

TEN STRATEGIES FOR TRAVELING
WITH A CHILD WITH AUTISM

OR

HOW DO WE SURVIVE THE TRIP?

BY
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INTRODUCTION

Vacations with a child with Autism Spectrum Disorder can be chaotic, nerve rattling and stressful! So stressful that many families do not take the vacation that they want to take - well, no more. Congratulations for purchasing the booklet dedicated to helping your family travel, tour and have fun!

This booklet is designed to aid you, your family and your autistic child in having a fun, relaxing and enjoyable trip. The following strategies are effective for children with autism spectrum disorder but many of them work for all children.

Use this as a working document. Mark it up. Highlight it. Discuss it.

Most importantly, go and have fun.

STRATEGY ONE

THE KEY TO SUCCESSFUL TRAVEL

The key to a successful trip, autism or not, is preparation.

Preparation for the autistic family has a different meaning. Yes, you should read everything and anything on your destination but you also need to prepare your children, neurotypical and autistic, for the trip. Preparation for a child with autism has a completely different meaning than for his/hers siblings.

Preparing an autistic child for vacation should begin with an understanding of their core problem areas. If sensory issues are a problem, then you need to address them. For example, an amusement park visit may require headphones/earplugs for a child with audio difficulties. If your child is on the gluten free/casein free diet, then reserve a room with a refrigerator. That's simple, right?

What about preparing your child in other ways? Perhaps a social story discussing issues that come up on the ride -- like hitting your sister or singing the Mickey Mouse theme song 91 times. Rent a video of your destination for your child to watch. Order a DVD from the tourism bureau. Or a library book on the destination. If they use visual schedules, then prepare a visual schedule.

Also think through the location. The beach is a family favorite but could be an issue for any child. The sound of the waves, feel of sand and wind, taste of the water, bright sun -- all together equals sensory overload. Maybe you put sand in a bucket and dip their feet in? Or you can buy a wave CD and play it at night for a few weeks before you leave. And if worse comes to worse, you divide and conquer. One parent takes the sibs to the beach and the other to the pool. Or you all visit the pool together.

Taking the time to prepare can help you anticipate several problems. This will allow you to roll with the problems you didn't anticipate. And you know those will happen . . .

STRATEGY TWO

TRY THE GREAT OUTDOORS

I have camped my entire life. As a child our vacations revolved around our old popup. My husband and I became weekend campers first with our tent then moved into a popup. When we first camped with my son, I admit I was very worried. How do I watch him? Prevent him from running into poison ivy? Keep him off the road? And on and on and on . . .

Actually, camping was perfect for him. Camping reduced the family distractions. We were able to focus on each other, which means we could easily watch him. Little did I know that watching him also meant that we could play with him -- on his level. For some reason, I was less self-conscious when I played superheroes and joined him in his mental movies. So was the rest of my family. When we took a walk or hike, he went right along. He even hiked some rather difficult trails. And loved it.

We did make some accommodations. We carried earplugs so he could go to sleep - in case the neighboring campsite was loud. We also had a family watch system. One of us was responsible for him at all times - rotating so no one was burdened. I also have cards that explain autism. Although I only had to give them out once when a neighboring group of kids made fun of him. After the card, they watched out for him too -- even inviting him to play! The cards work well for all trips and reduce my anxiety when a tantrum ensues. I no longer worry about how our family appears -- I hand out the card instead!

Budget wise - this is a no brainer. We all have thin pocketbooks due to the costs of raising a child with autism. Camping cost on average \$25.00 per night and there is a reservation system that allows you to choose your campsite. This works out well because

you can choose a site that will better accommodate your child. For example, if he has trouble with the bathroom at night, choose a site near the bathroom.

If you don't have a camper, tent or equipment – don't fret. Many state park systems rent tents, yurts or cabins. Even the most urban family can enjoy nature in a deluxe cabin!

The parks often have free activities for the children. We recently spent one evening playing bingo and watching the stars with a naturalist. My son lay on his blanket cuddled next to me as I tried to identify the different constellations per the naturalist's instructions. What a peaceful feeling!

STRATEGY THREE

THE MAGICAL TRIP TO MOUSELAND (OR ANY AMUSEMENT PARK)

The family favorite trip to mouseland often seems out of reach to many families. Reasons such as money and planning should not exclude you from this wonderful family experience. As always, the key to a fun vacation is advance planning. With a well-planned trip, you can relax there and enjoy your own *magical moments*.

