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Spring/ Summer 2020

Volume 8, Issue 2

Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

Challenges and Tips for Summer on the Autism Spectrum

By Lisa Jo Rudy

Summer is challenging for most families with young children. For families with [autistic children](#), the challenges increase dramatically. Fortunately, families have a wide range of options for summer programs, as well as a long list of tips and tools for making summer more fun and less stressful.

WHAT'S SO CHALLENGING ABOUT SUMMER?

Many parents face summer with a combination of excitement and dread. On the one hand, summer means more time with the kids; on the other hand, summer means more unstructured opportunities for kids to get bored or, worse, get into trouble.

For working parents, summer can mean a stressful rush to find a summer camp program that's fun, affordable, and reliable. Parents with autistic children face a very different and more imposing set of challenges.

Loss of Structure and Routine

For children with autism, structure and routine are synonymous with comfort and security. Provide it, and life is predictable and manageable. Withdraw it (as happens every year in June) and the world turns upside down. When children with autism feel stressed and anxious, they typically show their feelings through behaviors that can be difficult or even impossible to manage.

Continued on page 2.



Loss of Therapies and Supports

Most children with autism have in-school programs or therapies that are paid for by the school district. These may include intensive or modified [applied behavioral analysis](#) (ABA), [speech therapy](#), occupational therapy, and/or [social skills therapy](#). Children may also have 1:1 aides in school who are able to manage difficult behaviors. At the end of the school year, these supports and therapies may disappear (though some families are able to continue to access some therapies throughout the calendar year).

Difficulty With Finding Appropriate Programs

School districts are required by law to provide [extended school year](#) (ESY) programs during the summer to students who might regress without them. These programs, however, are rarely full-time and are unlikely to include all the elements of a school year program. Meanwhile, typical summer camps are unlikely to say "yes" to including a child with more than a very mild version of autism spectrum disorder. Special needs camps and programs are increasingly available in some areas, but they are not available everywhere and may not be appropriate for your child's needs.

High Costs Associated With Appropriate Programs

Even if you do find a summer camp or program for your child, chances are the costs will be much higher than they would be for a typical child. That's because autistic children often need much higher counselor: camper ratios, and may also require specialized care. Another alternative, sending a child to a typical program with an aide, may cost you almost as much as "special needs" camp.

Stress Related to Childcare

In some families, a parent or other caregiver is able to stay home with the children over the summer. With an autistic child, this can be a very stressful experience. Not only is it often difficult to care for an autistic child and keep him or her occupied, but having an autistic child in the family can make whole-family outings more difficult.

Challenging Vacations

Summer vacations are supposed to be a time for relaxation, though many parents find vacations to be stressful. Parents of autistic children can be overwhelmed by the challenges of leaving home with an autistic child, navigating restaurants and hotels, and at the same time finding opportunities for fun with siblings. Add to that the stress of feeling judged by extended family or other vacationers, and you may need a vacation from your vacation.



HOW TO OVERCOME SUMMER CHALLENGES

Luckily, you know exactly when summer is coming and how long it lasts. That means you can plan for success well ahead of time and have all your ducks in a row when the last day of school arrives. It also means you can prepare your child and his or her support staff with plenty of time to spare. Here are some tips for making the experience less stressful and more successful with each succeeding year.

1. **Start early.** Start researching your options in September. Start conversations and plans before Christmas. Have your ducks lined up by the end of February. Start preparing your child and others by April. Slide into summer with less stress in June

Continued on page 3

CHALLENGES AND TIPS FOR SUMMER CONTINUED....

2. Understand and apply for ESY. Extended school year programming is almost certainly available to your child, but parents aren't always well informed about the process by which children are evaluated for ESY. In addition, while some districts offer full-day ESY, others offer just a few hours while yet others are willing to provide support to children in non-school settings such as summer camp. All should provide at least some therapy (often speech, ABA, and/or occupational therapy) during the summer months.

