

SEED Study to Explore Early Development

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The Study to Explore Early Development (SEED) Newsletter goes to a variety of households with children and young adults with and without disabilities. We strive to change the focus for each issue of the newsletter and include tips that are relevant for children and teens. Stay tuned for more newsletters to come.

SEED Follow-Up Update

Recruitment has begun for SEED Follow-Up. The goal of this follow-up study is to better understand children with and without autism spectrum disorder (ASD) as they grow older. We also want to learn more about the successes and challenges faced by SEED families since their initial participation. We have partnered with Chickasaw Nation Industries (CNI) to contact eligible families who previously participated in SEED Phases 1, 2, and 3 about an opportunity to take part in a follow-up survey. This survey can be completed online, by phone, or by mail. We hope that you consider participating in this important and meaningful study.

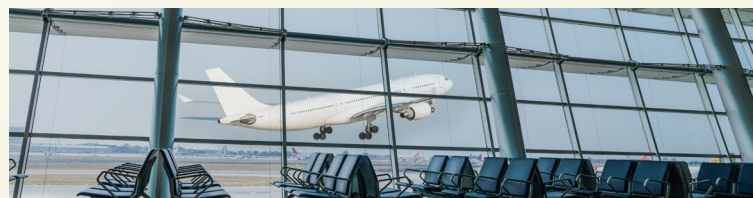
Traveling with Children with Special Healthcare Needs

Children with special healthcare needs can face additional difficulties while traveling. Their routine may be upended, they may find themselves in an unfamiliar environment, and they may face new sights and noises that could lead to overstimulation or meltdowns. Not only that, different methods of travel also bring different challenges. Luckily, with a bit of extra planning, you'll be able to figure out what is best for your family and how you can support your child during travel to make it a positive experience for everyone involved.

Preparing for Travel

- Make sure you have enough medication for the entire trip beforehand. Take any doctor's notes and/or documents that you may need.
- Anticipate your child's needs and bring things such as allergy and pain medications in case they are needed.
- Create a picture or video story of the upcoming trip that shows difficult to navigate scenarios such as air travel or going to a theme park. This will help make the trip process more predictable for your child.

- Simulate the vacation as closely as possible in as many ways as possible—show pictures or movies of the location or search the Internet together; teach your child what to expect before you go; or make a calendar to count down the days until the trip.
- Tailor the vacation to your child's interests—plan activities you think they would enjoy as a way to get them to try new experiences.
- Limit the number of things you do each day and plan for downtime at the hotel.
- Consider traveling with groups that arrange and coordinate travel for special needs families.



Traveling by Airplane

TSA Cares is a helpline that provides additional assistance during the airport security screening process for travelers with disabilities, medical conditions, and other special circumstances. Anyone flying on any airline may contact TSA Cares within 72 hours of travel with questions about screening policies, procedures, and what to expect at the security checkpoint. You may call (855) 787-2227 or [submit an online form](#) to request assistance from TSA Cares.

Other tips for traveling by airplane:

- Cross-reference your takeoff time, length of flight(s), and possible layovers against your family's daily routines and plan for the least disruptive timing.
- Consider where your child would prefer to be seated. Would they enjoy looking out the window or prefer an aisle seat? Is having easy access to the restroom on the airplane important?



- If feasible, visit the airport before the trip to simulate what would happen when your child goes through security, step by step. (The Arc’s Wings for Autism Program holds rehearsal events periodically around the country).
- Alert security about your child’s needs.
- Pack items for your child to pass the time on the airplane, such as new crayons and a coloring book, blocks, or play dough.
- Download a new game, show, or movie to your phone or tablet before travel so your child can play or watch during the flight.
- Request bulkhead seats in advance to have more space.
- Pack some gum or hard candy in your carry-on luggage (this is particularly helpful if your child has difficulty telling you if their ears need to pop).
- Be patient with your child. Even with good preparation, travel by airplane may not be easy for some kids.

Lodging

- Start small—try one night in a nearby hotel or plan an overnight at a friend’s house before attempting a longer vacation.
- Call ahead and request adjoining rooms or anything special you might need.
- Take your child’s familiar bedding and blankets.
- Request a room away from the elevators and ice machines or at the end of the hallway to minimize noise.
- Consider staying in a rental where you can prepare your own food.

