

SEED

Study to Explore Early Development

Summer 2024 | Volume 25

Summertime Fun For All Ages

Summer is a great time to try new things and spend extra time together as a family, especially outdoors. Below are some ideas of things to do at or near home with your kids. Don't forget the sunscreen!



3–8 years old

- Ride bikes together
- Go swimming
- Camp in your backyard
- Set up a lemonade stand
- Go fishing
- Draw chalk art
- Blow bubbles
- Make homemade popsicles
- Go on a bug hunt
- Have a picnic

9–12 years old

- Camp in your backyard
- Explore in your neighborhood
- Learn to cook or bake something simple
- Stargaze
- Set up and run through a backyard obstacle course
- Create a scavenger hunt
- Play card games or board games
- Have a water balloon fight

13–19 years old

- Relax in a hammock
- Try a new sport
- Plant a garden
- Read a new book
- Learn to play a new game such as Chess or Spades
- Clean up litter along your street

20–23 years old

- Start or join a book club with your child
- Plant a garden
- Have your child teach you how to play their favorite video game
- Do an exercise video together
- Try meditation



Things to do away from home

- Play mini-golf
- Visit a local park or state park
- Visit a farmers market
- Go for a hike
- Visit a museum
- Plan a road trip
- Go antiquing or thrifting
- See a concert
- Find your local community garden and work together at it
- Volunteer together at a local rescue mission or food bank
- See an outdoor movie



Things to do locally

Colorado

See the wildflowers along many Colorado hiking trails:
<https://www.uncovercolorado.com/hiking/>

Colorado Renaissance Festival:
<https://www.uncovercolorado.com/events/colorado-renaissance-festival/>

Explore the natural world at the Denver Museum of Nature and Science:
<https://www.dmns.org/>

Georgia

Cool off at a splashpad or spray ground:
<https://mommypoppins.com/atlanta-kids/11-cool-spray-grounds-and-splash-pads-around-atlanta>

Atlanta Ice Cream Festival:
<https://www.atlantaicecreamfestival.com/>

Stay cool in the shade at the Summer Shade Festival:
<https://summershedefestival.org/>

Maryland

Visit the Maryland Science Center:
<https://www.mdsci.org/>

Learn about sea life at the National Aquarium in Baltimore:
<https://aqua.org/>

Go to the Cherry Hill Festival:
<https://cherryhillfest.com/>

Missouri

Stroll through the Missouri Botanical Garden:
<https://www.missouribotanicalgarden.org/>

Visit Legoland:
<https://www.legolanddiscoverycenter.com/kansas-city/>

Tour the Gateway Arch:
<https://www.gatewayarch.com/plan-your-visit/>

North Carolina

Festival for the Eno:
<https://enofest.org/>

Visit the Blue Ridge Parkway:
<https://www.blueridgeparkway.org/parkway-maps/>

Visit the Greensboro History Museum:
<https://greensborohistory.org/>

Pennsylvania

Use your imagination at the Crayola Experience:
<https://www.crayolaexperience.com/>

Explore at the Please Touch Museum:
<https://www.pleasetouchmuseum.org/>

Learn about science and technology at The Franklin Institute:
<https://fi.edu/en>

Wisconsin

Take in scenic views down the Wisconsin River Road:
<https://www.wigrr.com/>

Visit the Wisconsin Dells:
<https://www.wisdells.com/>

See the AirVenture Show and Museum:
<https://www.eaa.org/airventure>



Tips For Helping Your Child Get Their First Job

As your teen or young adult begins thinking about a job, there are some general things to consider as well as some age- and ability-specific factors to consider. Young people with little or no work experience need to build skills and may have different needs at different periods in their lives.

For example, preparing to get a summer, or temporary, job might be a bit different from preparing to obtain a full-time or career-focused job. Temporary or summer jobs can help your teen or young adult build skills to support a longer-term career.

General things to consider before looking for jobs include the following:

- » What are your child's **strengths and interests**?
- » Do they need **part-time or full-time work**?
- » Do they need a **resume**?
- » Do they need or want **benefits** such as paid leave time or health insurance?
- » Do they need any **special accommodations** in the workplace?