Ask questions, and check-in with other parents to find out what services they have been able to access. Districts may not tell you how to access services, so it's up to you to know your rights and options. [Wrightlaw](#), a premier website providing advice to special needs parents, says:

"If you have questions about a legal issue, you need to do your own legal research. This is especially true for extended school year because courts in different states and federal circuits have issued decisions that create different standards, and the standards for ESY have changed quickly. "

3. Build a summer routine. If you have a child with autism, you may need to forgo summer spontaneity—at least for a few years, until your child is able to go with the flow. Rather than making plans day by day, [know what you'll be doing every day and every week](#). Mark plans on a calendar (or use a visual daily chart) and go over tomorrow's plans with your child. If you're doing something unusual, use pictures and social stories to help your child prepare. If your activity is weather-dependent, have an alternative in mind and share it with your child ahead of time (if it's sunny we'll go to the pool; if it's rainy we'll go to the library).

4. Find, create, or pay for support. Parents with autistic and typically developing children have a unique challenge in the summer: how do you provide your typical child with ordinary summer fun while also supporting an autistic sibling? The obvious answer is "divide and conquer," meaning splitting the children up and having one parent take each child. Sometimes, however, that simply isn't feasible. Another option is finding a friend or relative interested in spending time with [your typically developing child](#) (it can be wonderful for a typically developing child to get special time with Grandma, for example). If you have the money or funding, you can also hire a student or even a teacher to spend time with your autistic child while you enjoy some much-needed respite.

5. Consider camp options. Special needs camps can be very pricey, but in some cases scholarships are available. In addition, some organizations, such as the Y, JCC, and Rotary, will accept special needs campers on a limited basis at a reasonable fee. If your child is willing and a camp is available, say yes! Bear in mind that such camps may not advertise; you may, therefore, need to do some research to [discover opportunities](#) for your child.

6. Plan vacations carefully. It's tempting to just "go on vacation," intending to discover and explore new destinations as you go. But if you have an autistic child along, a spontaneous vacation is a recipe for disaster. Sure, you can have downtime (in fact, you'll certainly need it) but even on a beach vacation, most kids with autism need a clear schedule and plan. This goes double for vacations that include extended family who are not already very familiar with and comfortable with your autistic child. Know exactly what will happen each day, and have alternate plans already in mind in case of an autistic meltdown or unexpected setback.

7. Become your child's therapist for a few months. While most parents aren't eager to become full-time therapists, there are forms of therapy that parents can take on while also enjoying quality time with their children. Read up and watch videos on play therapy, [Floortime](#), or the Hanen speech method (to name a few options) and learn how to turn ordinary together time into a therapeutic session. Even if your child doesn't have formal therapy over the summer (and he should, through ESY!), he'll learn a lot from his time with you.

8. Build "me time" into your summer. Spending quantities of time with an autistic child can be rewarding, but it can also be frustrating and exhausting. To be your child's best advocate, therapist, caregiver, and parent, you need time to step away and recharge. That may mean arranging your time to take advantage of ESY hours, or, if that's not an option, spending a little extra money for a babysitter who "gets" your child. Either way, don't allow yourself to become so overwhelmed that you're not able to be fully present for your child.



<https://www.verywellhealth.com/challenges-and-tips-for-summer-on-the-autism-spectrum-4163801>

'I know you feel invisible. I see you running your child to therapy when friends take their kids to Little League. I see you cringe when people whine about petty things that pale in comparison to your day':

Mom pens touching letter to special needs parents By: Alethea Jo, Writer

"Dear Special Needs Mom,

I want you to know that I see you.

I see you running your child to therapy when your friends are running their kids to Little League.

I see you slipping out the of conversation when your friends are all chiming in about milestones and test grades.

I see you juggling appointments and meetings, always making sure you do the best for your child.

I see you sitting at your computer for hours researching what your child needs.

I see you cringe when people whine about the petty things that pale in comparison to your day.

I see you spread thin, but still going the extra mile for your family, and managing to do it with a smile.

I see you digging for depths of strength you never dreamed you had.

I see you showing appreciation to the teachers, therapists and medical professionals who serve your child with you.

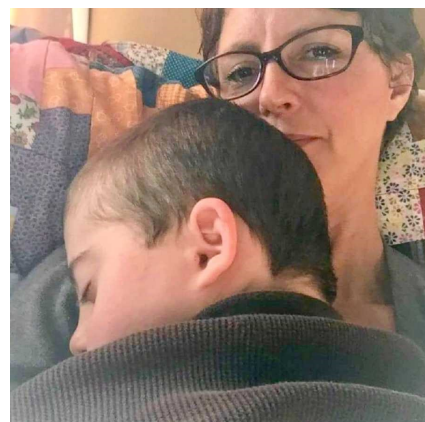
I see you reluctantly rising early in the morning to do it all again after another chaotic night.

