SEED Reaches a Milestone – and Forges Ahead

Thanks to the participation of thousands of families, the third round of SEED (SEED 3) is now complete. In total, this means nearly 10,000 families across the country have joined SEED during the last 15 years! As a result, we’ve learned a lot about what factors are associated with autism spectrum disorder (ASD) and other developmental disabilities – and we are learning more every day. Please visit us at Research Findings from the Study to Explore Early Development | Autism Spectrum Disorder (ASD) | CDC, and check back often. We will be working hard to let you know about all the new results of this long-term study.

SEED 3 may be complete, but our work is not yet finished. We are entering a new phase of the study that will allow us to better understand how ASD and other developmental disabilities can impact children and families across the lifespan, from early childhood to early adulthood. We will be reaching out to SEED families soon to ask if they’d like to participate in this new research.

We can do this type of study because our participants now have a wide age range. For example, the children who joined SEED 3 as toddlers are now school-aged. We are interested in learning more about how these children learn, grow, and develop their cognitive skills as they mature. The children who participated in SEED 2 are currently adolescents, so we can ask questions about changes during the teen years. Children who joined us for SEED 1 are now young adults! This allows us to ask questions about how ASD affects careers, relationships, health, and autism-specific services in adult life.

To learn more about the transition to adulthood in people with ASD, we asked Megan Farley, PhD, some questions. She is a licensed clinical psychologist working in the Autism and Developmental Disabilities Clinic at the University of Wisconsin’s Waisman Center.

Conversation Corner with Megan Farley, PhD

What are some common problems young adults with autism face, and what can be done to address them?

Young people with autism have a wide range of abilities and interests, so the answer will be unique to each person. That said, many young adults with autism struggle with a few general things. These include getting a job that is a good fit for them, developing new social relationships, and advocating for their own needs. Many young people without autism struggle with these same things, too.

Learning practical skills for living independently, getting pleasure in life through rewarding leisure activities, and developing skills that will be needed at work will be important. Practice begins in childhood. Parents, children, educators, and therapists can all cooperate to form an education plan for children with a disability with this in mind. Occupational therapists outside of school can help, too.

While it’s best to build these skills throughout childhood, it is never too late to achieve greater levels of independence in adult life. Young adults with autism may launch into jobs, college, or romantic relationships years later than their peers. This is OK. The important thing is having life experiences in a way that is successful and satisfying, whenever it happens.

You mentioned jobs and employment. How can young people with autism prepare to enter the workforce for the first time?

Many young people, including people with autism, get a job before they turn 18. This is a great idea because it helps them learn how to show up when scheduled, work through a shift, and develop skills like how to interact comfortably with customers and co-workers. Sometimes, schools can offer internship placements during the teen years. Having previous work experience and references always puts a person in a better place when seeking a job next time.

Further, each state has a special division of human services designed to help people with disabilities get prepared for work and find jobs. Families should search for your state’s vocational rehabilitation department or division. People using the program work with a counselor to develop an individual plan for employment. The program then contributes funds to help people work through their plan, including actually helping them to get a job.
You mentioned social relationships, too. Can you give any helpful information for young adults with autism about making and keeping friendships? What about romantic relationships?

People usually make friends with others who are similar to them, so some of the most rewarding friendships may develop based on shared interests. For example, attending a board game group or volunteering at an animal shelter may be a good opportunity to meet friends. Try committing to a new group or activity for at least 3 months before deciding if it is a good fit. This is important because it may take a while to get used to a new activity and group of people. Other people will also need time to see that you are really interested, and to learn a little about you, before extending friendship.

Today’s young adults often find real friends in online interest groups or through online gaming. These are real friendships that sometimes turn into important relationships in real life, including life partnerships. Whether these are friendships or romantic relationships, however, it will help to be aware of your own communication strengths and weaknesses. You might talk about this with someone else who already knows you, and who you trust. In the relationship, letting the other person know you are on the spectrum, at a time that feels right to you, could help when social communication differences happen. It may also increase understanding in the relationship, overall.

Finally, please tell us more about self-advocacy.

Asking for what you need or want tends to be challenging for young adults with autism. There are a few reasons for that. One reason has to do with how hard it can be to know what you don’t know. You might make assumptions about how a job should be done, for example, only to find out that maybe you should have asked for help.

Another reason it might be challenging has to do with how you may have been treated across your life in our culture. People with good intentions may have communicated that your needs or behaviors are “not quite right.” This message can be repeated over and over in thousands of little ways during your early life, which can make it hard to consider that you actually could ask for things to happen in a different way. Figuring out what things you could ask for, and when and how to ask for them, will probably be another new challenge. It’s also an important opportunity to make your adult life into what you want it to be.

Getting Children Vaccinated and Staying Positive during the COVID-19 Pandemic

Vaccines are an important tool for controlling the COVID-19 pandemic. Children ages 5 years and older are now eligible to get a COVID-19 vaccination. COVID-19 vaccines are widely accessible in the United States. More information on COVID-19 vaccines can be found here: Benefits of Getting a COVID-19 Vaccine | CDC.

Tips for keeping younger children and anyone else in your household safe if they are not eligible to be vaccinated can be found here: Families and COVID-19 | CDC.

In the meantime, here are a few tips to keep you feeling positive:

• Think about your kids hugging their grandparents or other loved ones without worrying about anyone getting sick;

• Imagine taking your family on a fun vacation or day trip;

• Envision going to your favorite restaurant or concert without the need for a mask; and

• Consider a future where kids can attend school without COVID restrictions.