

UCCCN Resources 9 20 17

Subject: UCCCN Resources for September 2017

Dear UCCCN members,

Here are your UCCCN September 2017 resources of the month.

## **Brainstorming**

Case #1 from Alison Lewis--9 year old pleasuring herself in the classroom and it's become an issue. She has a psychiatrist and a meds Rx.

Gina suggested identifying a good therapist able to work with the child to limit the behavior to the bedroom only. It's largely an issue of education and understanding for all; our children are sexual beings. There will have to be consistent prompting and redirection every time and very structured without drawing too much attention -- "No, you cannot do that here, the only place you can do that is in the bedroom or bathroom at home." One staff member said, "You CAN teach the child what is appropriate and where and give her her own "private time" in her room. My daughter has some fairly significant intellectual disabilities but she understood what "not appropriate" meant and it worked, now she doesn't even do it. It was like it was a phase and once we were matter of fact about it, it wasn't that big of deal to her. It was about that age (9) when she was at her peak of exploration. Also, if it is a problem within the classroom there may be some strategies that the school can also work with on behavior." The family can call the Utah Family Voices staff at the Utah Parent Center directly to get some peer to peer assistance and resources.

Also, suggest the family get her full dance unitards to put under her clothes. It is also nice to have pants that tie snugly.

### Clothing, Assistance

Wearing onesies or unitards (example [unitard "biketard"](#)), or pants that are securely fastened. May find at DI, Savers, etc. to save money.

### Family Support Organizations

[Utah Family Voices](#) staff can offer peer-to-peer assistance and resources: 844-838-8275. [MHP 10171](#)

## **New Resources**

Eric Christensen--[Patient and Family Housing, University of Utah Health](#) Patients who travel more than 100 miles to see specialists affiliated with the University of Utah and receive care may stay for affordable rates (\$50/night), billable to Medicaid. [MHP 27768](#)

Gina Pola-Money -- Primary Children's has a [Forever Young Zone](#) offering recreation therapy to provide tools for exercising the imagination of children who face emotional and physical challenges. [MHP 27857](#)

Also, the [Ronald McDonald Family Room](#) provides parents of children being treated at Primary Children's Hospital with a home-like environment where they can turn to for rest and support while staying near their loved ones during treatment. [MHP 10683](#)

**Presenter: Colin Kingsbury, [Autism System Development Program, CSHCN Bureau, UDOH MHP 23907](#)**

The Bureau of CSHCN has a new program. Its mission is to advance, educate and empower the lives of those affected by Autism Spectrum Disorder (ASD) in Utah.

Annual Performance Measures:

1. Analyze current data collected by URADD and disseminate data throughout Utah.
2. Partner with the Utah Autism Initiative to identify system gaps and address needed improvements in services.

Two big pushes from the Utah Autism Plan:

- Screening with the M-CHAT at 18-24 mo at office visit
- Transition to adulthood services for 14-year-olds (and older) with ASD

44% of kids diagnosed with ASD in Utah were NOT screened with the M-CHAT; terrible statistic for the state. Presume that the way to improve our stats is through digital opportunities, [MCHAT.org](#) and a new app called "[Baby Noggin](#)" for parents. M-CHAT screening can start at 16 mos, but if they fail at that age, try again at 20 months.

Transition services: Colin says all are at capacity, but he would recommend [Peer Connections](#) (Janet Wade) [MHP 27769](#) and the [Columbus Community Center](#) [MHP 10538](#).

As part of ASD Resource Management, the ASDP:

- Refers individuals with ASD to services for evaluation and treatment
- Refers to care coordination programs
- Updates ASD diagnostic providers list
- Updates ASD treatment resources list
- Expands previously conducted ASD services survey to assess service needs and identify barriers for care across Utah
- Compiles annual report summarizing ASD needs in Utah

Colin keeps a list of resources, including diagnostic providers. Evaluation is hard ... it's important to get it right the first time, so Colin tells parents to do their research and make sure to get a good evaluator. Schools can do some evaluations, but not ADOS, and school's purpose is for education-related services, not medical. UDAC charges the least and has sliding scale option. Sometimes the private pay option for an ADOS is cheaper; many with private pay options have sliding scales. The Hope Grant through the [U's Autism Spectrum Disorder Clinic MHP 3979](#) can help with up to \$200 of testing.

Help to identify and close the gaps by:

- Attending an Utah Autism Initiative (UAI) quarterly meeting to participate in problem solving
- Calling your legislator to renew autism insurance coverage [Legislation SP-57](#).

Colin is a resource for autism information and resources in Utah. Reach him at (801) 584-8455 or [CKingsbury@utah.gov](mailto:CKingsbury@utah.gov).

### Other autism-related resources

[Ages and Stages Questionnaire, Help Me Grow](#)—parent-administered screening for ages 0 – 65 months  
[MHP 13266](#)

[Melisa Nellesen Center for Autism](#), UVU. A University support center for students with autism spectrum disorder. Objectives include: facilitate diagnostic support for UVU students, serve as first point of contact for families in Utah County and provide service coordination & resource support for Autism Spectrum Disorder. [MHP 27755](#)

[Passages Program](#), UVU. Provides support for individuals on the autism spectrum to more fully realize their potential and utilize their strengths for enriched lives. Classes offered every semester focus on the skills needed to succeed in college as well as in everyday life. [MHP 24769](#)

*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: [Sept 2017 UCCCN Resources of the Month](#).*

### Other

The [Rett Syndrome diagnosis module](#) on the Medical Home Portal has been completely updated. Rett Syndrome is a severe neurodevelopmental syndrome which affects 1 in 11,000 females as well as some boys. Children with Rett syndrome have significant developmental problems; many also have seizures, gastrointestinal problems, heart and breathing difficulties. In most cases, Rett syndrome is related to a mutation in a gene called MECP2.

Our next meeting will be **October 18th** at the Utah Parent Center. The Utah Asthma Program team will be presenting.

Here's the link to the 2017 Meeting Recording playlist, which includes the 9-20-17 meeting recording: <https://www.youtube.com/playlist?list=PL6ahjvQtYjoPyb28vQyufZDWmGWU9U8WH>

Have a great weekend!

Tay & Mindy

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