



AAPC Community of Support: For Parents, Professionals and People on the Spectrum

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★ **Welcome to AAPC's Newsletter!**



Join us for our special family holiday issue! In order to meet the needs of our community, the newsletter is undergoing a transformation. Over the next year you will continue to notice changes and new additions, including contributions from columnists who are well-regarded authors and experts in the field of autism spectrum disorders. We will cover a wide variety of topics for Parents, Professionals and People on the Spectrum.



We'd also like to hear from YOU, the reader. Perhaps you have questions you'd like to have addressed in future newsletters by our panel of professionals, or maybe you have a touching, heartwarming or encouraging story to share. Communities are stronger if we pull together and lend our mutual support. We invite you to be a part of our growing community; we will all be better for having you with us.

As the holidays are approaching, we continue to carry the survivors of the recent hurricane disasters in our hearts. It is a time to be thankful for our own well-being, but also to remember those who have suffered. It has been especially difficult for the families who have children with autism and other disabilities. As a mother, I cannot help but feel tremendous empathy for the overwhelming difficulties they must have

experienced trying to keep their children safe. Tragedy strikes randomly, and we are often caught unprepared. I encourage you to take a moment to visit the Autism Society of America homepage at www.autism-society.org Please read through the disaster preparedness list and follow their suggestions for your own family. And as we enter this time of giving, let us not forget the organizations that support our autism community. Peace on Earth.



Kristi Sakai, Editor

★ **In This Issue:**

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★ Sibling's Eye View:

Everything I Learned About Life I Learned From my Brother



I grew up in the 80s when “autism” was not a household word and not a celebrity cause. Having an autistic brother who was hyperactive was not always the greatest fun in the world, but it was interesting, and I learned a lot about life and how to live it from him. Here's what I learned from David.

1. Never be afraid to show your feelings: Love, sadness, happiness, or anger.
2. Be fearless.
3. Be willing to try and to learn new things.
4. Make the best of what God gave you.
5. Learn patience.
6. Communication is more than talking, reading, writing and listening. It's also watching, showing and paying attention.
7. Live each day to the fullest.
8. Nurture your inner child.
9. See the good in others.
10. Always know where the bathroom is located.



-Deborah Reagan

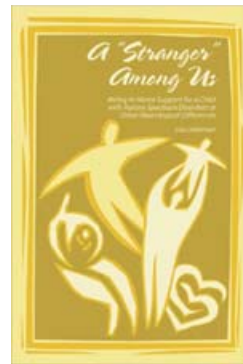
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★ Browsing the Bookstore



**A Moment with
Lisa Lieberman
*A Stranger Among Us:
Hiring In-Home
Support for a Child
with Autism Spectrum
Disorders or Other
Neurological
Differences***

“Hiring in-home support is truly not work for the faint of heart. For those of you who choose to bring that stranger into your home, or assist others in doing so, I hope it is clear how everyone wins – parents, children, spouse, providers, and ultimately the community in which you live. My family has been truly enriched by the presence of wonderful ‘strangers’ who have entered the circle of our family.”



Lisa Lieberman has written a new book, *A Stranger Among Us: Hiring In-Home Support for a Child with Autism Spectrum Disorders or Other Neurological Differences*, to help families in need of in-home care

systematically find and hire effective caregivers. Based on her personal experience—her husband of 26 years has multiple sclerosis, and her 17-year old son has autism—she has years of experience hiring caregivers for her family.



Lieberman is a trainer, writer and speaker with over twenty-seven years of professional experience. She maintains a private psychotherapy practice and travels nationally to present on issues related to living with disability in the family.

While working to juggle a challenging home life and a busy career, finding an effective caregiver was a critical element of the functioning of the family and home. While seeking options, she tried child care in community settings, day care at work and day care in private residence. She ultimately came

to the conclusion that having an individual come into their home was the best solution. After years of trial and error, defining her family's needs, finding and hiring a suitable caregiver and adjusting the process over the years to meet the changing needs of her husband and son, Lieberman gained extensive insight into what worked and



what did not. She decided to write a book to share her knowledge.

A Stranger Among Us starts by emphasizing the importance of defining your own family's culture. Armed with a clear understanding of your family's philosophy, values, lifestyle, level of formality, roles and responsibilities privacy issues and boundaries, makes it easier to write a more substantive and accurate job description for a prospective caregiver. Questions checklists and itemized "red flags" are included in the book.



Reprinted with permission from the Autism Society of Oregon's Insider newsletter & can be ordered at: www.asperger.net

★ [Adreon's Advice on ASDs](#)

Ten Skills to Teach Your Child in Preparation for Life After High School

Teaching adaptive behavior is one of the areas that are often overlooked for high-functioning individuals with autism spectrum disorders. However, adaptive behaviors have a tremendous impact on our ability to use our skills in common situations in everyday life. The following adaptive behavior skills are important if our children are going to experience

success without our daily assistance. Of course, every child is different. Often it is not possible to master these skills by the end of high school. However, most of our children can improve and become more independent if we consciously work on skills in these areas.

