

SEED Study to Explore Early Development

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Navigating Social Events and New Experiences

The teenage years are a time of many physical, mental, emotional, and social changes. Teenagers begin to make more independent decisions regarding friendships. They may also begin to feel more prepared to handle increasing responsibilities in school. During these times, people with autism spectrum disorder (ASD) may have problems with social communication and interaction. Parents of adolescents with ASD may face unique challenges helping their child navigate social events and new experiences.

Below are some parenting tips for people with preteen or teenaged children:

- Talk with your child about the importance of having positive friendships. Meet and get to know your child's friends.
- If your child has social media accounts, periodically monitor their online presence. Remind your child of these items:
 - » Think twice before sharing or sending a social media post. It may be hard to control who sees the content.
 - » Don't feel pressured to accept random friend requests from people they do not know.
 - » Reach out to a parent or other adult if they encounter uncomfortable online chat messages, photos, or friend requests. Many social media platforms have a 'report' or 'block' function.
 - » Reach out to a parent or other adult if they experience online bullying.
- Encourage your child to join school and community groups, such as a sports team, or to volunteer for a charity.
- Talk with your child about respecting others. Talk with them about what to do when others are not kind or are disrespectful. Help them plan ahead for situations such as difficult conversations with friends or setting boundaries.

You can also visit these websites for additional resources:

- CDC's website for more parenting tips for all ages: www.cdc.gov/ncbddd/childdevelopment/positiveparenting/index.html
- Cybersecurity & Infrastructure Security Agency: [Keeping Children Safe Online](https://www.cisa.gov/keeping-children-safe-online)



Navigating Romantic Relationships

Navigating social relationships can also include romantic relationships. As teenagers mature and develop, they may also start experiencing romantic feelings or wanting to explore dating relationships. These relationships can be complicated for any teen, but they may be more complex for a teen who has ASD. To start the conversation with your teen, you might need to explain attraction. For example, when your child is attracted to another person, your child might feel a tingly sensation in their body, or your child might think about the other person a lot and want to be with them a lot. A [social story](#) might help you explain.

Below are some resources on dating and romantic relationships:

- "Tips for Romantic Relationships" from Pathfinders for Autism: <https://pathfindersforautism.org/articles/social/pfa-tips-romantic-relationships/>
- Strategies to promote healthy teen relationships: [Dating Matters® Toolkit | VetoViolence \(cdc.gov\)](https://www.cdc.gov/violenceprevention/datingmatters/toolkit/)

Navigating Social Events

In middle school and high school, proms and other school events may be meaningful and memorable occasions for preteens and teenagers. However, social settings can be overstimulating for teens with ASD. The following tips may help your child prepare for prom and other school events.

- Do your research into the arrangements. Are there staff and chaperones in case your child needs help? Have staff and chaperones been guided on how to work with students with special needs?



- Prepare your child about what to expect in terms of noise levels, flashing lights, and other sensory features. Perhaps ask the school organizers to consider scheduling a time for a sensory-friendly music playlist. Identify safe areas within the venue to decompress.
- Consider buying high-fidelity ear plugs that may be helpful for lessening excessive noise.
- Teach your child how to find bathrooms in an unfamiliar location. Visual cues may help with this. You may also contact the venue to find accessibility options and maps.
- Practice how to dance! For many teenagers, school dances may be the first time they will slow dance. Listen to a range of slow and fast dance songs.
- Finally, be positive and relax. Chances are, your child will have a great time!

Transitions through School

Transitioning to a new school can be a particularly stressful time. This may be more complex for a teen with ASD. Planning for the transition is a process that may involve several important people, including your child's teachers, school administration, social workers, and guidance counselors. Strong, consistent communication is the foundation for helping teachers understand your child and their learning needs. If your child has an IEP (Individualized Education Plan), review this with their team and work together.