The Most Important Tip

Many of the following tips apply to any large amusement park. The most important tip is to visit guest services first. Amusement parks provide passes for a guest with special needs. The family making the request needs to be specific. Think ahead to what your child needs and express these needs to guest services. Guest services should issue a pass that will allow for certain accommodations for your child. This does not mean you can cut a line – but perhaps use the Fast Pass line. When we visited WDW we requested that we keep our four-year old son in the stroller and they permitted us to use the alternate entrance – right up until we entered the ride. Take a letter from your physician specifying your child’s disability. Unfortunately with autism the disability is not visible so some cast members may not be amenable -- especially if the park is crowded.

Read, Research and Remember

A year prior to the trip, before you make your reservations, purchase a few good books about the park. The traditional Fodor’s guide is an excellent visual book that gives you an overview of the parks. I prefer the Unofficial Guide that is comprehensive in coverage. Read the book prior to visiting. You do not necessarily need to read it cover to

cover, however, you need to familiarize yourself with items such as hotel reviews, ticketing, special accommodations, etc.

Keep the books to read again three months before your trip. Pay particular attention to the rides and their descriptions. Many of the books describe the rides and fear factors such as noise, spinning, waiting, etc.

Use the book to create a top ten list of the attractions your children want to visit. I let my children each develop a top ten (or five if you have many children) and an ultimate top ten list. This method helps keep the family focused when touring the park. It also prevents disappointment because they have ridden the rides they want to ride.

What Could Trip You Up

Take a quiet moment and list your problem areas. Yes, this is difficult with children but squeeze in the time. It is worth it! My son has problems with sound. We took earplugs because they are small and fit in our pockets.

I have problems with spinning. For those rides, I separated and rode a ride that my children wouldn't be interested in or I stayed and watched my children turn green. That was fun as well!

Take your list of problems areas and compare them to your top ten list. Then you can prepare, as you know exactly what you need to be ready for each ride.

The WDW website has a great feature that allows you to order maps in advance (give yourself three months). You can also preview videos of several rides. This is great feature to sit down and watch with your child. My son's fears were greatly diminished by watching the videos. Visit www.disney.com for other amusement parks; contact the park in advance requesting a guide or accommodations directory.

Slow Down

In the midst of the seeming mass chaos of WDW, remember why you are there ~ to spend with your family. Slow down. Sit on a bench and lean against each other. Find a quiet shady spot and lick ice cream cones. The Unofficial Guide lists quiet places for each of the four parks. I can attest for each of them. These breaks saved my sanity and that of my family. Slowing down, taking breaks, resting is essential in the midst of sensory overload, heat and exhaustion.

Pack Your Own Food and Read the Restaurant Reviews

WDW checks all bags upon entering the parks. But they don't tell you that can't take in water bottles, granola bars, carrots, etc. I pack small snacks every day to every park. These saved us for the times when we had to stand in line and the kids are hungry. (Aren't they always hungry?) And we just couldn't afford all the meals and snacks. We refilled the water bottles and purchased energy drinks in the afternoon for when we really dragged. This allowed us to wait through the lunch crowd and eat in the mid afternoon when it was much quieter. Plus we paid the lunch price and put off dinner until after the park.

Several of the restaurants in WDW will make meals for special diets. For those children and families on the diet, select the restaurants ahead of time – make your reservation and then request your dietary needs. They will accommodate if possible. Again, several of the review books will help you select the right restaurants for your family.

You Won't Do It All

Even with a guest assistance pass, you won't do it all unless you can visit in the slowest times of the year and can dedicate three weeks to it. Don't worry about it. Follow Pumba's advice, "Hakuna matata!"

STRATEGY FOUR

BLISSFUL CAR RIDES WITH CHILDREN

Ten hours, eight hours or even four hours can all be too long when facing a car ride with children. The smells, whines, cries, requests coupled with maps, traffic and construction are enough to send a saint into road rage. Facing my last car trip, I cringed when I calculated it would be eight long hours with my three children ~ including my autistic son.

