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Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

Enjoying the magic of Christmas – autism style

By Liz Becker

As Christmas approaches I can't help but reflect on the years past and how my son Matt has changed in his own way to embrace the spirit of the season. Matt is almost 26 years old, so there's plenty to reflect upon. As I thought about all of our unique experiences I wondered, "Do other parents of autistic children have this much fun?"

I use the word "fun" because looking at it from my point of view it would all make such a great movie, a comedy I think, about learning the true meaning of Christmas. Don't get me wrong, there were a few years with too much family drama. Some were budget-breaking extravaganzas, while others were completed on a shoestring, financially. Some were tearful - due to overwhelming joy, and others tearful because they were absolutely heart-wrenching. Yet all, every single one, ended with the warmth of a love-filled home, smiles on children's faces, full bellies, and plenty of unforgettable (and sometimes pretty hilarious) memories.



We always went on a drive to see Christmas lights and decorations on or near Christmas Eve and we always waited to put the toys and gifts under the tree until after the kids were asleep. This was a challenge as every year for 10 years Matt would camp out in the hallway with his pillow, blanket and fan (he has slept with a humming fan next to his head all his life) to await the arrival of Santa (maybe catch a glimpse) and we had to traverse this blockade without waking him. It was a two-person job - a team effort - just to get the packages from point A (bedroom closet) to point B (under the tree.) Matt never knew, never awoke even once and it kept the magic of Christmas alive, and the illusion of presents just suddenly appearing under the tree safe for another season.

There was the year of my divorce where I had nothing to give my children, no money to buy gifts and no tree decorated and blinking. Just days before Christmas friends and family got together and delivered a small decorated tree, supplied gifts for my children and took us into their home for a holiday feast. Just days before I had been caught crying by Matt. He responded by crawling into my lap, putting his hand on my face and said "momma" for the very first time. It turned out to be one of the best Christmases ever for me.



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AUTISM CHRISTMAS CONTINUED...

There was the first Christmas after autism set in when Matt loved the boxes more than the toys that came in them. There were several where he fought Santa tooth and nail at the Mall, and another where the one toy he wanted was the one toy we searched for in store after store for weeks to no avail and had to leave a note under the tree that promised one would arrive soon. The Christmases after he could write were much better because we encouraged him to write to Santa (you know, that bearded guy he fought tooth and nail just a year before). The letters gave us insight to what he really longed for and sent us on a mission to obtain said items early in the season to make sure a note would not have to go under the tree ever again. Matt asked for a wide variety of items over the years: building blocks and Lego kits, Ninja Turtles, Ghostbusters, Jurassic Park vehicles, Toy Story action figures, Thomas the Train VCR tapes and train accessories, space shuttle models, airplane models, a Big Wheel, a bike, Home Alone tapes and art supplies, books, clothes (as a teenager he became aware of his appearance and actually wanted clothes!), and sports paraphernalia for Virginia Tech. Take a look at that list again - nothing in it says autism . . . nothing.

Church plays and concerts were met with tantrums and meltdowns - Matt hated the loudness of the music and although fascinated by the plays, did not wish to partake as one of the shepherds. Instead, Matt crawled under the pews or walked the periphery or explored any region of the church he could get away with. This meant I was constantly looking for where Matt was while trying to watch our other children perform. And there were times when I had to miss something - a line, a song, a part of my other kid's holiday, to run after or console a weeping Matt. But children of all ages act out at times or are afraid and must be consoled. I would wager that most parents at one time or another miss their other children's stuff too. Autism doesn't cause the problems - childhood does.

And while visiting Santa was traumatic as a small child, he finally did grow a desire to talk to the big guy in the red suit and it evolved almost overnight into a must-do ritual. Did it really matter that he was now 10 - 12 years old and twice the height of the other children in line? Did it matter that he would only stand next to Santa and talk, not sit on his lap? It never fazed Santa, it never fazed Matt and it never fazed us.

Then one year it happened - Matt no longer wanted to see Santa. He had become skeptical of the magic tale and he needed something more. It was finally *time*. We all know it will happen and we all know we have to eventually break the news to our kids, but how you do it matters - it matters a lot. Breaking the news of the childhood lie was something I had thought about for years - literally. When it came time to sit him down I was ready. I told him that little children believe in a Santa Clause because it is magical and fun. I told him that as a child becomes an adult they know something is amiss - this is because they get smarter. I told him that adults are Santa and when they become adults it is their job to keep the magic a secret and be the Santa for others. Matt especially liked this idea. He would be the secret Santa and keep the magic alive -- he took this responsibility to heart.