New School Survival Guide

- Practice walking to each class before the new school year begins. Find important areas such as the bus stops, homeroom, bathrooms, the cafeteria, and the gym. You may also help your child practice how to read and navigate different room number formats.
- Practice using their locker.
- Review the school faculty web page together to help your child become more familiar with staff and faculty members of the school.
- Get a planner and get organized early. Organize a notebook with subject dividers for your child to keep homework and handouts in the right place.
- Seek out academic support or accommodations if needed. Bring the necessary paperwork to ensure that accommodation is provided if needed.

The Interagency Autism Coordinating Committee (IACC) has compiled toolkits and guides that provide guidance for teenagers

with disabilities on how to prepare for transition to adulthood: <https://iacc.hhs.gov/resources/transition/toolkits/>

The Organization for Autism Research (OAR) also has compiled comprehensive guidebooks for families of children with ASD. Topics include transitioning to adulthood and navigating the special education system:

<https://researchautism.org/families/guidebook-series/>

Check out these links to other resources related to teen development:

- [Information for Parents with Teens \(Ages 12-19\) | CDC](#)
- [Essentials for Parenting Teens | CDC](#)



Results Corner

Researchers working on the Study to Explore Early Development (SEED) continue to publish important findings related to ASD.

Check here for the latest findings of SEED studies:

<https://www.cdc.gov/ncbddd/autism/seed-research.html>.

One highlight of SEED data is included below.

SEED Teen

SEED Teen was a pilot study that surveyed families of more than 800 children who previously participated in SEED Phase 1. Children were between 12 and 16 years of age when their parents participated in SEED Teen. The goal of SEED Teen was to explore the changes in health, functioning, and service needs and use that occur between childhood and adolescence among children with and without ASD and other developmental disabilities. The information gained from SEED Teen helps us understand how we can better support teenagers with ASD and their families. SEED Teen included families from sites located in Georgia, Maryland, North Carolina, and Pennsylvania.

For this study, parents of teens were asked questions about their child. The questions were related to the teen's everyday activities, ASD symptoms (such as problems interacting with other people), general health status, problems moving their body or hands, problems with their stomach or sleep, problems with behaviors relating to emotions or other health concerns or conditions, and visits to a doctor in the past year.

In one study using SEED Teen data, researchers found that, when compared with teens without ASD,

- Teens with ASD were less likely to have excellent overall health. They were less likely to be able to talk with others.
- Teens with ASD were more likely to have problems using their hands for activities such as holding a spoon or pencil. They were also more likely to have problems moving their body.
- Teens with ASD were more likely to have other conditions, such as anxiety and attention deficit/hyperactivity disorder (ADHD).
- Teens with ASD were more likely to need, but not get, different types of health care.
- Most teens with and without ASD did not talk to their doctor about changing to adult care.

These findings are important because teens with ASD need support but may not get the help they need. It is important for all teens—including those with ASD—to talk to their doctor about how to get the help they need now and when they become an adult.

NEW STUDY OPPORTUNITY: SEED Follow-Up

The goal of SEED Follow-Up is to better understand children with and without ASD as they mature. To accomplish this goal, SEED Follow-Up will survey families of children who were previously in SEED Phase 1, 2, or 3 (when they were 2–5 years of age) when they are 8–21 years of age to learn more about them through adolescence and young adulthood.

- SEED is inviting families who have already completed SEED Phase 1, 2, or 3 to take a survey online, by phone, or mail. The participating sites for this new component are California, Colorado, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, and Wisconsin.
- Additionally, some families will be invited to test their child's cognitive abilities in person. These assessments will be done with the study team in the following states: Colorado, Georgia, and Maryland.

In Maryland, the in-person assessments will be conducted by study investigators Dr. Rebecca Landa and Dr. Christine Hess at the Kennedy Krieger Institute Center for Autism and Related Disorders (KKI-CARD), located in Baltimore, MD.



In Colorado, the in-person assessments will be conducted by Dr. Nuri Reyes. The Colorado clinic is located at JFK Partners at The University of Colorado Anschutz Medical Campus in Aurora.



In Georgia, the in-person assessments will be conducted by Dr. Lisa Wiggins. The Georgia clinics are located at the Whiteford Health Center and Peachtree Pediatric Psychology in Atlanta.



Invitations to this new and exciting phase of SEED will come out in summer 2023!