In typical mother fashion, I called on friends to help. What advice did they have for long car rides? I figured the mother of an autistic child would have the best advice for surviving albeit enjoying a car ride with the family. They are experts and I needed more than a DVD player.

Marlo, mother of seven and three with autism, advises customized activity bags she keeps at her feet. Filled with inexpensive toys, she can toss them back and keep a child happy for hours. She also recommends earplugs for them and yourself. On her recent ten-hour trip to the ocean, she relied heavily on LeapPads with headphones to keep her children entertained. “I can’t afford an individual DVD player for each child and they don’t agree on any one movie. LeapPads are affordable with specific books for that child’s interest. I also use inexpensive toys for bribery.”

Flushable wipes are a necessity for Monica, mother of two and one with autism. “Not only for cleaning sticky fingers but also indispensable for a child not potty trained. We also take a vinyl pad to place under hotel bed sheets and even more important, under Grandma’s bed sheets.”

Monica keeps her child calm in the car with a variety of library CD’s. “A stack of CD’s keeps him happy and we don’t go out of our mind listening to the same one over and over,” she explains. She also keeps a backpack in the trunk filled with

Magnadoodles, suckers and Smartees. “For those tricky moments when you are waiting for food to arrive at the inevitable restaurant stops. Crayons and the back of a menu don’t always work.”

Driving at night is the key for Lisa, mother of two and one with autism. “We leave at midnight so the bulk of the drive is quiet.” She also packs sensory toys such as vibrating beanbags, weighted toys or teethers to help her child remain calm. “Of course, the DVD is essential. I plan out a portion of the trip dedicated to the DVD player and use those CD over the visor storage units. Saves room. We also use headphones. You need to keep Mom and Dad sane as well.”

Marlo has also taken the nighttime drive with her children sleeping quietly in the back. “These past few years it just hasn’t worked as well. The first day is such a killer for the parents and the children are manic to start vacation. Now we start very early with the children still sleeping so some of the trip is quiet.”

In the past I have paired my older daughters with my son on a rotating basis. If they limit their time with him, and each other, fewer fights break out. At each rest room stop we look like a fire drill as the children all rotate seats in the car.

I compiled the advice and evaluated the advice. Nighttime driving was not an option for this trip. We did decide to start out after dinner with the hopes that the children would fall asleep. It worked partially. My middle child fell sleep and we couldn’t wake her to trade seats. After ten o’clock my five-year-old son fell asleep drooling on his fourteen year old sister’s shoulder.

The activities packets worked very well for the trip there. They didn’t work on the trip home. My son kept asking repeatedly for his ‘new’ toys. We almost had a melt down on Highway 80. My daughters averted the crisis by sharing their toys with him. My daughters loved their gift bags and enjoyed them thoroughly. My son enjoyed the

inexpensive dollar store items more. I carefully selected items that did not propel, launch, pop or crack. We didn't want Dad to worry about gunfire or blown tires.

I rented several CD's from the library. I selected movie soundtracks they enjoyed as well as sing-along CD's of pop songs. We enjoyed those for a few hours. My husband even joined in much to our surprise and then dismay. We all laughed loudly when Mom and Dad couldn't keep up with the pop song words.

The restaurant backpack was a lifesaver. My son does not color so he loved playing with his own toys and sucking on candy while waiting for his kid's meal. He showed his waitress that he brought his own toys. He told her she could keep the crayons.

The Leap Pad was a great hit. I selected a few books on topics that interested him. Classics like Spiderman, Superman and Sponge Bob. The headphones and Leap Pad kept him entertained for almost a whole hour! I admit that he has played with it since the trip during his quiet time.

Another unexpected benefit was having the headphones in New York. My son is sensitive to sound. The headphones helped him deal with the noise and keep him calm during our visit.

Of course, the biggest hit was the DVD player. Fortunately, I had rented several newer releases from the library. Utilizing the storage solution over the visor, I cut down on the floating debris around my feet.

I do wish I had purchased those disposable wipes. I must not be a good housekeeper to not have those in the car. There are distinctive handprints on the windows. Guess whom they belong to? Another item that I will purchase for the next trip is behind-the-seat organizer for the clutter. I am still finding pens, lip-gloss and shoes in the van.

All in all we made the eight-hour trip without killing each other. Not entirely blissful but we did end up having a good time. The experience has taught me that the key to any travel is in the preparation.