I see you when you're hanging on to the end of your rope for dear life.

I know you feel invisible, like nobody notices any of it. But I want you to know that I notice you. I see you in the trenches, relentlessly pushing onward. I see you keep choosing to do everything in your power to give your child the best possible care at home, in school, at therapy, and the doctor. What you're doing matters. It's worth it. On those days when you wonder if you can do it another minute, I want you to know that I see you. I want you to know that you're beautiful. I want you to know that it's worth it. I want you to know that you aren't alone. I want you to know that love is what matters most, and you have that nailed.

And on those days when you have breakthroughs, those times when the hard work, pays off and success is yours to cherish, I see you then too, and I am proud of you.

Whichever day today is, you're worthy, you're good, and I see you."



How Families of Individuals with Autism Can Meet Pandemic Challenges

The COVID-19 crisis has changed many lives in unexpected ways. Families of individuals with autism are navigating new challenges including increased stress and disruptions to routine. As some regions begin to lift their stay-at-home orders, families are confronting a new normal that may include wearing face masks and a greater focus on hygiene.

Children with autism look to their parents and caregivers for help adjusting to these new challenges. At the same time, parents and caregivers may struggle with personal feelings of confusion and anxiety. It is important to remember that you are not alone in helping your loved one navigate the challenges of the pandemic. Your care team can provide help and support during this difficult time.

CONTINUED PANDEMIC DISRUPTIONS TO ROUTINE CAN TRIGGER ANXIETY

Anxiety is a [common comorbidity](#) among people with autism and can contribute to behavioral issues. New situations or changes to routine may increase anxiety. When stay-at-home orders first went into effect, many families had to adjust to new schedules and routines. Now, as the orders change, families are being challenged again. People with autism may struggle to understand why the requirements keep changing. Caregivers and care teams can help them handle this challenge.

Here are three ways you can [help your child with autism reduce anxiety](#) caused by disruptions to routine and the stress of the pandemic:

- 1 [Explain the situation](#) using visual supports like the ones on our [COVID-19 resources page](#).
- 2 Reassure them that you will help keep them safe.
- 3 Discuss challenges with your behavioral therapist or other members of your care team. They may be able to share anxiety management strategies that your child can use.
- 4 Pay attention to your child's behaviors to help them recognize when they are feeling anxious and encourage them to use self-soothing strategies.



SENSORY OVERLOAD FROM WEARING MASKS

The [CDC is encouraging](#) people to wear masks when they go to a public place where social distancing may be difficult. As a result, an individual with autism may see people wearing masks or may have to wear a mask themselves. Both the change in the physical appearance in others and the sensory discomfort of wearing a mask can be challenging for anyone, but particularly so for some individuals with autism. Parents and caregivers can help by using these strategies:

- 1 Use this [social story](#) to talk to your child about why people are wearing masks. (see page 7 & 8 of this newsletter)
- 2 Try to limit the time your child spends wearing a mask.
- 3 Give the individual freedom to choose their mask, one with fabric that feels good on their skin and characters or colors that appeal to them.

For some individuals practicing with a mask at home may be helpful.

Continued on page 6.

HYGIENE IS MORE IMPORTANT THAN EVER

Talk to your loved one with autism about the importance of handwashing and covering their nose and mouth when they cough or sneeze. Everyone in the family should wash their hands after coming in from outside, after coughing or sneezing, before eating and after removing a mask. Keep hand sanitizer in a convenient place when hand washing is not possible.

Here are three ways to help your loved one with autism practice good hygiene to avoid illness:

1. Talk to your loved one about handwashing and other hygiene concerns.
2. Ask therapists and other team members to help you focus on hygiene.
3. Use [this handout](#) to practice proper handwashing techniques at home. (page 9 of this newsletter)

YOU CAN ASK FOR HELP

The pandemic adds unique challenges for everyone. You may be feeling overwhelmed right now, but remember that you are not alone. Get support from your care team, other caregivers, and online resources. Telehealth options are much more widely available due to the pandemic as well. Check with your insurance company and community resources for information on how to access these services.

Find more resources to help your loved one deal with the challenges of the pandemic on our [COVID-19 resources page](#). There you can watch webinars, download social stories, and share your own story about coping with the coronavirus crisis.