Every year since our talk, Matt has been the essence of the Christmas spirit. He hunts for items for each family member and wraps them and puts them under the tree. Matt even buys for himself. He wraps it up and puts a tag on it - *to Matt from Santa* - and on Christmas morning he opens the gift that he himself wrapped and is wonderfully surprised and excited to find exactly what he wanted. His joy at watching Charlie Brown and Snoopy, the Grinch and Rudolph are contagious as well as his excitement at decorating a tree, stringing lights and wrapping gifts. Matt lights up our home and our hearts. Our other children are all grown up and moved away into their own homes and are creating their own season of magic. Yet even with our children grown and our house mostly empty we still have plenty of the Christmas spirit lighting every dark crack and crevice. Matt remind us daily that it is love that matters most - not the gifts or twinkling lights or Christmas songs but the deep desire to give the gifts, wanting to display the lights and to sing the songs that makes it all so magical. Autism does not prevent the desire and it does not prevent the love from being felt. Autism is just the surface. What is inside each of us is what matters, autistic or not. For my husband and me, Matt makes Christmas, Christmas.

I know it sounds too warm and fuzzy to some of you. I can assure you it was not always this way. We felt the aloofness of extended family members, the constant veil of stress, and jumped the hurdles that appeared almost daily from out of nowhere. But that was "then". Something changed along the way and it wasn't just Matt - it was me too. I am now the one who rides the waves of autism with him taking away from each experience the comedic factor and laughing away the conformist part of me that used to think everything had to be just so perfect. I understand now that life really is what we make of it - should Christmas be any different? Enjoy the quirks, survive the stress, and be ready to look back and laugh. Think of the stories you could tell!

Matt just finished wrapping another gift he bought for himself and placing it beneath the tree. I can't wait to see his surprised and joyful expression when he opens that same gift on Christmas morning! It's Christmas - autism style.

Courtesy of [Liz Becker](#)



Holiday Road Trips: Five Tips to Reduce Stress

This is a post by Autism Response Team Senior Coordinator Emily Mulligan. For resources and information, contact the Autism Response Team at familyservices@autismspeaks.org or by phone at 888-288-4762 (en Espanol 888-772-9050).

Although the holidays are a wonderful time to spend visiting with family and friends, holiday travel can be stressful for many individuals with autism and their families. For some families affected by autism, even driving to visit relatives can become a complicated endeavor. However, with a little planning you can make car trips go more smoothly for everyone. To help, we have compiled some tips to keep in mind when preparing for a car trip during the holidays.

1. Bring Supplies.

One great strategy for keeping kids happy in the car is packing a bag with a variety of toys, games, and distractions for your child. Consider purchasing some small, inexpensive (think Dollar Store) toys and items and putting them together into a car goody bag – this will be exciting for your child to open, and discovering the array of new toys may keep him occupied for longer. Other things to bring:

- Preferred toys
- Books
- Music player or CDs
- Noise-canceling headphones
- Small fidget toys, such as Slinkys, koosh balls, etc.
- Portable sensory items like a weighted lap pillow or a soft arm brush.



Change of clothing

If your child communicates using an alternative method, make sure you have all the necessary supplies (including a portable charger for any electronic devices).

If you have an iPad, tablet, or portable DVD player, these can be great to keep your child busy in the car. Download a movie ahead of time, or bring a few favorite DVDs to watch.

Make sure you also bring some favorite snacks and drinks, particularly if your child has dietary restrictions, to avoid any hunger-related issues.

2. Use Visual Supports

Children with autism often do well with pictures and visuals. Before you leave, it could help to make a visual schedule of your trip so that your child knows what to expect. Include things like bathroom breaks, stops for meals, and activities your child may do in the car.

Social stories are another great tool to help your child prepare for and rehearse events that are out of the ordinary, like a car trip or vacation. You can find some examples and templates to help you create a social story here: [Forms and Personalized Stories from Microsoft Word](#)

For more help with visual supports, download the [ATN/AIR-P Visual Supports and Autism Spectrum Disorder Tool Kit](#).

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HOLIDAY ROAD TRIPS CONTINUED...

4. Take a break!

Before leaving, consider the length of your journey. How long can your child reasonably sit in the car before beginning to get antsy or upset? If you are planning to drive for a few hours or more, map out some strategic stops where your child can get out, stretch his legs, use the bathroom, and escape the car for a few minutes. Make sure to listen to your child if he indicates he needs to take a break – better to lose a little time than to face a potential meltdown on the highway!