Strengths and Interests

Does your child have any general or specific ideas about the types of jobs they want to do? Helping your child understand how their strengths do (or do not) overlap with their interests will help them set realistic ideas about the types of jobs to seek.

If your child does not have enough skills yet to get the job they want, they can do things to help build skills, experience, and/or qualifications for jobs. Your child might also need help developing communication, social, and organizational skills needed to be successful in the workplace. These are called “soft skills” and they are important for all jobs.

Skill-building options are available for young people with or without autism or other special needs. Here are some online help options:

- An employment support service, such as
 - » [Ticket to Work or other job training and employment programs](#) for people with disabilities
 - » The [U.S. Department of Labor's Employment and Training Administration \(ETA\)](#), which supports a wide variety of programs to ensure that all youth have the skills and training they need to make a successful transition to adulthood and careers
 - » [Career One Stop](#), sponsored by the U.S. Department of Labor, which has resources to help build skills and credentials to advance their career
- A university or technical education course or vocational education or training
 - » Start with your local community colleges or your state's Department of Labor
- A training program run by a disability support agency
 - » Start with your state's Department of Health and Human Services
 - » Or contact a national agency such as [Easter Seals](#) or [The Arc](#)
- A volunteer organization, club, or other organized activity to help your child build skills such as teamwork, problem-solving, and social skills
 - » Start by asking your school guidance counselor for available programs at your child's school or in the local community
 - » Visit a training website such as [Youth.gov](#)
- Support and advice from a mentor
 - » If there is a family member or adult family friend who works in an area of interest to your child, see if that person would be willing to talk with your child or allow your child to shadow them at work for a short period to see what their job is really like.

Part-Time vs. Full-Time Work

If your adult child has a disability and is receiving social security benefits, it may require careful planning. Consider seeking benefits counseling resources in your area or start with the [Social Security Administration](#).

In general, when deciding between part-time or full-time work, consider these things:

- Your child's existing school schedule or family commitments
- Your child's ability to sustain effort or concentration for long periods of time
- Your child's need for transportation assistance to get to and from work

Any or all of these might influence the types of jobs your child could apply for.

Resume Writing

A resume is a way to organize your child's personal details, experiences, and qualifications into a format that is easy to read. A resume is often the first impression a potential employer gets of a job applicant. Some tips for a good resume:

- Keep the format simple and easy to read.
- Make sure the contact details are up to date.
- Tailor the resume to suit the job your child is applying for.
- Focus on the positives—your child's strengths, abilities, and achievements.

For more tips, see: <https://www.indeed.com/career-advice/resumes-cover-letters/resume-examples-for-teens>

Talking About Special Accommodations

Self-advocacy means knowing your strengths and needs and having the skills to talk about what you need in the workplace. Your child can learn self-advocacy skills to help them speak for themselves about what they need to be successful at work. An online tool to locate self-advocacy learning resources by state is available at Self Advocacy Online.

<https://www.selfadvocacyonline.org/find/>

Ask An Expert: Feeding / Food Questions For Families of Kids With Autism

Adrienne A. Harris, PhD, is a licensed psychologist and clinical assistant professor at the Carolina Institute for Developmental Disabilities, a University Center for Excellence in Developmental Disabilities at the University of North Carolina at Chapel Hill (UNC). Dr. Harris completed her doctorate in psychology and neuroscience at Duke University with a focus on eating disorders and autism. She completed her predoctoral internship and postdoctoral fellowship at UNC where she was a LEND fellow (Leadership Education in Neurodevelopmental and related Disabilities). She has more than 20 years' experience in research and clinical work focused on intellectual and developmental disabilities. We asked her to talk about some of the major issues facing families with respect to food and eating for their children on the spectrum.

1. Are kids with autism more susceptible to feeding issues or eating challenges? Why?

Yes! While prevalence rates vary, research suggests that more than half of autistic individuals have some feeding or eating challenges. The "why" behind those can vary and often has more than one answer. There can be physical issues related to motor planning, swallowing, allergies, reflux, and gastrointestinal differences. There can also be more intense sensory experience of and response to certain textures, smells, or tastes of foods. There can be fear of new foods or insistence on sameness or predictability in foods such as the way their food is presented (having a plate they prefer, not wanting things touching). Children on the spectrum may also be less aware of their internal cues (for example, hunger, fullness) or have more difficulty with transitioning to or away from eating. These systems also work together. For example, if a child is constipated or has reflux, eating might become uncomfortable so they start to avoid eating or eating certain foods.