Perhaps we could survive a trip out west? Well, not yet.

STRATEGY FIVE

SURVIVING THE URBAN JUNGLE

With children in tow, we have visited several large urban cities from Cleveland to Pittsburgh to Orlando and even New York City. Visiting large urban centers presents unique challenges. Traffic, crowds and transportation all create an overwhelming experience for many of us – let alone a child with autism.

All of the strategies mentioned apply when visiting a large urban city. The most important is keeping a close eye, hand or grip on your child. One dart away from the family would mean disaster for everyone. There are two options that a family should consider in any situation but especially when visiting a large city.

A personal locator product operates quite simply. There is a base unit that can be carried on your person or placed in the home. A watch or attachable belt unit is placed on your child. If your child leaves the “safe zone” an alarm emits and the base unit enables you to find your child. Cost of a personal locator system ranges from \$200 to \$500 depending on options. Several of the systems viewed did not have monthly fees. Portable GPS tracking systems also work well for your child. The unit can be used as a watch or belt system. Several units are as small as a set of keys. Units begin at \$400 with monthly service fees.

For those of us who are not comfortable in large cities, the first rule of thumb is to relax. Just like the advice for an amusement park, stress and anxiety can exacerbate your child’s self-stimulating behaviors. If you relax and take the visit in stride, everyone in your family relaxes and enjoys the trip.

Preparation is crucial for a trip to a large city -- especially a city like New York. Transportation is confusing for a native and even more so for a tourist. Take some time before and read everything you can about subway systems, cabs and walking. Purchase a

small pocket size map that is readily accessible. If you are at concerned about getting lost, or not being safe in general, take a cab. The expense is often offset by ease and convenience.

We took the subway in NYC. I spent several weeks reading and rereading everything I could. I knew that cab fare would greatly tax our budget and the subway was only \$2 per person per trip – not accounting for transfers. I entered the subway at a large center, such as Rockefeller center, and stood to the side. I watched the people and read the signs. After understanding the crowd flow, machines and information centers, I approached a policeman and asked questions about tickets. Within minutes I had purchased passes and boarded a train. The subway system is well marked and people were very friendly. My children loved the experience – especially my autistic son who loved the train!

Of course, the most economical solution is walking! And do you walk! And walk and walk and walk. Wear good shoes. This is not a time to worry about fashion. You will walk more than you ever anticipated!

Have an emergency back plan. I spent several months teaching my children what a policeman looked like and coached them on approaching the police officer in case they were lost. I had military like dog tags engraved with pertinent information in case of emergency. We also role-played the situation several times. This is an excellent use for social stories.

All in all, we visited Chinatown, Little Italy, Soho, Manhattan, Times Square and Wall Street. The children went everywhere we did and had a wonderful time. Not as peaceful as a camping trip or exciting as an amusement park but definitely a family favorite!

STRATEGY SIX

LEAVING ON A JET AIRPLANE

By now, many of these strategies begin to blend together. Preparation, preparation and preparation should be engrained in your mind. A trip on a plane is whole different situation.

You need to think of not only the flight itself but also booking the flight, airport security, airport and airplanes. There are several tricks you can employ to make your experience hassle-free.

Before you pack, you purchase a ticket. Even if the expense is more, minimize your connections. If possible, book direct. One up and one down. Less ears popping and less hassle in the aisles. Notify the airlines that your child is autistic and has special needs. They will allow you to board early or late – whatever your need to make the experience easier.

On a previous trip to Florida, we booked a cheaper flight with a layover in Atlanta. Due to bad weather, we were stranded on the runway for 2 ½ hours while all the direct flights continued on. Last summer I was smarter. We flew to Florida again and I booked a direct flight despite the increased cost. Within two hours we were in Florida with luggage and at the car rental counter! Heaven!

When considering the airport, think of it as similar to a mall. Implement all of those strategies for your child that you use for the mall and apply them to the airport. Remember, once you cross security, you are subject to the merchants on the other side. If your little tykes only eat gluten free food, be prepared to bring it. Options will be limited. As well as expensive. There is a 3 oz limit for liquids and they need to be in a zip lock bag. On the other hand, there are lots of caffeinated beverages to help you cope.

