

Advice from Experienced Autism Parents



Children's National®

PARENT ADVISORY COMMITTEE, CENTER FOR AUTISM (CASD), CHILDREN'S NATIONAL HOSPITAL

We are a volunteer group of parents of autistic children and adolescents who act as community liaisons for CASD. We have all been through the experience of having a professional diagnose one or more of our children with autism.

On first hearing the autism diagnosis, many of us felt sad, angry, lonely, or even utterly devastated. Some of us were also relieved that we had finally found a professional who understood our child, and who might hold a key to interventions that would help. We all reacted differently, and sometimes our reactions were very different than those of our partner.

For some of us, the fact that our child suddenly had a diagnostic "label" was highly significant: It validated our sense that our children are extraordinary in complicated ways, and that our parenting struggles were not due to inadequacies on our part. On the other hand, some of us were not terribly interested in whether or not our child had a label, as long as s/he could get necessary services: After all, we adore our endlessly fascinating, wonderful children just as much with or without their labels. Following is some advice we compiled based on our experiences parenting autistic kids.

"Parents need as much love and professional help as their autistic child needs, maybe more. Most people get through parenting by the seat of their pants; parents of autistic children aren't even provided pants. If the autistic child has siblings, provide proactive professional help to them as early as possible."

You and your other children need as much love, support, and professional help as your child with autism needs – maybe more. If you don't take good care of yourself, you won't be able to take the best care of your children.

- Ask for help often, from many people.
- Find someone (partner, friend, family, spiritual leader, doctor) to talk to about your feelings. Surround yourself with people who reflect the positive aspects of a situation back to you.
- Don't neglect your close relationships. Often partners have different emotional reactions to their child's diagnosis, have difficulty sharing their feelings, disagree on how to proceed with evaluations and interventions, and experience stressful financial and time constraints. Communicate, protect your time together, and try not to judge each other.

Connect with other parents of children with autism, for example by joining a support group.

Parenting a child with autism can be extremely isolating. Our children look beautiful; people can

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think they act out because they're just "brats" or we're bad parents. Other parents of kids with ASDs will "speak the same language" as you. They'll understand why your child had a meltdown in the grocery store, or why you're so frustrated with your child's school. When you're going through tough times with your child and you're looking at everything up close, you'll need another parent who has been through the same thing to help you regain perspective.

Focus on the positive, be very selective in what you choose to be upset about, and keep your sense of humor. Sometimes things get too intense, and we just need to doggie paddle to the side of the pool and regroup. If we worried about every little thing, we'd be overwhelmed – in fact, we'd be gelatinous blobs on the floor. It can be very freeing to focus only on things that are really important.

Helping your child will probably involve addressing your own or your loved ones' challenges. Autistic-like traits, including social differences, language difficulties, and rigidity, tend to cluster in families. For many of us, our child's diagnosis led us to understand ourselves and our families in new and empowering ways. This increased our tolerance and strengthened some of our relationships, but it also sometimes led us to be more frustrated and irritated with our own and our partners' autistic-like traits. Don't feel guilty if you feel your child has inherited your or your partner's weaknesses. Your child is amazing, just like you are!

The professionals may be experts on autism, but you're the expert on your child. You can understand and communicate with your child in a way that professionals simply can't. Professionals can be wrong; evaluate their recommendations with a critical eye. Sometimes relying on professionals won't work, so you'll need to use your own instincts to get things moving the right direction again.

Read and ask questions until you fully understand your child's evaluations, IEPs, and other documents. Professionals have a responsibility to explain jargon to you, and to include you in your child's interventions and education. If you understand what is going on at school or in therapy,

"A professional told me my son is transition age, and asked about my expectations for him. I said he loves the computer. The professional looked at his record, and I know saw my son's IQ score. He told me and my husband that my son needed to do things like stuff envelopes. Well guess what...I asked at my son's last IEP meeting that he begin to do some typing. We had a parent conference recently and the teacher told me my son typed sentences that he thought up himself, and that he typed really fast. When I see the professional for a follow-up appointment, I will tell him the 'paper tasks' my son should do ARE on the computer!! Yes!!!"

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you will be more able to reinforce those interventions at home. For example, if a report recommends your child has a visual schedule at school, ask the professional how you can make a visual schedule to use at home also.

Get organized early. Keep every report, evaluation, and IEP-related document in one place. Save examples of your child's schoolwork so you have hard evidence of positive or negative trends in their work. If your school has an online portal for tracking assignments, take dated screenshots throughout the term to show trends in grades and missing assignments.

You are your child's best advocate – no one else is going to fight as hard for your child as you will. Emotions will make you forget what you wanted to ask in a meeting or appointment, so be sure to go into a meeting prepared. Write down your questions in advance, and don't be afraid to ask them. It can help to give a list of your questions or a copy of your agenda to professionals in advance, or at the beginning of the meeting/appointment.

Don't ever let a professional tell you what your child can't do. There are many examples of kids whose abilities were underestimated because of their disabilities. Your job is to get professionals to focus and build on what your child *can* do.

When to Seek Help

Parents often find that seeking out mental health support for themselves helps them to care more effectively for their children. You should talk to your doctor or a licensed mental health provider if:

- You find yourself taking out your feelings on your child or loved ones
- You feel trapped, like there's nowhere to turn
- You worry excessively and can't concentrate
- The way you feel affects your sleep, eating habits, job, relationships, or everyday life
- You feel unsafe, like having scary thoughts of harming yourself or someone else even if you would never actually act on these thoughts.

Additional Information

The Organization for Autism Research has guidebooks for families on safety, siblings, transition to adulthood, and many other helpful topics: [Family Guidebooks | Organization for Autism Research \(researchautism.org\)](https://www.researchautism.org).