

SEED Study to Explore Early Development

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Study to Explore Early Development (SEED) Begins Follow-Up Phase of Research

Who? and when? We will be starting a new follow up phase of SEED in which we will contact families who participated in one of the three earlier phases of SEED. If you had previously informed us that it was OK to contact you for another study, you may hear from us in the next year or so to see if you want to participate.

What? We plan to ask families about some of these topics:

- Educational/community/social supports,
- General and mental health,
- Bullying and discrimination,
- Safety and suicide,
- Family and financial impacts,
- Independence,
- Transition planning,
- Employment, and
- Vocational training.

We will also invite some families for an in-person developmental evaluation.

Why? This information will be used to guide future research and help establish new approaches to meet the needs of adolescents and young adults with autism spectrum disorder and other developmental disabilities in the years to come.

How? and where? Like previous phases of SEED, CDC is funding the follow-up study. CDC will continue to work with these partners:

- The University of Colorado Anschutz Medical Center,
- Johns Hopkins University,
- Kaiser Foundation Research Institute,
- Washington University at St. Louis,
- University of North Carolina at Chapel Hill,
- The Children's Hospital of Philadelphia, and
- The University of Wisconsin-Madison.

For this next phase of SEED, we will have a new partner, Chickasaw Nation Industries (CNI). CNI will help CDC and our partners collect information from you for this new study.

CNI will help CDC make sure all your information is kept safe and secure and that no one outside the study team receives information that identifies you unless you say it is OK. Some of the consent forms that families completed when they first participated in SEED stated that study data would be stored at Michigan State University. For this next phase of SEED, all study data are being stored at the CDC—where CNI will help CDC make sure that it is safe—and at the SEED sites where data were originally collected (California, Colorado, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, or Wisconsin).



Sleep Tips for the Family During COVID-19



By Dr. Ann Reynolds

Ann Reynolds is a Professor of Pediatrics at the University of Colorado School of Medicine and Medical Director of Developmental Pediatrics at Children's Hospital Colorado.

For many people, sleep problems may have worsened during the COVID-19 pandemic. Children with autism spectrum disorder (ASD) are more at risk for sleep problems. Sleep problems can be caused by many factors, including anxiety, depression, and attention deficit hyperactivity disorder (ADHD), which many children with ASD have. Also, sleep problems tend to happen when there are significant stressors for the family and child, such as concerns about older family members, hospitalization or death of a family member, and job loss. Children with ASD may struggle more than others in response to this kind of negative news.

Disruption of schedules can also interfere with sleep. COVID-19 caused significant changes in routine for school, therapy, and family member work schedules. A daily routine can help to keep the family's sleep patterns optimal.

Some helpful strategies to improve sleep:

- Dim lights an hour before bedtime; avoid white and blue light (such as tablet and cell phone screens) during that time.
- If television or computer screens are unavoidable, put them on dim and use a filter that reduces blue and white light. Red light is recommended when a night light is needed.
- Remember that lights in the bathroom should be dim and/or red because turning the overhead light on even for a brief time to brush teeth or go to the bathroom can disrupt sleep by decreasing the body's natural melatonin production.

Resources from Autism Speaks

English:

[Sleep Strategies for Children with Autism](#)

Spanish:

[Estrategias para Mejorar el Sueño de los Niños con Trastornos del Espectro Autista](#)

Conversation with Dr. Jessi Solomon Sanders



Conversation with Dr. Jessi Solomon Sanders about an Adult Behavioral Neurology Clinic

Dr. Jessi Solomon Sanders specializes in Neurodevelopmental Disabilities at the University of Colorado and cares for pediatric and adult patients.

Can you tell us about the adult clinic?

Many individuals with autism spectrum disorder (ASD) and other neurodevelopmental disabilities (NDD) see developmental specialists in pediatric settings; for example, developmental pediatricians or child neurologists. There are no "adult" developmental pediatricians and unfortunately some of the reasons children need to see a developmental pediatrician do not go away when they become an adult.

I wanted to create a clinic where adults with ASD and other NDD could be cared for in an age-appropriate setting. I partnered with the Behavioral Neurology section at the University of Colorado to create a specialty clinic for adults with NDD.

What is the main issue young adults with ASD face when transitioning from pediatrics to adult medicine?

When young adults with ASD become too old to be seen by their pediatrician, they can have difficulty finding adult providers who know ASD. I do think, however, that many adult providers are willing to learn ASD. Unfortunately, a big barrier is that ASD and other NDDs are viewed in medical training as pediatric issues. For example, adult neurology residents learn about ASD on their pediatric neurology rotation, not within their adult neurology rotations. I hope this will change, but understanding the different backgrounds of different providers, and having patience while new doctors learn about you or your loved one, can help you develop a strong care team that knows you or your loved one, and, in time, ASD.

Conversation with Brian Be



Brian Be is an autistic, artist, advocate, alumni of the University of Colorado's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, and autism/neurodiversity self-advocate. He helps lead the Denver-based [Metro Autism Consortium \(MAC\)](#), a peer support group for adults on the autism spectrum and their allies. We asked him to tell SEED about the MAC group.

