



## Summer 2020: Challenges and Changes

For families across the country, the summer of 2020 was anything but normal.

Because of the COVID-19 pandemic, in-person school ended weeks (if not months) earlier than usual, community-based activities and services were disrupted, childcare and employment plans changed, and stressors increased. Many families in the autism and developmental disability community felt they were among the hardest hit by the challenges of this summer, but some say not all changes were bad.

“Honestly, [my son] does better at home than in public,” said the mother of a 4-year-old with autism. “Now that we have a routine, we are doing ok with quarantine.” This experience is reflected by [data collected from over 8,000 families in SPARK](#), a national research network sponsored by the Simons Foundation. Families reported identifying a range of strategies to manage stressors, including [social stories](#), taking breaks for rest and relaxation, and enjoying home hobbies.

Families have also found new ways to access professional supports. “Telehealth has been a game-changer,” said Darren Olsen, PhD, a clinical psychologist at Children’s Mercy Kansas City (part of the Missouri SEED site). “Before COVID-19, we could only offer telehealth at approved clinics. Now, I’m delivering therapy right into families’ homes. They don’t have to travel for appointments, and we all get to limit our exposure risk.” Even with improved access through telehealth, 63% of families still reported significant disruptions in their child’s services or therapies.

Families of adults who need ongoing support have also faced many logistical challenges. One Midwest mother of an adult daughter with autism and intellectual disability shared some of these struggles. “[My daughter] couldn’t stay in her day program and is back living with us for the time being. All of these changes have been really hard on her.” Another [SPARK survey collected data on 636 autistic adults](#) from around the country. This survey found that 89% of adults reported disruptions in their employment due to the pandemic, but 75% reported coping with these changes at least moderately well.

The COVID-19 pandemic was not the only crisis impacting families this summer. Nationwide protests addressing systemic racism prompted challenging conversations for all families. “Knowing when and how to talk about race is very difficult,” said Trista Perez Crawford, PhD, another clinical psychologist at Children’s Mercy Kansas City. The good news, she

said, is that “kids are sponges, and are ready to learn from a very young age. The most important thing you can do is to set the example of being open to learning about others, especially those who are different from you.”

While parents often worry that youth with developmental differences may not know how to respond to law enforcement officers, “we can’t ignore the obvious differences that race plays out within the disability community,” said Kim Riley, founder of [The Transition Academy](#) (a special needs college and career planning resource center) and mother of an adult with autism. The risks already faced by Black and minority youth interacting with police can easily be compounded by the core social, communication, and behavioral differences associated with autism, and this weighs heavily on families. One father of a Black teen with autism living in the Midwest shared that “officers and the public do not... understand that he’s just being him, and it makes it tough. It makes it scary for us.” Even when it is hard, communicating more about health and safety disparities is the first step toward addressing them. “Let’s all vow to get comfortable being uncomfortable,” said Riley.

## Teaching Kids to Learn to Wear Masks

Wearing masks can be hard for all kids, especially for youth with autism and disabilities. The good news is that use of evidence-based teaching approaches can help kids learn this critical safety skill. Cy Nadler, PhD, co-investigator from the Missouri SEED site and a clinical psychologist at Children’s Mercy Kansas City, has the following suggestions for helping children get used to wearing a mask:

Be strategic. Pick a mask that is comfortable (soft, doesn’t tug on the ears, etc.), appeals to the child (favorite color, themed fabric, etc.), breathable, and fits properly (covers the mouth and nose, fits snugly, and does not leave gaps around the face). Let the child pick from a few choices that you select based on [CDC’s guidance about masks](#).

## Practice makes perfect.

1. Start by practicing for short amounts of time (a few minutes, or even 10-15 seconds if it is hard). Some children may need to start with just touching the mask to their face. Use a timer or visual cue so the child knows how long they need to wear the mask. “Mask up” with them to model the right behavior!
2. Praise the child throughout the practice time for keeping the mask on and show excitement when they wear it the whole time. Set up a “First – Then” to help motivate the child to practice (“First mask practice, then play outside”).

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3. Gradually increase how often the child practices and how long the child is expected to wear the mask (e.g., once a day for one minute to three times a day for one minute). Then start practicing in other settings and during routine activities (during first 15 minutes of screen time, while taking a walk, etc.).
4. Practice taking the mask off properly.

**Rehearse the rules and praise success.** Before going in public, re-state the rule (e.g., “Masks on in public”) and praise success early and often (e.g., “Nice job talking with your mask up!”). Provide reminders as needed (“Keep your nose covered – great!”), and use incentives (special activities, privileges, or small rewards) to encourage success (e.g., “Since you wore your mask for the whole shopping trip, you get extra screen time”).

**Remember: Any mask wearing is better than none, and slow, steady practice and encouragement can lead to improvement.** Talk with your child’s teachers, therapists, and other care team members about helping to build this important safety skill. Wearing masks, social distancing, and other safety skills might even be added as school “behavior goals” for children who receive special education services. See the following links for additional guidance on supporting health and safety.

## Resource Links

### General Resources on COVID for Children

[CDC COVID-19 Resources for Children](#)

[Parent Resources](#)

[Parent, Caregiver and Guardian Checklist](#)

[Preparing for a Safe Return to School](#)

[Use of Masks in Schools](#)

[How to Wear Masks](#)

### ASD-Specific COVID Resources

[Supporting Individuals with Autism Through Uncertain Times Toolkit](#)

[A Toolkit for Helping Your Child Wear a Mask during COVID-19](#)

[Coping during the COVID-19 Pandemic: Yale’s Guide for Families with Children with Autism Spectrum Disorder](#)

### School & Remote Learning Resources

[CDC Considerations for Schools & Students with Disabilities or Special Healthcare Needs](#)

[Online Learning & ASD](#)

[Council for Exceptional Children resource library](#)

[Educating All Learners resource library](#)

[CCHMC Home and Remote Learning tips](#)

### Talking to Your Children About Race

[EmbraceRace.org](#)

[Talking to Kids about Race](#)

[Child MIND Institute – Talking to Kids About George Floyd](#)



## SEED & COVID-19 Update

SEED has relied on extensive in-person assessments since the study launched in 2007, but clinic visits were suspended in spring 2020 to minimize risk of exposure to both families and staff. Investigators from across the country are working together on an amended plan, including measures to help understand how the pandemic has impacted children and families.

## Highlights of SEED Progress



1 leaf = 100 families who finished

## SEED 3 is growing!

The families joining SEED 3 are adding to the knowledge gathered in SEED 1 and SEED 2! More than 5,100 families finished the first two phases of the Study to Explore Early Development. The data from new families who finish SEED 3 will help us get a better idea of what puts children at risk of developing autism spectrum disorder.

Watch for future newsletters to see how SEED grows and visit [www.cdc.gov/seed](http://www.cdc.gov/seed) to see all the editions of the SEED newsletter.