1. Teach your child to wake up to an alarm clock. It is common for parents to wake their children for school. However, as your child grows older, it's a good idea to teach him to wake up to an alarm clock. You may have to experiment with buzzers, music, and various degrees of volume. Sometimes, for individuals who are particularly hard to wake, you may need to have them walk across the room to turn off the alarm clock. Eventually, this skill would include having the child learn to set the alarm clock. A more advanced skill would involve developing the child's ability to accurately estimate the amount of time needed to get ready and determining to what time the alarm should be set.

2. Teach your child to refer to a clock and/or watch to complete a task in a certain period of time. A visual timer, such as the Time Timer*, may be helpful. The Time Timer dial graphically shows the child how much time is left. One way to begin teaching this is to have the child guess how long the task will take and then comparing how long the task really took to accomplish.



3. Teach your child grooming (shower or bathe within the last 24 hours, hair combed or brushed, deodorant, clean clothes). Our children find routines comforting. Therefore, help your child establish healthy routines. Many children find it easier (in the long run) to follow rules such as having a shower or bath

every day, rather than every two to three days. Specifically teach your child each step in washing properly (i.e., 4 times across each armpit with a soapy washcloth). Poor hygiene is a problem



poorly tolerated by the community (Peter Gerhardt, personal communication).

4. Teach your child to be responsible for his/her belongings. Start with things such being responsible to keep track of the toy train that he/she brought to your relative's house or into the car. Build into the routine that it is the youngster's responsibility to find the toy after the visit, bring it to the car, & bring the toy from the car into the house. Progress to items such as school backpack & supplies.



5. Teach your child to learn to use visual cues to remember tasks. This might be keeping medicine in a certain place, so he/she remembers to take it at breakfast each morning. Or, it might mean, writing lunch on a piece of paper & taping it onto the school backpack to remember to bring lunch.

6. Teach your child how to cook. Young children can learn to make a sandwich and prepare snacks that do not require cooking. Later, teach your child to follow a recipe independently and use kitchen appliances safely.



7. Teach your child to use the phone. Start by teaching your child to answer the phone, take a message & relay the message to the appropriate person. Progress to skills such as calling information to obtain a phone number, calling a store to see if they have a particular item in stock, calling technical

support to fix a computer problem, and ordering take-out food.

8. Teach your child how to go places independently. This may be walking to areas nearby, riding a bike, using public transportation or driving.

9. Teach your child to carry certain items when he/she leaves the house. This would include: Important phone number, money, house key, and possibly a cell phone.

10. Teach your child about personal safety. Consider skills such as knowing who to hug and kiss, and when it is more appropriate to shake hands, how to discretely carry money, **NOT** giving personal information to others over the internet, and what to do if you are walking down the street & someone unfamiliar approaches you or you feel that you are being followed.

** The Time Timer is available for sale on the AAPC website, www.asperger.net*

Diane Adreon, M.A., is associate director of the University of Miami/Nova Southeastern University Center for Autism & Related Disabilities. She is also the co-author of *Asperger Syndrome and Adolescence: Practical Solutions for School Success*, which is available for purchase at asperger.net

★ **Coming Soon!!**

Spectrum Perspective

with Stephen Shore

Kids Corner

with Haley Morgan Myles

Helpful Hints

with Elisa Gagnon

Circle of Friends

Reader Contributions



★ Family Support Holiday Meal Suggestions

Holidays are supposed to be Norman Rockwell picture-perfect moments: The extended family gathered 'round the heavily laden table with an enormous turkey, everyone happy and thankful. The only mischief involves children peeking through their fingers



during the prayers. Okay, now back to reality! Frankly, how often is it really like that for any family, much less AS families like ours? Before we

bask in cruel disappointment, with a little planning you can swing the odds in your favor to have a happy family holiday after all.

1. *Call ahead to family members whose support you want to enlist.* This includes clarifying to the host so he or she understands why/how you are planning to do certain things. For example, "We'd love to stay longer, but we are planning to leave at 7:00 p.m. because need Johnny to stick to his regular bedtime routine." This can help avoid the last-minute, "You're going already! But he's fine! We haven't had dessert yet! See, he wants to stay."
2. *Take along a couple of food items you know your child will eat.* If he decides to try something at the party, wonderful! But if not, you're covered. And if your child is on the GFCF (gluten-free casein-free) diet, take food even if the cook reassures you, "It's fine!" Not everyone understands what contains these ingredients, so better safe than sorry.



3. *Define expectations in advance for your child.* You can write a story, draw a picture or make a list. "We will play with cousins, sit down for dinner, grown-ups will visit for one hour, we will pick up the toys and say good-bye and drive home." Making concrete decisions ahead of time not only helps your child, it can help you think ahead about what potential problems you might encounter.
4. *Remember that it is not everyone else's responsibility to consider your child's needs.* Ideally they would want to, but practically, they probably do not even have the skills. The weight of making sure your child is okay falls on you entirely.
5. *Plan how you want to supervise/monitor your child.* If there are other kids, most other adults will probably leave them to play together in another room, only checking on them from time to time (if at all). If your child typically has difficulties in social situations with peers, it is the same even if these peers are cousins. You can choose to "see how it goes" by letting them play without any intervention, taking the risk that it may not go well. You can have a project that the kids can do together, such as a craft or a game (although that's tricky if you child is inflexible about how others play). You can check on them frequently, unobtrusively (walk by and peek into the room every so often without signaling your child or interrupting unless things aren't going well).