Reference: <https://www.autism.org/how-families-of-individuals-with-autism-can-meet-pandemic-challenges/>

Coping with Covid-19 Pandemic

Disruptions to our personal and professional lives, schedule changes, and school closings present unique challenges individuals on the autism spectrum and their families. In these challenging times, we are sensitive to the needs of these individuals and their families. To help, we have compiled these resources aimed at reducing anxiety and restoring a sense of routine during the COVID-19 pandemic.

Jump to category: Go to <https://www.autism.org/covid-19-resources/> to view the following resources.

[Share your story](#)
[Past webinar recordings](#)

[Free upcoming webinars](#)

[Social stories and priming videos](#)


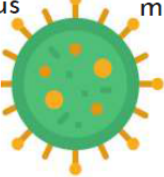










WEARING A MASK SOCIAL STORY

I Can Wear a Mask Social Story

Courtesy of the Autism Research Institute

www.autism.org

Right now, some people around the world are sick with a virus called COVID19.	sick 
I cannot see the virus because it is very small, but people with microscopes have seen the virus.	virus  microscope 
The virus can pass from person to person through tiny droplets that come from a person's mouth or nose when they cough or sneeze.	sneeze or cough  particles
I can help prevent catching and spreading the virus by staying home. When I need to go out, I can help prevent spreading germs by wearing a mask.	stay home  wear a mask outside 
I can practice wearing a mask at home.	 practice with masks at home
Masks are made of paper or cloth. The mask will cover my nose and mouth and may have fasteners that go around my head or ears.	around ears  around head 
It may feel different to have a mask on my face. It may feel different to have fasteners around my head or over my ears. This will help the mask stay in place.	mask around ears 

WEARING A MASK SOCIAL STORY CONTINUED...

I Can Wear a Mask Social Story

Courtesy of the Autism Research Institute
www.autism.org

I can ask for help putting my mask on if I need to.
The mask may become warm from my breath, and that is ok. I can still breathe with a mask on my face.



help putting
on mask

If I see other people wearing masks, I do not
need to feel afraid. Underneath the masks, they
are just like me.



masks are
good!

When I wear a mask outside, people can see I
am helping to prevent spreading the virus.
If my family prefers to wear masks that is ok too.



family wearing masks

Some people may not be wearing masks.
This may be because they do not have masks, or
they have forgotten or for another reason.



mask

no mask

We should stay six feet away from other people
whether or not they are wearing a mask. That's
about the length of my bathtub or couch!



6 feet away

When I get home, I can take the mask off care-
fully and then wash my hands.



wash hands

I can ask for help removing my mask if I need to.

help taking
off mask



HAND WASHING SOCIAL STORY

Hand Washing Social Story

Courtesy of the Autism Research Institute
www.autism.org

Sometimes my hands get dirty



dirty hands

My hands can get dirty when I play with my toys or when I go outside



toys



outside

Clean hands help prevent spreading germs. I can help keep germs off of my body by washing my hands.



clean hands
prevent spreading
germs to my family
and friends

I can clean my hands with soap and water



water



soap

To clean my hands I turn on warm water and get my hands wet



water on

Next, I need to rub soap all over my hands, wrists and in-between my fingers for 20 seconds. While I do this, I can sing a song like "Happy Birthday" two times.



soapy hands,
rub for 20 second



Then I can wash the soap off and turn off the water.

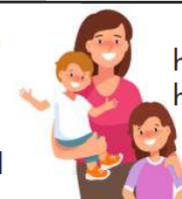


wash soap off
with warm water

Last, I dry my hands with a clean towel.
Then I am finished.



clean towel



happy
healthy

KEEPING FRIENDS SAFE

DURING SUMMER PLAY



To keep my friends and I safe while playing this summer, things will look a little different than summers in the past.



We will be outside more often and lots of my friends will be wearing masks so we do not spread germs.



We will play games that allow us to stay far apart from one another. These games may include Shadow Tag, Red Light/Green Light or going for a scooter ride.



We will need to avoid crowded areas such as playgrounds and beaches.



We can still have fun on the hiking trails, beaches, or open fields as long as we don't get too close to one another.



On rainy days we can still have fun while staying apart. I can grab an umbrella and go for a walk or talk to someone with one of my devices.



