

GRANDPARENT POWER



Pat Schissel, LMSW
President, AHA
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AHA is proud to announce the start of its 11th free monthly support group this January, a group for Grandparents. When I first learned of my adult son's diagnosis of Asperger Syndrome 15 years ago our group had only 1 support group that met in Smithtown monthly in the evening. It was the first time I had ever heard anyone talk about someone like my son, anyone who understood the issues that we had faced or that my son or that we were facing now. As time went on we added another group in Nassau, then on the East End of Long Island, Queens, Manhattan and partnering with GRASP (the Global and Regional Asperger Syndrome Partnership) we added a group for teens and adults. Now, partnering with GASAK – a grandparent group that has been meeting in Nassau and Suffolk daytimes for 20 years we will be at the Mid-Island Y JCC from 7pm-8:30pm one Wednesday per month. For schedules, times and locations of all support meetings go to the AHA website and look at the top of the main page under SUPPORT.

www.ahany.org

Even though my son did not have a correct diagnosis until age 25 we had the love and support of his grandparents. We were all working in the blind, not knowing what was best to do but I did know how rare the relationship that Eric had with my mom, his dad's mom and step-mom and father. The article below called GRANDPARENT POWER is from Dan Coulter – one of the gems in the world of autism. Dan has a son who is a young adult with Asperger Syndrome who was diagnosed as a child.. After working in the field of autism for many years producing fabulous educational videos Dan was diagnosed about 4-5 months ago with Asperger Syndrome. He has shared his thoughts on his recent diagnosis in articles as well. www.coultervideo.com has many other fine articles that he has written.

Grandparent Power!

How Extended Family Can Enhance the Lives of Kids on the Autism Spectrum

By Dan Coulter

The word "family" can evoke powerful memories and emotions. Thinking of family recalls the Robert Frost line, "Home is the place where, when you have to go there, they have to take you in." When grandparents are involved, the line could often be changed to, "...they can't wait to take you in."

The relationships between kids and their grandparents can provide some of the strongest extended family ties. When families have children on the autism spectrum, these ties can be a tremendous resource for both the kids and their parents. Of course, that resource works best when parents and grandparents cooperate closely.

I remember a shopping trip with my grandfather early in elementary school. We lived in Maryland and my mom's folks had taken the train from Missouri for a rare visit. It was magical to be with these wonderfully attentive folks who I only really knew from stories and pictures. My grandfather took me to the store to buy some school supplies, including crayons. The list in his hand called for a pack of twelve colors. But, being a grandparent, he bought me the box of 64. When we got home, my mom laughed and said, "Oh, daddy, you didn't have to buy that big box! The smaller box would have been fine."

It was a small substitution that didn't cause any problems and also made me happy, so this "grandparent indulgence" was no problem. For a child on the spectrum, however, having grandparents who act in accordance with a parent's directions and approach -- sometimes even on small things -- can be extremely important. Consistency is often an obsession for kids on the spectrum and they can have rigid likes and dislikes. If you don't know your grandchild really well, you could be stunned when buying the "wrong" flavor of ice cream sends a smiling child into a sudden emotional meltdown.

Tried and true parenting techniques that work fine with your other grandkids may just not work with autistic children. Also, each child with autism is an individual, so parents often have to go to great lengths to determine what works best for their child. The brains of kids with autism are wired a bit differently, so even if they're on the higher-functioning end of the spectrum, with a condition such as Asperger Syndrome, some things that are easy for other kids can be tough for them. For example, many have a difficult time learning and applying social skills. Parents often have to pick out the most important behaviors to work on and let the less important ones slide. As grandparents, you don't want to be too quick to make judgments about parents' actions when you may only see part of a very complicated situation. Did you ever get frustrated with your parents because they criticized your actions based on only part of the picture?

If you're a grandparent of a child on the spectrum and you're close to the family and providing lots of support, bless your heart! You're probably already tuned in to what we're talking about here. If you're a grandparent who's been separated by distance or other factors and you'd like to be closer, here are some steps you can take to build bonds with your grandkids.