6. *Give countdowns to the child to prepare him.* “We’re leaving in 30 minutes. We’re leaving in 15 minutes.” If you lose track of time and you’ve stayed longer than intended, don’t rush the child. He still needs the transition time. Say, “Okay, you can play for 10 more minutes, then we’ll pick up the toys and leave.”
7. *Prepare to leave early.* Decide to cut things short if your child looks as though he is beginning to fray around the edges. Start the countdown early if necessary.
8. *Keep it light if your child really loses it.* You may feel some pressure that you should “lay down the law” to your child in front of your family members so they can see you’re a “good parent.” If you feel you need to say anything, you might choose to say the following with a smile, “Holidays are so stressful. He’s tired and I think we’ve overstayed our welcome.” If your child is in total meltdown mode, you can retire to a quiet room with him until he calms down. If there is no way to salvage the situation, we have often chosen to leave even while our child was still upset because the sooner he is out of the situation, the sooner he will feel better. Our kids often stop crying the moment they are out the door, or in the car.

Ultimately, you may choose not to do family holidays at all. Some families decide to do their own quiet holidays at home where they can control the atmosphere, menu, etc., and find it more relaxing and enjoyable. You can still get together



with your extended family for dessert, or have an after-holiday get-together with less pressure. When you first suggest this break with tradition, you may meet with disapproval from extended family members, but remember that it’s okay to choose to do what is best for your own family regardless of what others think.

From pages 100-102 of *Finding Our Way: Practical Solutions for Creating a Supportive Home and Community for the Asperger Syndrome Family*, by Kristi Sakai. Available for purchase at asperger.net

★ Take a Moment to Laugh! Turkey Day

This year we spent Thanksgiving with our friends Elizabeth and Dave, who have 10 (!) children, after I was inspired by her email to me. (It turns out the menu did NOT include Dr. Pepper and chocolate ants after all.)

From: Elizabeth
Subject: Thanksgiving



Hi Kristi,

When it comes to food I always find it helpful for my child to be “in a phase.” As in, “Oh Aunt Margaret, the turkey is lovely, but she’s in a chocolate ant and Dr. Pepper phase.”

How about the fad defense? “Well Uncle Ray, wearing only flannel pants and socks with seams on the outside is the fad right now.” And, “Oh yeah, refusing to brush hair is all the rage in the fourth grade, we wouldn’t want to spoil his self-esteem by making him act differently than the other kids in his class now would we?”

I like your suggestion of saying the kids have allergies, Kristi. You could get pretty far with that one. "No, Grandpa, he's not taking your chair to be rude. Please understand that he has a severe long-chain poly-carbon allergy and your chair is the only one in the house that doesn't contain them in the fabric. I would make him sit on the carpet, but just think of all the long-chain poly-carbons in the shag carpet." You could even buy one of those epi-pens with the red cross on it and it as an allergy bracelet for whatever he's adverse to this week. "Oh, so sorry, nothing with chlorophyll can even touch his plate or he'll go into anaphylactic shock. I have an epi-pen, but I'd hate to have to use it."



After years of these lovely holidays, when Dave asked me what I thought I'd make for Thanksgiving dinner, I told him, "Reservations."

My idea of the perfect Thanksgiving would be to invite all the kids with Aspergers, Bipolar, or whatever, and their parents. Each kid could submit two of their favorite holiday foods and wouldn't have to eat other people's stuff if they didn't want to. "Okay, I'll try the Dr. Pepper, but I ain't touchin' them ants." The adults could sit around eating what they want without stressing over what the kids eat or that everybody thinks they're weird. Dinner conversation would be along the lines of, "My favorite Pokémon is Pikachu." And "Oh did you know that the hydrogen bomb has only one electron?" or "You won't believe what I found in my belly button yesterday."



Parents smile and have a glass of wine with their dessert.

-Elizabeth Merritt

Also from *Finding Our Way: Creating a Supportive Home and Community for the Asperger Syndrome Family*. Available at Asperger.net

★ **Soon to be Released from AAPC**



A Rock and a Hard Place

By Anne Sutcliffe

A Rock and a Hard Place, a novel, draws the reader into the heart-breaking dilemma faced by

Lucy, mother of three children, the oldest of whom has severe autism. Due to 9-year-old Hollie's erratic and often destructive behaviors, the day-to-day life of the rest of the family is fragmented and chaotic, putting a strain on Lucy's marriage and affecting her younger children, who are beginning to show signs of low self-esteem and lack of focus. In trying to get the best possible educational services for her daughter and at the same time preserve her family, Lucy is stuck between the proverbial rock and a hard place.

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