2. What are the most common challenges around food and eating encountered by parents of kids with autism?

Every family faces different challenges, especially in terms of allergies, gastrointestinal (GI) issues, or other possible medical complications that might lead to tube feeding. Some of the most common challenges include highly selective eating (for example, only wanting a few specific foods or types of foods), rules or preferences around when, how, or what meals look like, food refusal, and related behaviors. These can have a big impact on nutrition and health, family stress, mealtimes, travel, school readiness, and budget.

Another common challenge parents face is judgment, comments, or advice from other family members, providers, or people in their community regarding their child's eating habits or preferences.

3. How can parents support their selective/picky eater? What are some tips or tricks parents can try?

The extreme selective eating, rigidity, or mealtime behavior sometimes found in autism can be different from just standard "picky" eating. In addition to the tips below, it's important for parents to (a) take a breath, find support, and know this is hard (you are doing your best!) and (b) check with your child's providers and get an evaluation to make sure there aren't any medical, physical, or additional sensory factors that may be contributing to food refusal or mealtime behaviors.

1. Encourage

- Curiosity around new foods, textures, tastes, smell.
 - » What textures does your child like? If trying to increase variety, start with new foods similar to ones they already like (for example, a different type of crunchy cracker).
 - » Is there a way to incorporate a food related to one of their interests?
- Coping skills.
 - » Sometimes children experience heightened anxiety around eating or new sensory experiences. It can be helpful to find a few relaxing or calming activities and practice those outside of mealtime so that they can use them more effectively at the table.

2. Avoid

- Prompting, force feeding, bribery.
 - » While these are natural impulses, allowing children some element of choice in what they eat can be helpful in building eating independence and trust.
- Hiding foods.
 - » While it can be helpful to add calories via additives at times, "sneaking in" veggies or other foods may backfire and lead to more suspicion around food.
- Commenting on your child's pickiness or responding to your child's disruptive mealtime behaviors (as long as everyone is safe).
 - » Keeping calm and highlighting what is going well, focusing on non-food interactions, can be a helpful way to reframe the focus of mealtime.

3. Try

- Routine.
 - » Try regular meal and snack times. Avoiding grazing, and having a clear routine around mealtime can help children become more aware of hunger cues and potentially reduce behaviors related to transitioning to or away from mealtime.
 - » Visual schedules, menus, and timers can be helpful as well.
- Plating.
 - » Presenting a plate with ample preferred foods as well as a new food. (Children may need to be exposed to a food more than 15 times before they engage with it.) This way the child always has some choice and options.
 - » If your child will only eat from a certain plate or if their foods cannot be touching, maybe start with having another plate with new food nearby.

4. When should parents seek help? What kind of help should they seek?

Parents should reach out to their pediatrician or other providers about any nutritional or feeding concerns (for example, limited independent feeding, difficulty weaning, long mealtimes, choking, gagging) as soon as they have them. Having a comprehensive evaluation to understand any potential contributing physical or medical factors is an important first step. Following that, your family might work with a team or a range of specialists including speech language pathologists, occupational therapists, physical therapists, gastroenterologists, and/or psychologists who specialize in feeding and eating concerns. For some kids, feeding difficulties start at birth and new challenges arise with each transition (for example, bottle to puree, puree to solid) while for others their intake may suddenly drop off or there can be problems with eating too much. If mealtime has become a major stressor, you have concerns about your child's nutritional intake, or your child seems to have issues with eating or food, we encourage getting help.