However, keep in mind that some children do have trouble with frequent transitions. If this is the case for your child, try to limit the number of times she has to get in and out of the car.

5. Practice and reward positive behavior.

Instead of waiting until your child has a challenging behavior, try to notice the times when he is sitting in his seat appropriately, reading quietly, sharing with his sibling, etc. Reward this with praise, a sticker, a token on his token board, a small toy, or anything else that is reinforcing for your child. You could even consider having your child earn a special reward at the end of the drive for following the “Car Rules.” These rules could include things like staying in his seat, keeping seatbelt on, no hitting siblings, and so on.

For children who do have a hard time with traveling, practice ahead of time! Start by taking your child on a short drive, and reward her for following the “Car Rules.” Then, gradually increase the length of time she is sitting in the car and following the rules. This will teach her what you want her to do, and help her practice tolerating more time in the car. That way, when she does have to sit in the car for a longer trip, she will be used to it!

Most families will have to take a trip in the car at some point, particularly around the holidays. While the prospect of several hours in the car can sound stressful, a little preparation can go a long way. By planning ahead you can make the journey much smoother and set your child up for success! For more great tips to reduce stress when traveling, see the following resources:

[Traveling Tips for Individuals with Autism and Their Families – Community Connections newsletter](#)

[Ten Strategies for Traveling with a Child with Autism, or, How Do We Survive the Trip? By Ann Schlosser](#)

[Travel Trips for Families with an Individual on the Autism Spectrum, By Chantal Sicile-Kira](#)

[Adventures with Autism: A Guide to the Airport Experience!](#)

[Safety Products, including Seatbelt Buckle Guard, from our Resource Library](#)



ADDITIONAL SUPPORT ARTICLES ON THE WEB

Holiday tips from Autism Speaks: before, day of, during the event

<https://www.autismspeaks.org/blog/2013/11/19/holiday-tips-kids-autism-spectrum-disorders>

Sensory Activities for the Holidays: Baking, Crafting, Making Music

<http://www.brainbalancecenters.com/blog/2011/12/sensory-activities-for-the-holidays/>

Meltdown Strategies: schedule, code word, family meeting, sensitivity support

<http://www.brainbalancecenters.com/blog/2012/11/special-needs-update-avoid-holiday-meltdowns/>

Helping a child with transitions: Being Child Centered & using tools to help

<http://www.wikihow.com/Help-Autistic-Children-Deal-with-Transitions>

SELF REGULATION

Self Regulation Strategies...How You Can Help Your Child

September 5, 2014

Before you get to this...

As we have discussed in the past, most Autistic children have issues with self regulation and tend to have difficulty expressing themselves. Zak typically struggles to tell us how or what he is feeling. And once that frustration takes over for him, it is too late. He explodes. He melts down. It is heartbreaking to see because, as we sit on our neurotypical high-horses, we feel like self-control should be easy by simply expressing himself. But that is not the case in our autistic kids (and any child or adult for that matter). There are many things that we are constantly doing to help improve his self-regulation and emotional responses.



Here are some tips we are learning and strategies to use if you child has difficulty with self-regulation.

1. Provide a predictable, structured routine. This has really helped Zak over the course of time and is especially helpful in school. Self regulation in school is very important to his success.
2. Provide visual supports (gestures, facial expressions, photos, schedules). Visual support is helpful for every child, not just one's affected with ASD. Most or autistic kids benefit from visual support materials when it comes to self regulation strategies.
3. Offer choices to your child. It is important to provide both verbal and nonverbal support and allows the child to feel more in control of the situation.
4. Recognize the signs. One of the most important things you can do is understand what causes your child to melt-down (not a tantrum which is handled much differently). Provide information before an issue occurs (Zak, you have only two more, you can do it!). This can be key in self regulation as the child knows there is an end point give them some control over the situation.
5. Follow your child's lead. Offer assistance or join in.
6. Use time-delay to encourage initiations.
7. Allow your child to work at his/her pace.
8. Ensure expectations are developmentally appropriate. Pushing your child is good. Pushing them over the edge, beware what is to come!
9. Model appropriate nonverbal and verbal communication and request imitation.
10. Define clear beginning, middle and end to activities. Use reminders and timers to help.
11. Provide repeated learning opportunities throughout the day for targeted skills.

It is a non-stop process and you must be focused to ensure the child's self regulating success. I can tell you it is not easy. Sometimes, stress or simply being tired are easy excuses – been there. It is the most important thing you can do to help your child is to help them understand how self regulation strategies will help them stay in control. Give them the tools and skills necessary to succeed and constantly work with them to ensure self regulation success.

