

Autism Support of West Shore

A place where everyone fits



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Benefits of Family Travel

Traveling, even when someone in your family has autism, is a rewarding experience. It opens your eyes to different cultures and experiences, which can be beneficial to all members of your family. Traveling with someone on the autism spectrum or other special needs does create unique challenges, but they are challenges you can and should face. The rewards are well worth the effort. With the tips in this article, you can head into your next travel experience with confidence, knowing that your child is as prepared as possible for the experience ahead. Just remember to stay positive and be flexible, and you will all enjoy a great vacation experience.

There are significant benefits to traveling with children who have autism and other special needs:

Reduce isolation. When parenting a child with special needs, isolation is a very real concern. It is all too easy to become isolated in your home because of your child's needs, and that is not healthy for you or for your child. Traveling allows your entire family to move out of your comfort zone and avoid the trap of isolation.

Enjoy family time. Travel brings opportunity to bond as a family. Both your child with special needs and your other children need time together to build strong relationships. You can also use travel experiences as an opportunity to visit other relatives that you may not see regularly. The family bonds and memories you create are worth the challenges and logistics you must tackle.

Life skills. Your goal when raising a child with autism is to encourage as much independence as possible, and that requires developing life skills. Being able to travel is a life skill that will benefit your child long after the trip. You can use travel to teach life skills like social interactions, map reading, budgeting and more, depending on your child's abilities and age. Learning a bit more flexibility, especially with neurology differences that often require strict adherence to routines.

Educational benefits. Seeing different cultures, exploring historic sites, and interacting with nature are all important for your children's education, and these are things that they cannot learn in the classroom. This, in turn, can increase your child's cultural appreciation and empathy for others who think or act differently than your child does.

Sensory desensitization. Most children with autism have sensory needs, and many respond negatively to sensory stimulation. One of the best ways to help them overcome this hurdle is to desensitize them to the sensory stimulation that they find challenging. Travel exposes your child to new things that can help with this process, and because you don't have access to the comforts of home, it makes the desensitization process more automatic.

Spreading autism awareness. For many parents of children with autism, spreading awareness about neurodiversity is something they are passionate about. When you travel, you are able to spread that message even further. Exposing other people to the neurodiverse world can help make the future world one that is more accepting of diversity and kids who have autism. This is a benefit not only for your family but for the rest of the world.

Early planning

Some of the tips you will need to make travel with your child comfortable require early planning. From choosing your destination to addressing your child's unique needs, these tips will need to happen ahead of your actual travel date.

Choose a destination that reduces stress based on your child. Children with autism are able to pick up on the stress of others. Though most families with a child with autism benefit from an unhurried destination, you need to consider your child's unique needs. Some children may find the heat of the sun and the scratching of the sand to be too troublesome for a beach trip. Some children may love amusement parks, even with their neurodiversity. Plan a destination that will be appealing for your unique child's needs. Even if the destination is not on your top ten list, plan around something they are interested in for your first few trips. You will be more successful introducing new trip adventures later.

Include your children in the planning. Include all of your children in your planning, including your children with special needs. Because "where would you like to take a trip to?" might be a might be an unknown concept or too big to choose have a few options you think might be of interest. This will help you choose a destination that is a good fit. Show your children online about what options you're thinking of. If it is a park or town show maps of all they might see.

Call ahead. Call the airport, train station, hotel, or attraction ahead to learn what accommodations can be made for your child's needs. Find out about special passes that may be available to help your child enjoy the experience with minimal stress.

Use pre-boarding if possible. If the airline allows it, use pre-boarding. This will give you the chance to settle your child or get extra assistance if the flight induces a meltdown.

Give yourself ample time. Parenting a child with autism will quickly teach you to expect the unexpected. When you head out for your day of travel, plan ample time. If something goes awry, you do not want to add the stress of a time crunch to the mix.

Practice with your child. Use social stories and even actual practice to help your child understand what to expect. This can help reduce anxiety and negative behaviors, because your child will face fewer unexpected problems. Anticipate areas where your child may struggle, such as TSA checkpoints, baggage claim, meals in unfamiliar restaurants, unfamiliar bathrooms, and sleeping in a hotel.

Reduce your own stress to improve your child's travel experience. The more stressed you are, the more your child will struggle. Whether you need to plan extra time, need down time for yourself, or need to bring an extra caretaker with you to help with your child, do what you can to reduce your own stress while planning and executing your trip.