Security is always a joy. I say with a touch of sarcasm. Before you leave or even dress for the flight, log on to www.tsa.gov for the latest regulations. The latest changes include regulations regarding carry on liquids, removing shoes and checking luggage. Plan to arrive early and take your time. Explain to security that your child has autism and they will try to accommodate you while ensuring your safety.

The flight itself can present challenges. I have a terrible time with the popping of ears and head pressure. For this reason alone, I take hard candy and gum. For my child, I include chew toys or pacifiers. My doctor even recommended a small dose of antihistamine to calm the child on the flight. Check with your doctor first if you are considering this alternative.

Make the trip more enjoyable. Plan with DVD's, MP3's, iPods, books, toys or just about anything that will keep your child occupied. Relax and enjoy the time you have together.

STRATEGY SEVEN

A VISIT TO THE RELATIVES

Nothing can be more stressful than spending several days at your relatives out of your element, your children's' element and your relatives element. For many a trip to the relatives is a time of great joy – for others, great stress.

In a hotel room, rented condo, or amusement park, you can be an island among a sea of strangers. At your relatives, you can be a group of strangers among seemingly normal people. Sort of like autism under glass. Not to mention the tide of well-wishers with a list of remedies guaranteed to cure your child. The list goes on.

After this introduction you will never visit your relatives. Don't despair. Remember your mantra ~ PREPARATION. You *can* enjoy family time again.

First, pick your battles. Stress over the holidays can send anyone over the edge. Instead of spending the holiday with your relatives, select the weekend before or after. For example, Christmas falls on a Wednesday. Plan a visit the weekend after Christmas but before the New Year's holiday. You could also skip the month all together and visit the first free weekend in January. Your relatives should understand, but if they don't, don't worry about it. Remember, this is your time as well.

Second, take your army with you. We all have someone in our neighborhood that could be a mother's helper. This is most likely a neighbor, who is not old enough to babysit alone, but great with the children. Hire her for the visit. Take her with you to play with your other children; a second set of eyes on your autistic child while you visit the bathroom or just an extra set of hands. Select a young person that reduces your stress not adds to it.

Third, develop a thick skin. Well-wishers will dump their sure fire methods of curing autism. Listen, nod your head and continue on your way. This is your relative so

don't make them your enemy by being combative. You won't have to see them until the next holiday anyway.

Fourth, take an arsenal. Take anything that will make your life a little easier. Sensory toys, obsessive objects, video games, movies – just about anything that will keep your child occupied. Don't worry if you commandeer the TV during the football game. They would rather your child be calm than tantrum during the fourth quarter.

Fifth, to continue the military talk – go AWOL. Take a walk around the block. Walk the mall. Visit a playground. Go for a bike ride. Take the children or go by yourself. Anything to keep your sanity.

Sixth, repeat after me – it is only temporary.

Most of all, relax. Visits to the relatives can be stressful. But they are temporary.

STRATEGY EIGHT

TAKE THE LEAP AND JUST GO

Fear is an illusion. That is the saying on the back of my daughter's rock climbing t-shirt. While traveling with an autistic child is not rock climbing, the stress, preparation and joy in accomplishment are equal.

For many people, the safest course of action is to keep the routine. Don't vary from it. Keep the tutors, therapies, teachers, play dates, speech, occupational therapy, etc. The focus is on your child and not on you or the whole family.

That is not necessarily a bad thing. It is good that you focus on your child. You should as parents do what you can for your child. Don't forget your family as a whole. Time away builds closer and stronger relationships. Your own internal family support can help through the bad times and enjoy the good times. The memories you build on a trip together will sustain through the worst of the bad times.

Even if you have tantrums, melt downs, odd behavior and the like, ask yourself "Who cares?" What does it matter? This isn't about the strangers around you but about you. Focus on the good time together such as the waitress who mixed up your order and how funny that was not that some of the food was cold. Mental attitude is half the battle.

Our first vacation with my son was a struggle. We booked a suite for spring break at a mountainous state park resort so my husband could nearby. Unfortunately, the hotel was under construction and very loud. We asked to be moved to a cabin. Within 12 hours, we experienced a freak snowstorm. I was stuck in a small cabin with three children for three days without winter weather apparel, television, toys or car. My son was completely out of his element and routine. Creativity was my savior. I was completely unprepared. I remembered that what I enjoyed most about vacation was the

slow speed and time together. I gambled that my autistic son would as well. We played paper basketball with the garbage can. We had sliding competitions down the hallway. The list goes on. While I remember that as a stressful time, my children really enjoyed the week.