Family Support for Autism Spectrum Disorder

A diagnosis of autism spectrum disorder (ASD) is hard for both your child and you. Autism symptoms can vary widely. Odd or incorrect behaviors, problems with communication, and repeated routines and rituals are all linked to ASD. This can make life hard for the entire family. Some children with ASD are less affected than others.

THE IMPORTANCE OF SUPPORT

Parents of a child with ASD must have a good support system in place. This will help your child cope with the unique aspects of his or her disorder. It will also help you learn how to manage your feelings when faced with the challenges of raising a child with ASD. Pay special attention to the needs of other children in the family. Sometimes siblings' needs get lost when so much attention is needed by the child with ASD. Spend one-to-one time with your other children. Look for sibling support groups that can provide a safe place for them to talk and share their feelings and fears.

Part of this support will come from the healthcare team that is treating your child and educating you as a parent. There is no cure for ASD. But most children can lead a happy, productive life by taking part in therapy. Therapy addresses the 3 main symptoms of the disorder:

- Poor communication skills
- Obsessive or repeated routines
- Physical clumsiness

Experts agree that the earlier a child starts therapy, the better the outcome often is.

SUPPORT FOR PARENTS

Parents also benefit from a strong support network. The term Asperger syndrome is no longer used to describe higher-functioning people with ASD in the U.S. But you may still find the following support groups helpful:

- **Autism Speaks**. This nationally recognized organization provides information for parents of newly diagnosed children. This includes app reviews, resources for children with ASD, and a 100-Day Kit with a step-by-step guide of what to do in the 100 days after an autism diagnosis.
- **GRASP (Global and Regional Asperger Syndrome Partnership)**. This group provides community outreach, online support, education, and advocacy for teens and adults on the autism spectrum. Membership is free.
- **ASPEN (The Asperger Syndrome Education Network)**. This New Jersey-based resource offers support for families and a listing of other online support groups.
- **Asperger Syndrome and High Functioning Autism Association**. This group reaches people in New York City and Long Island, N.Y., with local activities and events and online support.

<https://www.stanfordchildrens.org/en/topic/default?id=family-support-for-autism-spectrum-disorder-160-24>

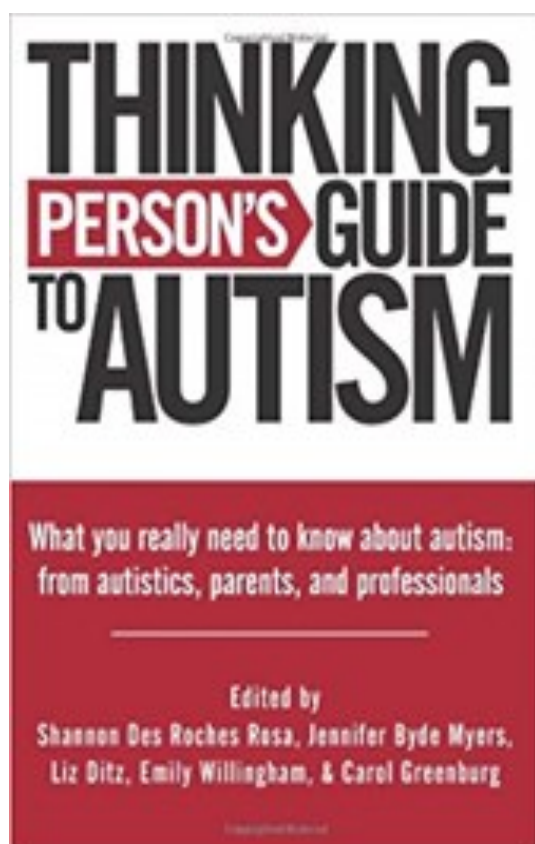
Ten Things Every Child With Autism

Wishes You Knew by Ellen Notbohm

One of the autism community's most beloved classics, ***Ten Things Every Child with Autism Wishes You Knew*** has informed, delighted, and guided millions of families and professionals the world over since its first edition was published in 2005. A child's voice leads into each chapter, offering a one-of-a-kind exploration into how ten core characteristics of autism affect our children's perceptions and reactions to the surrounding physical, sensory and social environments. The third edition sharpens the focus on these basic aspects while expanding on how our own perspectives shape the life of our child and ourselves, today, tomorrow, and for years to come. An all-new section illuminates the surprising breadth of our power of choice and outlines potent strategies for strong decision-making in every situation.