Creating a safety plan

Safety is one of the biggest concern parents of children with autism face when away from home. Many children with autism wander and some have communication difficulties that would make it difficult for emergency personnel to help them find their parents if they become separated. Here are some ways to make your trip is as risk-free as possible.

Have a plan for dealing with wandering behavior. Make sure you have a plan if your child has wandering tendencies. Using tether backpacks can be helpful when traveling, as it gives your child a measure of freedom while ensuring you know they are close by at all times.

Consider a GPS tracker. Products like AngelSense give parents the peace of mind of knowing they can find their child if he or she wanders off, and that can alleviate much of your stress when traveling with your child with special needs.

Use a medical alert bracelet. If your child has speech concerns or other considerations that emergency personnel should know if an accident occurs, use a medical alert bracelet. Include an emergency phone number on the bracelet that you will have on you during your travels.

Keep a form of identification on the child. Children with autism should have a form of identification on their persons when traveling, just to ensure emergency professionals can provide the right help if a problem arises.

Have an ID kit with you that can be used to help find your child in an emergency. A recent photograph and an accurate description, including current height and weight, can help emergency responders locate your child should you become separated. The National Child Identification Program offers kits you can use to easily create an ID packet for your child, including a fingerprint and DNA sample, which is a good starting point.

Teach your child what to do if separated. From staying within a safe area to identifying safe strangers, like police officers or store workers, give your child skills to handle dangerous situations in case you are separated. Of course, this needs to suit your child's abilities and understanding, but it is something to practice at home.

Consider temporary safety tattoos. These temporary tattoos can be placed on your child's arm to contain your

Sound too Overwhelming?

Keep all the strategies of a longer trip in mind but just go for a day. Even an overnight trip to a hotel in a not too far away town with a pool might be a fun get away. Build future plans off of success. If your child has a "moment" roll with it and regroup. Even neurotypical children get tired and ugly sometimes. Give yourself and your child some grace when trying new things.

Day Trip. Consider starting with a day trip to somewhere out of the ordinary. West Michigan is full of interesting events, especially in the summer.

- County fairs not only have animals but often have interesting evening shows like monster

trucks, rodeos or stunt riding. Mid-day at the fairs often have performance animal shows.

- Evening musical events throughout the week. Grand Rapids (Rosa Park Circle), to the lakeshore (Central Park in Grand Haven) check your town's calendar of events or better yet a neighboring town's summer events calendar.
- Evening at the drive-in movies. (Getty Theater in Muskegon) the comforts of your car and your child's favorite treat all while seeing a movie or two!
- Check out one of Michigan's zoos. Did you know in Alto there is a wildlife zoo called Bolder Ridge? They take pride in their rare and endangered animals. In fact, some of the animals are difficult to find anywhere else in the United States.
- Beaches abound in West Michigan. Something as simple as water shoes might make walking on sand easier for the child with sensory issues.
- Splash pads. Also, in many towns. Maplewood Park (Jenison), Allendale Community Park (Allendale), Lamar Park (Wyoming), Oriole Park (Wyoming), Chinook Pier (Grand Haven), Southlawn Park (Grand Rapids), Muskegon Splash Pad (Muskegon), Rosewood Park (Jenison) are just a few of the listings.
- Within the boundaries of West Michigan there is no limit to high impact activities. John Ball Zoo (zip line), Michigan Adventure amusement park, RebounderZ, Skyzone and Planet 3 Extreme trampoline parks, Action Wave Park are just a few of the local offerings.

Whatever you choose to do enjoy time with your entire family. Have a fun trip!

Looking beyond test scores to find the gifts

Susan Judd

"Intelligent Lives" is a compelling documentary that strikes a familiar chord in the hearts of parents of students with special needs.

The 70-minute film produced by Dan Habib challenges the viewer to look beyond IQ scores and see the potential in every individual. The message is that intelligence looks different on everyone and talent is developed one day at a time — not like in the movies when a maverick teacher comes in and saves the day.

Academy Award winning actor Chris Cooper sets the tone for the rest of the film by recounting his own experience advocating on behalf of his son Jesse, who suffered a brain injury at birth and has cerebral palsy. They were told to put their son in an institution, but Cooper and his wife were dedicated in making sure that Jesse had the same opportunities as his typical peers. Jesse used a computer to communicate, he aced his high school Latin classes and he wrote gorgeous poetry.