Safety

- Be sure your child is wearing identification—include the child’s name and diagnosis, your cell phone number, and anything a person might need to keep your child safe and calm until you are reunited.
- Carry a recent photo of your child to show police in case you become separated.

No matter your method of travel or means of lodging, it is important to make sure your child knows what to expect. Remember, there is no “one size fits all” approach. You may try different techniques for your child and see what method best suits their needs.

You can visit these websites for additional resources:

- <https://www.luriechildrens.org/en/blog/travel-tips-for-children-with-autism-how-to-prepare-for-air-travel/>
- <https://www.autismspeaks.org/traveling-autism>
- <https://www.theautismconnection.com/blog/special-needs-parenting/how-to-travel-with-kids-with-autism/>
- <https://autismtravel.com/2022/01/19/lets-fly-air-travel-tips/>
- [Travel Tips - Six Tips for Traveling with an Autistic Child - TIME](#)

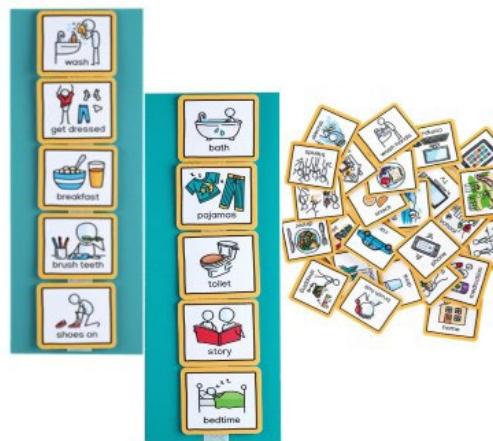


Supporting Children During Family Events

The holidays can be a very stressful time for all families, especially for families who have a child with special healthcare needs. Routines are disrupted, more people are present, and expectations are high for children to perform in certain ways. Katy Tepper, PhD, a clinical psychologist with Missouri SEED at Children’s Mercy Kansas City, responds to some frequently asked questions from families about how to handle the exciting, yet challenging, holiday season.

How can I prepare my child for a holiday gathering?

Start by discussing the event with your child in advance. It may be helpful to use visual aids and create a social story to explain what to expect.



What can I do if a family member insists on hugging or kissing my child, but my child doesn’t want to?

This can certainly be a challenging conversation to have with family members, particularly when they are insistent on hugs and kisses even when children are uncomfortable. This is an appropriate time to explain to family members that you respect your child’s boundaries and they do not want to hug or kiss. If your child is comfortable,

you can suggest that family members offer a high five or fist bump instead. If your child is able, encourage them to advocate for themselves by suggesting a greeting that feels comfortable. If not, you can explain (or support them in explaining) that they are most comfortable with a wave or smile. It is also important to remember that you are your child's best advocate, so preparing family members in advance for ways your child would like to interact can decrease the pressure for your child during the actual event.

What can I do if my child becomes overstimulated at an event and needs to take a break, or we need to leave early?

It is always stressful when a child gets overwhelmed at an event. If your child needs a break, just mention to someone close to you that you are going to step out and that you will be back shortly. If you need to leave early, share what you are comfortable with, but remember that you do not owe anyone an explanation and you know your child best. When your child is calm and regulated, it is important to reinforce that they did a good job at the event. It is not helpful to dwell on the fact that it was overwhelming for them. Additionally, encourage your child to advocate for themselves if they need a break by using strategies similar to those you would use at home.

My child is a picky eater, and mealtimes are a struggle for us. How can I support them during meals when family members pressure them?

This is certainly another challenging question. It could be helpful to bring a preferred food item for your picky eater, so they have a food that is known to them and that they are comfortable eating.



Again, you can assist family members in understanding that eating new foods can be challenging for your child and that you respect their boundaries regarding food choices. You can request in advance that family members not comment on your child's food choices and remind them in the moment if it comes up. In addition, practicing self-advocacy during family meals with your child prior to these events can be helpful to give them confidence in advocating for themselves in unfamiliar situations.

My child thrives when we stay in our routine, but we get a lot of pressure from family to change our routine to fit with family events. How can I best support my child?