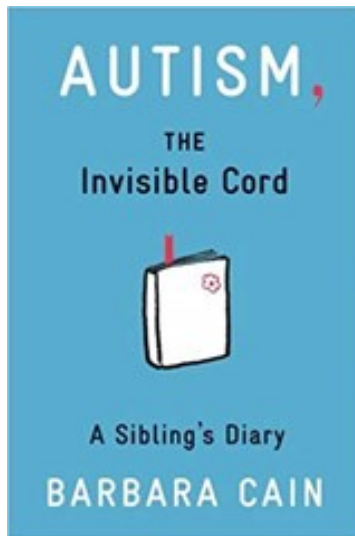
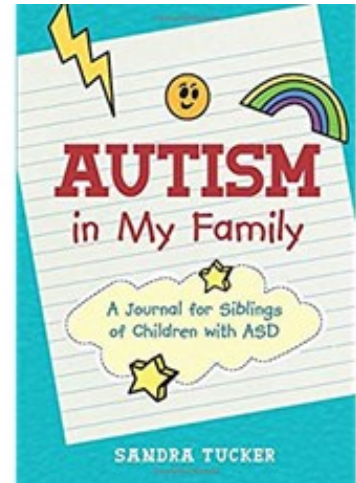
The Thinking Person's Guide to Autism: What You Really Need to Know About Autism from Autistics, Parents and Professionals, edited by Shannon Des Roches Rosa



This book is a one-stop source for carefully curated, evidence-based information in the form of 74 essays and articles written by autistics, autism parents, and autism professionals. Topics delve into the nuts and bolts of what you as a parent *need* to know to help your ASD child navigate this world: bullying, grief, finding joy, designing an IEP, sensory issues, potty training, preparing your will and finances for an adult child requiring lifelong care, neurodiversity, the causes of autism, getting the most out of therapy, puberty, medications, and much more. In short, there isn't much about autism this book doesn't eloquently and concisely address. The underlying message is that however tough things may be, however difficult they may get, don't give up. Things can and generally (but not always) get better, and there are resources available and people willing to help you give your child the best possible life.

Autism in My Family: A Journal for Siblings of Children with ASD by Sandra Tucker

This interactive workbook is designed for siblings of children with autism. Introducing the experience of autism in simple language, children are encouraged to complete activities, either on their own or with parent guidance, that identify differences and strengthen relationships. This book is focused on understanding and supporting a sibling while developing individual emotions and identity. The pages are designed to be drawn on and personalized by the child. Ideal for children aged 8-12.

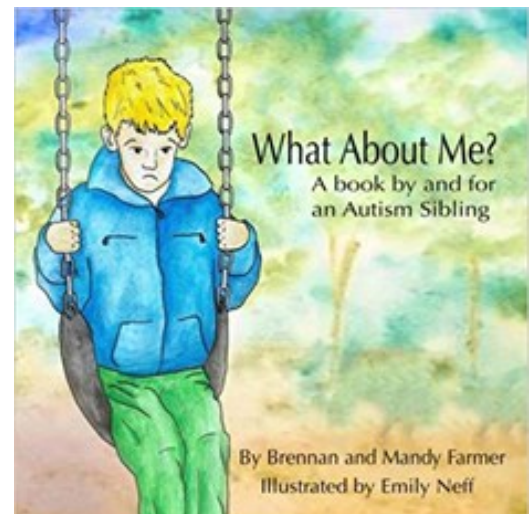


Autism, the Invisible Cord: A Sibling's Diary by Barbara Cain

This young adult novel, for ages 12-15, follows 14-year-old Jenny as she describes her day-to-day life with her younger autistic brother, Ezra. Ezra can be both her best friend as well as her biggest obstacle to living a normal life, and Jenny often finds herself stuck worrying about her younger brother. Through taking care of Ezra and a very special school project, Jenny ends up learning about her own character and strengths, and a way to shine despite everything else.