Cooper hit a roadblock otherwise known as the Stanford Binet IQ Test, used in 49 of 50 states as a determining factor in student placement. He cited the lunacy of the test questions, such as asking Jesse if he dusted the dresser at home.

"The IQ tests told us nothing about my son as a person," Cooper said.

The film then introduces three students with special needs — Micah, Naieer and Naomie — who are successfully navigating the quagmire known as transition to adulthood. Not surprisingly, all three had strong family support and experienced meaningful inclusion. Through snippets of the students' lives, the viewer is captivated by what can be accomplished with empowerment, creativity and adaptability, when thinking occurs outside of the box.

Micah's story might be familiar to Michigan audiences. His mother is author, speaker and social worker Janice Fialka, a staunch proponent of inclusion. He is his own guardian, has completed a program at Syracuse University and is now a teaching assistant. He continues to advocate for individuals with special needs, he has a strong social network and he clearly loves life.

"My parents talk to me, but it's my decision on how I want to live my life," Micah said.

Micah recalled seeing a sheet of paper in the mail that said he had an IQ of 40. "Intelligent Lives" stresses that IQ tests measure limited ability and miss the student's desire to engage and to take things in context.

Naieer is a talented artist who has autism spectrum disorder whose parents fought hard for him to be included in high school. The film shows Naieer creating art in class and excitedly assembling his portfolio for college. A nurturing teacher describes him as "a hardworking, committed student." His parents spoke very forcefully and passionately about their son's future, emphatically stating that he *is* going to college.

"He's such a sweet boy," his father said. "I want him to go into this world as a citizen of this world, not as 'He's a tall black guy, let's call backup.'"

Naomie has Down syndrome and from age 15 to 21, she attended a vocational center in Rhode Island where expectations were low. Students were segregated, underpaid and worked in harsh conditions. She now excels in a part-time at a local beauty salon where she is loved and valued — and earns a decent wage. To aid her quest for employment, she places she frequented and the people she knew were placed in circles. She already knew someone who worked at the beauty salon. She also is shown singing and dancing with her brother, and at her church.

"Intelligent Lives" is an honest depiction of how far we have come and how far we still have to go to give equal opportunities to *all* students. The students' stories are uplifting and inspiring. By contrast, the grim statistics about disability are alarming. Only 15 percent of the 6.5 million adults with disabilities in America are gainfully employed and nearly one in three are living below the poverty line. Only 17 percent of students with intellectual disabilities are educated in regular classrooms and the film refers to them as the "most systematically segregated people in America."

Like many parents of children of special needs, I long for the day when *all* students have the opportunity to attain a meaningful education and are valued for their gifts and talents, not their test scores. I had the privilege of watching this film during the May meeting of the OAISD Transition Network. "Intelligent Lives" is a must-see for anyone who cares about someone with special needs.

What about parents?

Dr. Kaarin Anderson Ryan, PhD, BCBA.

6-19-19 blog post

<https://positivebehavioridoctors.org/2019/06/19/what-about-parents/>



Making Time for Yourself This Summer!

We have so many options for things our kids can do over the summer. As I wrote about in my last post, there are activities in every community, for kids both with and without different needs. These activities can include things for all ages, interests and budgets. Setting up these activities, and managing the logistics of them, is a lot of work. Put this together with the regular daily demands of work, home care, and making sure everyone eats and you may find that there is no time or energy left for yourself at the end of the day.

Although it might not be something parents pay as much attention to while they are raising kids in a busy world, there are many things available in our communities to help adults with their work-family-self balancing act. Before we get into some of those ideas, let's spend a minute to consider why it is important to fit time for yourself into the agenda.

We have all heard that you can't take care of other people unless you take care of yourself. As common-sense as this is, often busy parents put this on the back burner or ignore this logic. Think about going on an airplane. One of the first things they say to you during the essential safety lesson is that if the oxygen masks are needed the adult needs to put on his or her oxygen before helping a child with the mask. Why? Because if you run out of oxygen, you can't help your child. In daily life it isn't as dramatic or critical, but it is the same concept. If you run yourself ragged, you aren't going to be the parent you want to be. By taking time for yourself, you may essentially reduce your own stress so you can be more effective in your parenting, you may

be more likely to take better care of your health by doing things for yourself, and you are being a good role model for your kids by showing them a positive work-family-self balance. If you think about your kids 20 years down the road, do you want them to continue to make time for themselves? Show them how to do that by doing it yourself.