How did MAC start and how did you become involved?

The Autism Community Store and two autistic adults started MAC in summer 2018. The store has been around more than 10 years. I visited MAC a few months after it began, then started helping lead the group.



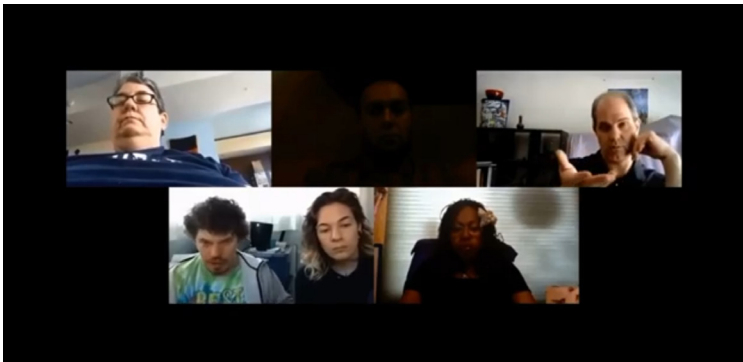
What do people get out of being part of MAC?

MAC provides (a) resources/supports, and (b) opportunities for fun/social interaction. MAC fosters leadership, confidence, connection, and self-agency, according to survey results.

Do you have any advice for people creating a group like this?

Plan 3 to 5 years out, as best you can—and that's just to start. Then plan to continue. It's been my experience that establishing a group like MAC is a long-term process. Creating a group like MAC requires relationship building and maintenance. Find community supporters who buy in. Get them to commit to a long-term process. The need for peer support groups is not going away, so ask yourself how a group can stay around for at least 4 years. For us, the Autism Community Store and its founders provided the basis for establishing the peer support group. I was well known in the autism community and was given the task of moving the peer support group forward. Our limited capacity enabled us to begin with one Saturday per month.

Build as you go, adapt. Find like-minded allies. Establish and grow funding. Modify as needed when dealing with issues such as COVID-19, disagreements, people who fade away, visiting presenters, new members, and deciding group norms such as confidentiality or boundaries around visitors.



How can someone find out more about MAC?

Call the Autism Community Store at (866) 709-4344.

Visit website at <https://autismcommunitystore.com/pages/mac-metro-autism-consortium>.

Watch Metro Autism Consortium (MAC) Interviews at <https://youtu.be/C-DktuVfS2g>.

Conversation with Kate Christofferson



We asked Kate Christofferson, a special education teacher at Prairie View Elementary School in the village of Oregon, Wisconsin, some questions about how teaching and learning have changed during the COVID-19 pandemic.

What skills do you think the pandemic has built up in kids, whether they are affected by a disability?

Children have faced a variety of hardships and changes over the past 2 years, but I think they have built resilience along the way. The pandemic created a situation where it was critical for schools to take the time and space to address the social and emotional learning of students like never before. It has given students a safe space to talk about their worries and concerns, and to practice positive coping strategies on a daily basis. In many cases, students have learned how to express their emotions during times of distress. This is such an important life skill.

Children have also learned how to be more flexible. During the pandemic, our schools and practices changed a lot, sometimes even day to day. Students watched their teachers try new things, make mistakes, and change their teaching plans on short notice when things didn't work well. Children saw firsthand that life does not always go as planned. I think they learned that though changes to routines can be hard, it's possible to work through it.

What new teaching methods and concepts do you think you'll continue to use, even after the pandemic ends?

There are many positive changes in classrooms. Teachers are lecturing less and giving students more time to talk and share. They are offering more flexibility to students in how they complete assignments. For kids who may have traditionally struggled in school, having more ways to show what they know is a great opportunity. For example, we now provide more ways to participate in class discussions nonverbally, which has helped increase engagement while reducing school stress for some students. The pandemic has also gotten teachers talking regularly about the need to focus on children's developmental needs, including play, outdoor time, conversations, and sleep. This is an exciting time for schools to build upon what we've learned since the start of the COVID-19 pandemic and improve our practices to better serve all kids.

Children who participated in SEED 3 are growing up during a pandemic. What long-term educational impacts are you seeing, both for bad and for good?

I think we have to continue to monitor how support systems operate during a pandemic, or other future disruptions. While schools may provide school supplies, food, devices, and Wi-Fi for families in need, it is much harder to provide mental health services, behavioral support, and social skills lessons to kids under these circumstances. Likewise, relying on instructional practices that involve too much screen time can be a problem.

Some really good things have come out of this too, however. One of the greatest benefits is increased communication between school and home. I have had many parents tell me how much they appreciated seeing the strategies I had once only talked about at parent-teacher conferences. In turn, I have appreciated seeing a student's home learning space and how they interact with their caregivers. It's been a great window for parents and teachers to see into each other's world.

The relationship students develop with a caring teacher can't be replaced, but I think we have discovered ways to work around the required restrictions effectively and have grown stronger in our home/school partnerships. I hope we can keep those great relationships going, moving forward.