I was very afraid to go on vacation again. In fact, the first camping trip of the summer was a rainout. We were confined to a small camper during severe thunderstorms. Learning from spring break, we created games in the limited space having a wonderful time. I learned that slowing down is the greatest preparation.

Most importantly, just go. As you go, you will develop your coping mechanisms that work for you. Probably more than I can list here in these articles. You are a competent person who can take care of your children and still have a good time!

STRATEGY NINE

DAYTRIPPER YEAH

Start out slow. Work your way up. Take your time. One small step. All of these colloquialisms have the same meaning. Before you take that whole week away, try a day trip first.

I mentioned in strategy eight that you will develop your own arsenal of coping techniques. This is the method to help you start.

Before you pack your bags for day, think about what you like to do. Visit a zoo, pool, local park, nearby state park/nature reserve, amusement park and more. Select one that best suits your individual interests. Make sure that the drive isn't too far and keeping in the one-day theme. Or one tank trip if you wish.

Keep the budget small. If you make the trip economical and it goes horribly wrong you won't feel double the guilt. You may just want to plan a trip to an outlet mall and walk the stores. Don't take any money – just enough for lunch. And walk the stores. You will gain an idea of what you need away to help your child. While keeping your money close.

Leave something in the car. Daytrips are usually easy to plan. Yet you can still over pack. So keep something in the car. While you are walking the zoo or hiking the woods, keep most of what you brought in the car. Only take the essentials with you. This keeps your hands free and the focus on your family. You learn what is really important to take as well. Valuable information for those further trips abroad.

Take the whole family. Everyone needs to go with you. You need to learn to cope as a unit with your autistic child. Not just parent and child. All of you. The sooner the better for you and your children.

Make a list. When you return home make a list of what worked and what didn't. Keep a file or notebook on your experiences. The list will come handy when you are ready to venture further a field.

STRATEGY TEN

FOR MORE INFORMATION

I am a firm believer of reading and rereading. Why recreate the wheel? Here are links to websites that hold a wealth of information.

Medical Travel

A website dedicated to assisting those with disability issues should visit www.medicaltravel.org. This website also provides information on accessible villas in Orlando, please visit <http://www.medicaltravel.org/housing/villas.htm>

Cruises for Families with Autistic Children

A part of Alumni Cruises, Autism on the Seas provides group cruises with dedicated services for families of children with autism. The services include, but not limited to, private dining rooms, private rock climbing, private children's activities and more. Four cruises are targeted for 2008. For more information, please visit www.autismontheseas.com.

Society for Accessible Travel

A non-profit association that promotes accessible travel and provides resources for individuals and families with disabilities. Visit www.sath.org

Airport Regulations

Are you flying instead of driving? New regulations in the airline industry can make any plane trip a hassle. One of the biggest recommendations if you are flying is to arrive early and pack a bag to keep your child occupied. For help with your trip, here is the

Transportation Security Administration web page for individuals with disabilities.
<http://www.tsa.gov/travelers/airtravel/specialneeds/index.shtm>

Taking the Train

Here is your www.amtrak.com information on services provided by Amtrak for those with disabilities.

Autism Awareness Cards Wording

Various agencies sell cards online. Here is a sample of the language.

*I apologize if my child was disturbing you. **AUTISM** is a neurological disability affecting about 1 in every 150 children born today. **Behavior that may on the surface seem rude is my child's ONLY way of dealing with the world.** If this is the first time autism has touched your life, be grateful--and please be understanding.*

MEET THE AUTHOR

Ann Schlosser is mother to a young child with Autism Spectrum Disorder and two neurotypicals. She is a high school English teacher, author and autism advocate. Living with her own medical problems, Ann and her husband decided early that their child would go where they went. Since the diagnosis, they have traveled to the New York City, Walt Disney World, ocean, mountains and camping. Knowing the difficulties of travel with neurotypical children let alone a child with autism, Ann wished to share her stories, critiques and tips to traveling with a child who has autism so that you can learn how to enjoy the wonderful adventures and magical moments that await you and your family.