Here are 10 ideas to help you make time for yourselves. You may choose solo activities, doing things with friends, or sharing time out as a couple. If you have a hard time finding child care to make time for yourself, consider a babysitter, respite service, a family member, or a mother's helper to give you a break. In some cases, you may need to take some time to yourself only at the end of the day when the kids are in bed, but even on these days it is important to make the most of the little bit of quiet time in the evening.

- Treat yourself to a coffee, meal, or glass of wine with a friend. A little bit of adult conversation can go a long way!
- Exercise. Go for walks or hikes, take a run, go to the gym, sign up for a yoga class. Any physical activity will benefit your body, mind and spirit.
- Look for adult classes in the community. There are numerous free or low-cost classes, including art classes, cooking classes, and library programs to meet every interest.
- Take some time just for yourself. Read a book for 30 minutes a day, or watch an episode of your favorite show, or just enjoy the sunshine with a few minutes outside.
- Plan a date night to help both parents rejuvenate and reconnect.
- Plan a game night or cookout with another family. This will give your kids time to interact with peers while you socialize with your friends.
- Consider something to pamper yourself – a manicure/pedicure, a facial or a massage. These types of activities can reduce stress and help you re-energize.
- Join a parent group, especially if you have kids with difficult behaviors or special needs. Connecting with other parents who have similar challenges can be affirming and helpful.
- Indulge in one of your favorite treats – some nice chocolate, ice cream, or other special item you don't normally let yourself enjoy.
- Journal. Sometimes writing down the things that happen during the day can be a therapeutic tool for processing everything that happens in our busy lives. For some people, journaling can help plan and organize thoughts for the upcoming days and can also let off steam about frustrating events or situations. Journaling can also be used to help us remember the things that have gone well, the things we are thankful for, and the things our kids have done to give us joy.

Save the Date

July 11-18, 2019 *Twice Exceptional*

Join Bright & Quirky for a very special screening, online and for FREE. ***Twice Exceptional*** examines the concept of “twice exceptionality” – bright children with learning differences – from the perspectives of the students themselves, as well as their parents and educators. These students have vexed their parents and are often considered “at risk” by traditional school systems. Yet they are our next-gen geniuses, mavericks and dreamers – Malcolm Gladwell's budding “outliers.” Sign up for your screening <https://brightandquirky.com/2e-movie-signup/>

August 7-8, 2019 Introduction to PODD Communication Books

This two-day course will demonstrate the use of a Pragmatic Organization Dynamic Display (PODD) approach developed by Gayle Porter (Melbourne, Australia). Generic templates for multi-page “light tech” communication books have been carefully designed to support genuine communication for a variety of functions throughout the day. These templates may be customized for a range of access methods and other individual needs.

Come learn strategies for creating multi-modal language learning environments that provide receptive models and expressive opportunities for language development. Learn strategies for teaching and using PODD with children and their communication partners. Videos and case examples will be shared.

<https://www.altshift.education/event/introduction-podd-communication-books-0>

August 10, 2019 Autism Awareness Walk

11:00a.m.

Grand River Park

9473 28th Ave, Jenison

Join families and friends for a one mile walk and cookout. Paths are barrier free. There is no cost to attend, however pledges are welcome to support autism initiatives. This is a free event please register name and number attending by August 7th at contact@asws.org

August 17, 2019 EFFECT

10:00 – 2:00

This program is appropriate for children 12 – 16 years of age, have and ASD diagnosis. Would benefit from the opportunity to interact socially with like – minded peers. <https://brainspotential.com/effect/>

September 18, 2019 Autism 101

6:00 – 7:00pm

This presentation is appropriate for: parents or caregivers of children and young adults who have been newly diagnosed with an Autism Spectrum Disorder (ASD).

Register <https://brainspotential.com/autism101registration/>



September 21, 2019 ASWS Annual Golf Outing and 19th Hole Party

8:00 am registration

Oakridge Golf Course

<https://www.asws.org/events-1/asws-golf-outing>

October 1-2, 2019 Emergent Literacy Instruction for Students with Significant Disabilities and Complex Communication Needs

Students with significant disabilities can and do learn to read conventionally with supportive print- and language-based experiences and interactions. Not unlike students without significant disabilities, this learning for students with significant disabilities begins with emergent literacy. Students who are emergent literacy learners should be provided many frequent learning opportunities that provide instruction and practice with functions of print and print conventions, phonological and alphabet awareness, and expressive and receptive language skills. This training is based on the work of Dr. Karen Erickson and Dr. David Koppenhaver.