Talk with your son or daughter and his or her spouse about your grandchild. Find out as much as you can about the child's condition and what they're doing to help and support him or her.

Ask how you can help and how they want you to deal with any challenging behaviors. Kids with autism often face a lot of rejection, so some of the most important things you can offer are love, patience, and unconditional acceptance. This comes more naturally to some grandparents than to others, but it can mean a lot to a child who others may see simply in terms of his or her problems. People often focus on the problems of autism, but there's another side to the story.

You may find that spending time with an autistic grandchild lets you be with a fun person who just looks at the world a bit

differently. Sometimes letting go of what a child might have been helps you truly appreciate who he is. My son, who has Asperger Syndrome, has a great relationship with his grandparents, who live nine hours away, but visit frequently. He's also lucky to have relatives who live close by, including a great-uncle who always enjoys swapping jokes whenever they're together. It's important to recognize that kids on the spectrum often have significant strengths as well as challenges. You may be the person who can help draw out those strengths and help your grandchild prepare to deal as independently as possible with the outside world.

What a feeling it is to make a real, positive difference in a child's life. Spending time with your grandkids can help build a relationship that gives parents the confidence to leave a child who needs special attention in your care. It can be hard to find spectrum-savvy baby sitters, so perhaps you can enable stressed-out parents to go out for some much-needed, worry-free recreation.

Sometimes, parents just need someone to listen. Lending your ear may help them put things in perspective. If you have advice to offer (you do, don't you?), it's more likely to be taken if you use the recipe of ten parts listening to one part advice. Also, make sure you know what you're talking about and focus on the benefits of what you're suggesting. Be aware that it's common for parents of kids on the spectrum to be wary of unsolicited advice, particularly if they've heard people routinely suggest therapies that don't apply, or make simplistic observations like, "He just needs more discipline." Even if you have good advice to give, you may have to overcome "advice burnout."

The best way to have your counsel taken is to really listen to the parents, really do your research and, hopefully, spend enough time with the child that you show his or her parents you really understand the situation. Always focus on the benefits of what you're suggesting. If you still sense resistance, you might try approaching the subject by asking questions. "I read about treatment 'XYZ' where children responded well. Is that something that you think might help Jimmy?" I've seen some situations where

one or both parents were in denial about a child's condition, and the grandparents diplomatically encouraged the parents to have the child tested or to seek support.

This encouragement can be a tremendous benefit to the parents and grandchild. With some parents, however, it's a challenge to help them see through their denial. If you push too hard, you risk having them throw up a wall that keeps you from helping your grandkids. Just remember that sometimes parents are mourning the loss of the child they expected your grandson or granddaughter to be. Again, patience and a lot of listening is a good strategy to put you in a position to influence the situation in a positive way.

I also know of situations where grandparents are actually raising their grandkids. It's a special kind of caring when "extended family" becomes just "family" because that's what children need. Even though grandparents have the full range of strengths and flaws that we all have, that special connection with grandkids often seems to bring out the best in people. Ideally, grandparents have just enough distance to see things realistically, are close enough to really care, and have the experience to be effective.

But caring counts most. When I think of my own grandparents, I realize that my best memories are not about the size of the crayon box granddad bought me. They're about special people caring a whole lot about making my life colorful and fun. They made me look forward to every minute I was with them. What better gift could you give?

ABOUT THE AUTHOR -- Dan Coulter is the writer/producer of the video, "ASPERGER SYNDROME DAD -- Becoming An Even Better Father To Your Child With Asperger Syndrome." You can find more articles on his website: www.coultervideo.com. Copyright 2006 Dan Coulter All Rights Reserved Used By Permission
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Patricia R. Schissel, LMSW
President, AHA
Asperger Syndrome and High Functioning Autism Association (AHA), Inc.
PO Box 916
Bethpage, NY 11714
P/F:888.918.9198
www.ahaNY.org
PatS@ahaNY.org