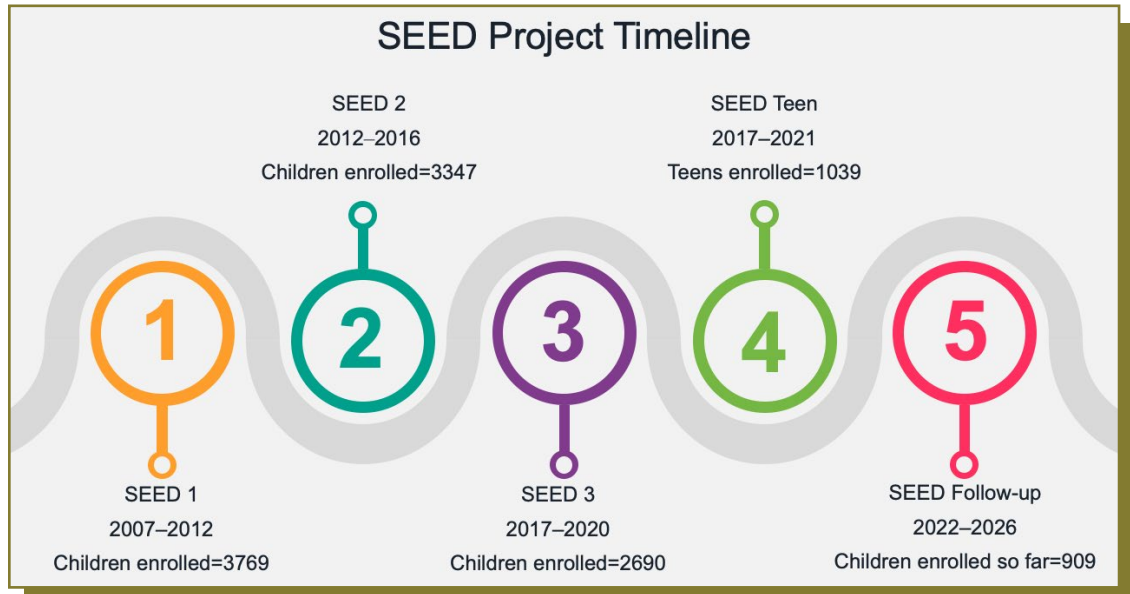
Additional resources

- Autism Speaks Guide to Exploring Feeding Behavior in Autism: <https://www.autismspeaks.org/tool-kit/exploring-feeding-behavior-autism>
- For Children with GI issues: <https://gikids.org/>
- Feeding Matters: <https://www.feedingmatters.org/>
- Nutrition by Life Stage: <https://www.nutrition.gov/topics/nutrition-life-stage>
- Setting the Table for Healthy Eating: <https://www.fda.gov/food/nutrition-education-resources-materials/health-educators-nutrition-toolkit-setting-table-healthy-eating>

SEED Updates – From Past to Present

The [Study to Explore Early Development \(SEED\)](#) has a long history. In 2007, SEED sites in California, Colorado, Georgia, Maryland, North Carolina, and Pennsylvania enrolled their first study participants. From 2007 to 2012, 3,769 children and their caregivers enrolled in the first phase of SEED ([SEED 1](#)). Data for the second phase of SEED (SEED 2) were collected from 2012 to 2016, enrolling an additional 3,347 children and caregivers. For the third phase of SEED (SEED 3), California and Pennsylvania sites did not participate and Missouri and Wisconsin sites were added, enrolling another 2,690 children to the study from 2017 to 2020. Data collection for SEED 3, which required in-person visits, stopped early due to the COVID-19 pandemic. However, a SEED [COVID-19 Impact Assessment](#) was conducted between January and June 2021 with families who had already enrolled in SEED 3. A few SEED sites received additional funding to contact former SEED 1 participants from 2017 to 2021, as they had become teenagers ([SEED Teen](#)). SEED Teen enrolled 1,039 teens and their caregivers.

Currently, all SEED sites are conducting a follow-up study called [SEED Follow-Up](#), and are contacting families who participated in the three earlier phases of SEED (SEED 1 to 3) to see if they would like to join the follow-up study. The SEED Follow-Up study consists of completing surveys online, by phone, or by mail. Data collection will continue until 2026, and we hope to enroll as many SEED families as possible. This information will help us better understand the needs of families as the children who originally participated in SEED 1-3 become adolescents and young adults. So far, we have enrolled 909 families, and 487 have completed their surveys.



Please visit the [SEED Follow-up Study](#) website to see a video that we created to encourage young adults to participate in the study.

We are grateful to [Autism Improvised](#) for working with us to create this wonderful video.