For years, we have been working with Zak. The therapy and the reinforcement, we know we are doing something right as he continues to improve every day. Especially when Zak come home with a positive day or when he gets on the phone and talks all about his day to grammy! Makes it all worth while.



(Prizant, B., "Module 4: Enhancing Social Developing for Students with ASD in General Education Classrooms." www.usm.med.sc.edu)

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HOLIDAY RULES

HOLIDAY RULES WHEN YOU HAVE KIDS WITH AUTISM

EMBRACE THE HOLIDAYS ON YOUR FAMILY'S TERMS.

It's OK if your holidays look different than ingrained expectations -- other people's probably do too!

ALWAYS HAVE SOMETHING ON THE HOLIDAY TABLE
YOUR CHILD LOVES TO EAT.

ALLOW YOUR CHILD TO MOVE IN AND OUT OF FAMILY
GATHERINGS.

GIVE YOUR KIDS THE GIFTS THEY WANT, NOT THE ONES
YOU WISH THEY WANTED.

It's hard to resist the educational toys your child needs, but ask yourself, "will they be excited to see what's inside?" if not, don't wrap it!

BUY GIFTS BASED ON THEIR INTERESTS -- MUSIC,
TRAINS, LIGHT - UP TOYS, EVEN FOOD!

It's OK to wrap candy.

WHEN IN DOUBT CHOOSE SENSORY GIFTS -- THEY ARE A
GIFT FOR THE WHOLE FAMILY.

Swings, weighted blankets, trampolines, etc. can make the child more comfortable and meaningfully engaged, giving the whole family the gift of peace.

HAVE WRAPPED GIFTS READY TO GO OUT OF THE
PACKAGE.

What child has the patience to wait for their gift to be detached from the packaging, assembled, batteries inserted or inflated?

UNDERSTAND THAT EACH CHRISTMAS OR HANUKKAH
CREATES YOUR CHILD'S MEMORIES AND ASSOCIATIONS

FOR THE FUTURE. *Enjoy, relax, make it fun and they will look forward to the holidays next year.*

AutismCommunityStore.com



“People Files” and Gift-Giving: Help Your Child Think About Others

People files (also known as social files or friend files) are a concrete way for students with autism to 1) understand that others have interests, likes and experiences different from themselves and 2) conceptualize how to remember and use this important information about others to foster relationships. The concept is pretty basic: each of us stores information about family, friends and acquaintances in our minds, in a sort of file. Thinking about it as a file in a file cabinet (or on a computer) gives kids a very simple image to remember and refer back to. In the file, we store information about someone’s **F**amily/friends, **I**nterests, **L**ikes and **E**ducation and past experiences. When we see someone, we bring up our people file on that person to help us generate topics of conversation or choose activities that the person would like – a crucial skill for building friendships. For kids who have difficulty remembering the information or understanding the concept at first, a physical file of details about friends can be made and kept in a safe place.

Gift-giving during the holidays is an excellent time to practice creating and using people files. Many children, not just ones with autism, become preoccupied with receiving their own gifts and do not take part in choosing or purchasing presents for others (other than perhaps signing their name on a present someone else bought for them to give). Because people with autism have difficulties taking the perspective of others, you will likely need to guide your child using the following process:

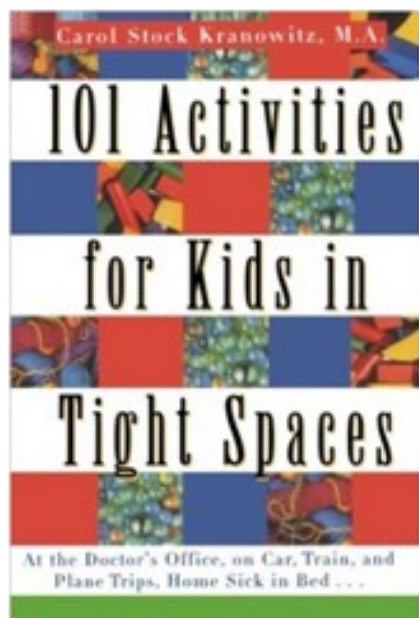
1. Choose a person to give a present to. It is recommended to start with an immediate family member or someone you know well, so you can best support the child’s planning.
2. Make a list of the person’s interests and things they like to do. If your child says, “I don’t know,” don’t immediately give them answers. Prompt their thinking by:
 - Asking leading questions such as, “Dad spends a lot of time in the garage. What does he do in there?” or “What does your brother always do after he finishes his homework?”
 - Investigate family member’s bedroom or other spaces they spend time in to find clues about what they like. Guide your child to look at relevant items (for example, poster of a music group on sister’s wall, sports team logo on father’s shirt, Lego bin in brother’s room).
 - You can also coach your child to ask the person what they like, but do some of the previously-described “detective work” first, to really get them thinking about that person.
3. From the list of interests and likes, generate some possible gifts. Brainstorm whatever ideas come to your minds, but only write down the ones that are actually feasible. Consider presents the child can make (by themselves or with assistance). Warn the child that some ideas may not be possible due to time or expense, but still praise them for thinking of such a thoughtful gift.
4. Have child choose a present to give from the list. For some kids, this much thoughtful planning is enough, and you can buy the present (though have them be involved in wrapping it somehow, or at the very least, let them see it before it is wrapped). Other kids may be able to handle going to the store to help pick it out, or if possible, create a hand-made gift.

