCCCN to learn about advocacy, legislation and policy change will be scheduled.

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: [January 2017 Transition, Care Coor, Car Seat](#)

Presenter: Deborah Watkins, Care Manager, Shriners

[Car Seat Specialty Clinic](#), for special needs children and youth. A new clinic staffed by seating and therapy specialists, the fourth Friday of every month. Shriners goes to great lengths to make seating possible for every child who qualifies.

medicalhomeportal.org/services/provider/27005

Other

- **Teen Suicide Awareness Breakfast** – Saturday, January 28 at 9:00 am. Sponsored by James Mason Recovery and Wasatch Pediatrics. 801 693-1192
teen-suicide-awareness-breakfast.eventbrite.com

Our next UCCCN meeting will be February 15th, 2017 at the Utah Parent Center. Find archived meeting recordings on the UCCCN YouTube channel:

<https://www.youtube.com/channel/UC7H5ZtFZ519prcGQh5iCZbw> .

All the best,
Mindy and Tay

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