

My child was just diagnosed with autism spectrum disorder.

What do I do now?

Receiving a diagnosis of autism can be an overwhelming and stressful time for parents. You are immediately thrown into the world of acronyms such as ABA, OT, PT, GFCF, CST. It can be confusing to sort through all the information and know what treatments will be the most helpful to your child. I know it was for me when my child was diagnosed with autism. Below are some tips I've learned on my journey that I hope will help make your journey easier.

Start with Healthcare Professional Recommendations: Now that your child has a diagnosis of autism, you will probably hear various opinions as to what you should do for your child. Start with the recommendations in the evaluation from the physician, advanced practice nurse, or psychologist making the diagnosis. This may include having more evaluations done to determine whether different therapies or services will be helpful for your child as well as possible testing to rule out medical conditions that can be associated with autism.

Prioritize: Focus on your child's main challenges at the present moment and stick to researching just these issues. Ask your child's healthcare professionals to recommend helpful resources. There is so much information out there with the increase in autism awareness, which is a good thing. However, it is easy to get side-tracked by all the information and not all of the information is reliable. Make a list of short term goals for the next 3 -6 months and a list of long term goals.

Build a Team of Experts for Your Child: This may include a speech therapist, occupational therapist, physical therapist, neurodevelopmental pediatrician, psychologist, teacher, grandparents, nutritionist, neurologist, gastroenterologist, just to name a few. These are the people who care about improving the quality of your child's life. Know who to go to for what and have contact information for each so when questions or concerns come up, it is easy to reach them.

Find Support: Connect with other parents in your area that have children with autism. Find and learn from parents that have been through what you are going through. They can make the journey easier for you. It can be comforting to be around other parents that understand the daily challenges autism can bring. They can help celebrate the good days and offer support for the hard ones. Children's Specialized Hospital offers support groups as well as a full day workshop for families of newly diagnosed children.

Time Management: Managing autism treatments for your child can be time consuming and all encompassing. It can quickly take over your life if you let it. It's important to make time for yourself, your relationships, and for siblings. It can be something small like taking 10 minutes each morning to have a quiet cup of coffee or something more significant like a monthly night out with your partner or friends. Your life should not be put on hold because of autism. Make sure to build time into your day and week for the things that matter.

Track Your Child's Progress: You are your child's biggest and best advocate, so it's important to know what treatments are working and what are not. Some ways to keep track of your child's improvements are journaling, keeping samples of school work throughout the year, and periodically making short videos.



Trust Your Instinct: No one knows your child better than you. If a doctor, teacher, or therapist makes a recommendation that you do not agree with, talk to them about it and explain your concerns and see what other options are available.

Breathe: Know that the help your child needs to reach his or her full potential is out there. It will take dedication and research on your part but there is help available all along this journey. Just take a deep breath and keep moving forward.

Find Credible Resources: When researching anything autism related for your child, you want to make sure you have reliable sources. I found it helpful to ask my son's healthcare providers for recommendations. Also, Children's Specialized Hospital has created an extensive online resource called The Community Hub. It provides practical strategies to enhance function and quality of life, increase safety, and improve the effectiveness of community services. It's filled with helpful resources right at your fingertips for family members, caregivers, professionals, and the general community. Go to www.childrens-specialized.org/KohlsAutismAwareness to learn more.

Some other resources that have been helpful for me:

Autism Family Services of NJ: Works with families, agencies, government entities, and individuals with autism to develop an array of support services and opportunities. Autism Family Services of NJ improves the ability of individuals to productively interact with the world around them. More information is available at www.autismfamilyservicesnj.org or by calling 1-800-336-5843.

Autism New Jersey: Is the largest statewide network of parents and professionals dedicated to improving lives of individuals with autism spectrum disorders. Autism New Jersey leads the way to lifelong individualized services provided with skill and compassion. For more information, visit www.autismnj.org or call 1-800-4-AUTISM.

Autism Speaks: Is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, and treatments for autism; increasing awareness of autism spectrum disorders, and advocating for needs of individuals with autism and their families. The website has a helpful resource guide that allows you to search for providers, support, and resources in your area as well as tool kits on a variety of topics such as advocacy, toilet training, applied behavior analysis, and many more. For more information, visit www.autismspeaks.org

MOM2MOM: By dialing 1-877-914-6662 a caregiver of a child with special needs will receive peer support, network of local service providers, and access to support groups within your community. For more information, visit www.mom2mom.us.com.

POAC (Parents of Autistic Children): Focuses its attention and resources on how best to help the children and families who are struggling with autism today. POAC strives to help individuals with autism achieve their highest potential in their homes, schools and communities and also offers many free trainings and fun family events throughout the state of NJ. More information is available at www.poac.net or by calling (732)-785-1099.

Statewide Parent Advocacy Network (SPAN): Is committed to empowering families as advocates and partners in improving education and health outcomes for infants, toddlers, children and youth. SPAN offers families and professionals information, resources, support and advocacy assistance. Visit www.spannj.org to learn more or call 1-800-654-SPAN.