If the family member or friend has a wish list, still go through steps 2 and 3. Then look at the wish list and make a choice. Notice if any of your ideas for presents are on the person’s list. If so, give praise for making a good guess about what they want. You may also decide to surprise them by getting something not on their list.

After you choose and purchase the present, encourage further perspective-taking by asking, “How do you think she will feel when she opens it?” or “How do you know he will like it?” Anything you can do to encourage your child to think about the thoughts and feelings of others, and to help them understand that they can make others feel good, will be instrumental in developing their ability to have reciprocal relationships.



BOOK SUGGESTIONS



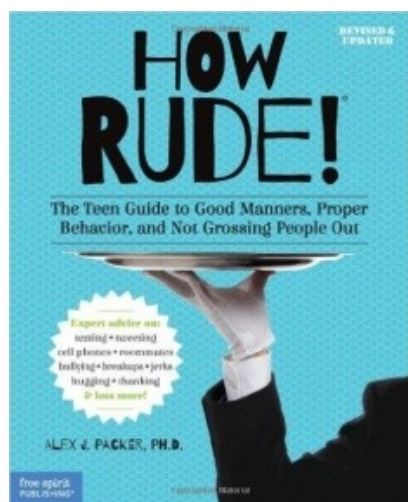
101 Activities for Kids in Tight Spaces:

At the Doctor's Office, on Car, Train and Plane Trips, Home Sick in Bed...

by Carol Kranowitz

If you need ideas for kid-friendly activities when traveling, staying at grandparent's house, or just hanging out at home over the holidays, check out this book by the author of *The Out-Of-Sync Child*. Kids need room to move around, but there are many times when they just plain can't have it – like cars, planes, trains, the doctor's office, the grocery store, being sick or housebound, waiting in line.

Kranowitz's activity ideas combine old standbys with new ones born of desperation and cramped quarters in her own experience raising two exuberant boys. They follow a philosophy that helps kids develop their different skills and abilities while entertaining themselves and interacting. Her easy-to-implement activities are fun for the three to seven-year-old – and can turn tough moments into teachable, terrific ones.



How Rude! The Teen Guide to Good Manners, Proper Behavior, and Not Grossing People Out

by Alex J. Packer

The different kinds of social situations that arise during the holiday season make it an ideal time to review manners. Explaining etiquette from A (“Applause”) to Z (“Zits”), the author blends outrageous humor with sound advice as he guides readers and explains why manners and etiquette are important—because people who know how to handle themselves in social situations come out on top, get what they want, feel good about themselves, and enjoy life to the fullest.

Full of practical tips for every occasion, *How Rude!* is a serious etiquette encyclopedia—and a hilarious read. In 480 pages, this revised and updated edition describes the basics of polite behavior in all kinds of situations at home, in school, online, and in the world.



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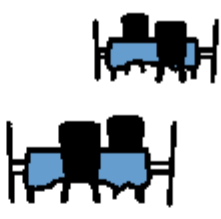
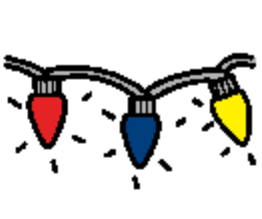




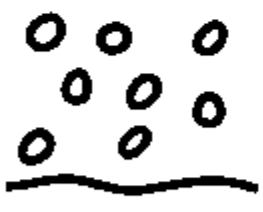






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VISUALS

thank you 	party 	restaurant 	lights 
ornament 	New Year's Eve 	snowflake 	snowman 
snowing 	gift 	Christmas 	caroling 
Chanukah 	snowsuit 	winter 	Kwanza 