What About Me? A Book By and For an Autism Sibling by Brennan and Mandy Farmer

Written by a seven-year-old boy, this book works through the day-to-day struggles and joys of being an autism sibling. "An honest, real, and age appropriate book for children who have sibs on the spectrum. This is a must read for neurotypical kids and their families. It doesn't sugar coat it nor is it sad. It's just real life and a wonderful tool to spark conversations." - Eileen Shaklee, *Autism with a side of fries*





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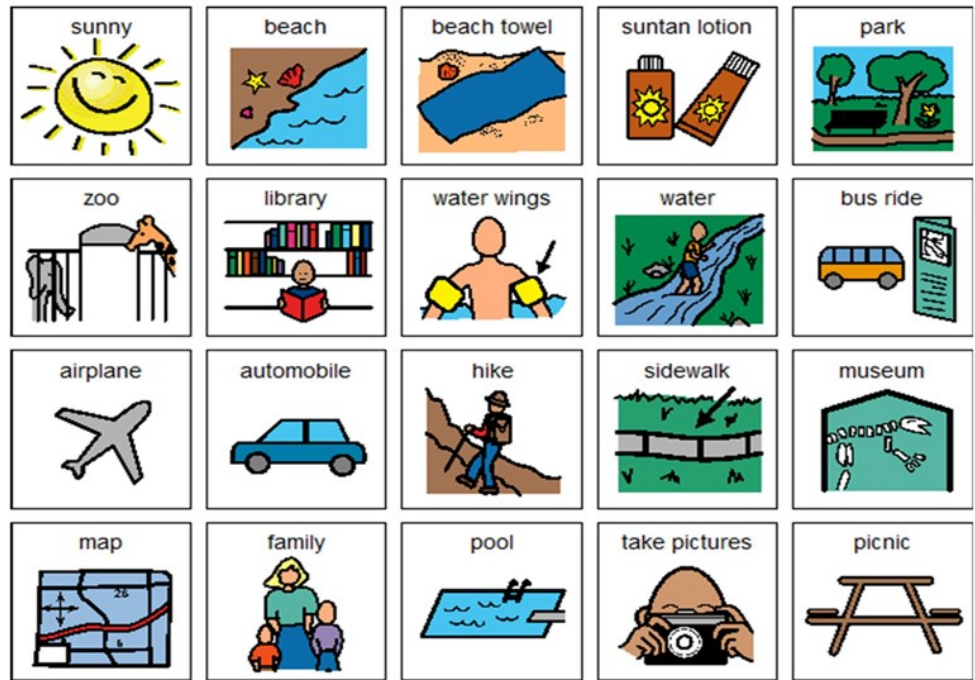
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VISUALS

4 Reasons You Need No-tech Picture Cards for Summer:

1. No-tech picture cards do not require batteries or charging.
2. No-tech picture cards cost pennies to replace if lost or stolen.
3. No-tech picture cards can get dropped in water, sand, mud with no worries.
4. No-tech picture cards are light weight and easy to use.



www.thesuccessbox.com

Au Talkz

AuTalkz

Peer Groups



Cascade Regional Program would like to apologize for a miscommunication in the Spring/Summer 2020 Autism Agenda Newsletter sent out on June 19, 2020. On page four of the newsletter, as part of a large article written by Lisa Jo Rudy, the following was written:

“2. Understand and apply for ESY. Extended school year programming is almost certainly available to your child, but parents aren't always well informed about the process by which children are evaluated for ESY. In addition, while some districts offer full-day ESY, others offer just a few hours while yet others are willing to provide support to children in non-school settings such as summer camp. All should provide at least some therapy (often speech, ABA, and/or occupational therapy) during the summer months.”

The above statement goes against the Oregon Department of Education Special Education Oregon Administrative Rules (OAR) <https://secure.sos.state.or.us/oard/viewSingleRule.action?ruleVrsnRsn=143188>.

To be clear, one does not “apply” for Extended School Year (ESY) services. A child is evaluated on an individual basis to determine if there is a significant regression of skills after a break in school services or the amount of time a student needs to recoup (relearn) skills after a break is profound. The ESY decision is made by the child’s team after capturing and discussing that evaluation data.

In addition, the purpose of extended school year services is to maintain skills, not teach new skills. It does not require specific therapy such as speech, behavior or occupational therapies. All services are determined on the child’s individual needs and skill deficits after a school break.

The LBL ESD Autism Agenda Newsletter is a compilation of national and regional resources designed to support families and school teams. Every effort is made to provide accurate and complete information in the newsletter; however, LBL ESD cannot guarantee that there will be no errors. Some resources from across the nation may not apply to Oregon.

Again, we apologize for the inaccuracy and thank you for your understanding. If you have questions, please feel free to contact me.

Be well,

Cindy Madden

Cascade Regional Program Administrator

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