<https://www.altshift.education/event/emergent-literacy-students-significant-disabilities-0>

It's Time to Sign Up!

Autism Support of West Shore Presents 2019 Annual Autism Awareness Walk

In coordination with Ottawa County Parks Association

AT GRAND RIVER PARK



Details:

- We will meet rain or shine under the pavillion.
- Barrier-free walk trail.
- The walk will take place at 11:00 AM with lunch following.
- There is no cost to attend, however pledges and donations are welcome to support initiatives in autism support.

Register: Please register by August 7 with family name and number attending (head count for food) to: contact@asws.org

Resources

Meet Up and Eat Up

The Summer Food Service Program (SFSP) was created to ensure that children in lower-income areas could continue to receive nutritious meals during long school vacations, when they do not have access to the National School Lunch or School Breakfast Programs. The SFSP, also known as Meet Up and Eat Up, is operated at the local level by program Sponsors and is administered in Michigan by the Michigan Department of Education (MDE), Office of Health and Nutrition Services.

https://www.michigan.gov/mde/0,4615,7-140-66254_34491---,00.html

Program Office: 517-241-5374

Michigan Alliance for Families has a DVD available: "Making the Most of *Early On*[®]", designed to help parents better understand and access the system of supports and services for children from birth through age three. This video is divided into six topics and is available with Spanish subtitles, Arabic subtitles, or English closed caption.

<https://www.michiganallianceforfamilies.org/dvd/>

PRE-EMPLOYMENT SERVICES FOR STUDENTS – See attached flier

In the News

Proposed Changes to Community Mental Health (CMH)

Over the last several weeks, our association, others within the Lakeshore Regional Entity (LRE) and its regional CMH and managed care partnerships, and others within our system have heard rumors that some within Michigan Department of Health and Human Services (MDHHS) were considering the termination of the MDHHS contract with the Lakeshore Regional Entity and turning the region over to a private entity.

Those rumors caused our association to take pre-emptive action and reach out to MDHHS to confirm or disconfirm this rumor. After several days of seeking such clarification, we learned that MDHHS is seriously considering such a contract termination." On June 19, 2019 a draft letter was circulated from MDHHS recommending the termination of the contract with and dissolution of the Lakeshore Regional Entity (LRE) and an email communication was sent to key legislators.

In response, the leaders of LRE, its CMH members, Beacon Health Options, and this association, wrote a joint letter to the legislative leaders whom had received the MDHHS letter. At the same time, we shared our concern with the advocacy community, asking them to voice their concern regarding this issue.

It appears that these pre-emptive and responsive actions, by many parties, have caused MDHHS to pause their actions on this front; MDHHS has not, as yet, sent a letter of contract termination to LRE. However, we believe a decision will be made in the near future.

REQUEST FOR URGENT ACTION: We are asking that everyone contact the Governor and if you live in West Michigan contact your Senate & House member(s) expressing your concerns with this proposed direction of eliminating the public governance and oversight of the Lakeshore area. Timing is critical – we believe it is important for the Governor and those key legislators hear from us before final decisions are made. Please make contact between now and July 3.

Click the link below to log in and send your message:

<https://www.votervoice.net/BroadcastLinks/VO6TkNOvHeadFwtHPusVuw>

Message from the Board,

It must be official – after several days of really warm weather summer really is here. We here at ASWS hope you and your family find multiple and fun ways to spend time together and enjoy the summer. Our camp resource list www.asws.org/summer-day-camps or <https://www.asws.org/local-parks-recreation> are good places to look if you're still wondering what there is available.

We would like to ask all our members and friends to seriously consider writing on behalf of the proposed changes in the structure of funding to Community Mental Health. Your child may not be a young adult who may

be impacted by potential changes but changes in the funding structure could significant change the ability to receive services through non-profit organizations now and in the future. The proposal is considering turning current funding over to for profit business. Non-profit agencies currently servicing special needs individuals such as Bella Vita and Momentum Center will no longer receive funding thus potentially limit the ability to provide services for individuals with special needs. Consider voicing your opinion.

<https://www.votervoice.net/BroadcastLinks/VO6TkNOvHeadFwtHPusVuw>

Thank you to our newsletter contributors Sue Judd and Kaarin Anderson-Ryan PhD. If you would like to write for the newsletter simply email your article to contact@asws.org

Linda Elenbaas and the ASWS board