Prepare your child for any changes in the schedule ahead of time and establish a visual schedule to help them anticipate what comes next. Try to keep schedules as predictable as possible during family events and assist family members in understanding how predictability and routines help your child to function to their fullest potential. It may also be helpful to schedule downtime for your child to enjoy preferred activities and allow them time to recharge.

How can I handle meltdowns or sensory overload at the gathering?

Have a plan in place for a quiet space where your child can decompress. Be prepared to offer sensory input or calming techniques that are helpful for your child. Remember, every child is unique, so it's important to observe and respond to your child's individual needs and preferences. Additionally, allowing and providing support for your child to advocate for themselves in these situations can be helpful and empowering. Open communication and planning can go a long way in creating a positive experience for everyone involved.

Additional Resources:

- <https://www.marcus.org/autism-resources/autism-tips-and-resources/reducing-holiday-stress>
- <https://childmind.org/article/how-to-take-the-stress-out-of-the-holidays/>
- <https://health.choc.org/tips-to-foster-a-happy-holiday-season-for-children-with-autism/>



Learning Through Everyday Activities: Cooking with Children

Below is a fun and easy wintery recipe for pretzel sticks that you can make with your child and even give to friends. It also includes tips on how to target specific skills that your child may work on during each step of the recipe.

Tips for cooking with children with special healthcare needs:

- Children with sensory issues can wear non-latex medical gloves to avoid touching unpreferred textures. You might want to keep a food journal to better understand what triggers your child's sensory sensitivities and find solutions or adaptations. For example, a longer spoon can create distance between the child and a specific food that they might not prefer.
- Motor skills play a huge part in the kitchen, and cooking provides an opportunity to train and develop hand strength and hand-eye coordination. Hand-over-hand support should be provided to ensure that your child does not develop incorrect motor habits. Alternative utensils, such as a garlic twist instead of a garlic press, can even be used to make your child's experience less challenging.
- Prepare for sensory challenges but be creative! When a child has a food aversion, it's typically based on the texture or the presentation of the food or meal. For example, if your child might not like poached eggs because of the liquid yolk, try scrambled eggs. You could also switch metal bowls and utensils for rubber and plastic, which make far less noise.



Recipe for Snowflake Pretzel Pops (for ages 5 and older with adult supervision)

The full recipe can be found on the Hungry Happenings Website: <https://hungryhappenings.com/snowflake-pretzel-pops-frozen-party-treats/>.

Step 1: Gather ingredients.

You will need a bag of candy melts (for example, white, blue, red, or green), 18 pretzel rods, and a jar of mixed wintery sprinkles for each batch. During this step, you can work on:

- **Counting:** Encourage your child to count the pretzel rods.
- **Vocabulary:** Label each ingredient and describe it as you prepare it, such as “blue snowflake” or “brown pretzel.”

Step 2: Prepare the pretzel pops.

Melt the candy melts according to directions on the package. Pour the melted candy into a tall glass, then dip one pretzel at a time. After waiting for the excess to drip off, roll in the wintery sprinkle mix that has been spread on a plate. Set on a baking sheet lined with parchment paper or wax paper. During this step, you can work on:

- **Following directions:** List items needed including the utensils and ingredients in their full form (for example, say one bag of [color] candy melts etc.). Narrate what you are doing or ask your child to tell you which order to do things in, such as, “First, we pour the sprinkles onto a plate, then we melt the candy melts,” or prompt them to carry out certain steps, such as, “Dip the pretzels into the melted candy.” This teaches your child that they don't have to memorize how to do a task, they can simply write the instructions and refer to them as they go.
- **Motor skills:** Let your child try to use their fingers to apply larger sprinkles.
- **Sensory and motor skills:** Your child may not be able to resist playing with the sprinkles (with washed hands!) on the plate.

Step 3: Serve and eat.

Allow the pretzel pops to dry completely before serving. Store in an airtight container. During this step, you can work on:

- **Social skills:** Ask your child about their favorite part of the recipe or encourage them to share this treat with others.
- **Vocabulary:** Describe the pretzel pop with words like “crunchy,” “salty,” or “sweet.”



**Wishing you and your family all the best
this holiday season! Happy New Year!**