**NEWLY DIAGNOSED WITH AUTISM**

Parents of children who have just been diagnosed with Autism Spectrum Disorder (ASD) often feel both devastated and panicked. In this section, we address some of the issues most on the minds of parents in this situation.

**IT'S NOT YOUR FAULT**

It is not uncommon for parents of a child who has just been diagnosed with ASD to blame themselves or each other. They worry about everything from that glass of wine mom drank before she knew she was pregnant to that chemical plant dad worked in for a couple of years in a frantic attempt to find answers to the reasons for their child's ASD.

Please remember: It is not your fault. It is not your partner's fault. What you did or didn't do earlier in your lives, whether your child was "wanted," how permissive or strict you were with your child, how much you loved or cuddled your child — none of that has any connection with your child having ASD.

We now know that there is more than one type of autism and that there is not a single cause. Scientists are just beginning to understand the genetic and/or environmental factors that play a role, and you certainly had no control over them. All you can control is what you can do next.

ASD is manageable with the right information. By educating yourself, you will be able to make wise decisions, educate others and advocate for your child and your family. This makes it important for you to seek reliable information from trustworthy sources.

**YOU ARE NOT ALONE**

The United States' Center for Disease Control and Prevention (CDC) estimates that 1 in 88 children in the United States has ASD and the number of adults with ASD may be similar. A recent door-to-door count in the United Kingdom found that approximately that 1 in 100 adults had ASD. [Learn more about ASD prevalence.](https://iancommunity.org/cs/understanding_research/prevalence)

This means that **you are not alone**. There are thousands of families across the world coping with the dilemmas of raising a child who is on the spectrum.

Each child with ASD has his/her strengths and weaknesses. As you read and learn, you will begin to get a sense of where your own child fits on the autism spectrum-- not just overall-- but with regard to different aspects of the disability like social understanding, language, repetitive behaviors, motor skills, sensory issues, etc. Celebrate their strengths and build on them. Identify weak points and make providing targeted interventions your top priority.

**GETTING A HANDLE ON IT: EDUCATING YOURSELF**

No matter the dilemma, in the end there's only one thing to do: Get up and keep going. This is even more true when you have a child who needs intervention, and soon.

In the case of a newly-diagnosed child, this process usually begins with educating yourself about ASD, something you may have begun before your child ever received a formal label. There are many books, articles, DVDs, workshops, and conferences about ASDs, not to mention websites like this one. A good place to begin is right on this site:

* [About Autism Spectrum Disorders](https://iancommunity.org/cs/about_asds/)
* [Challenging Behaviors](https://iancommunity.org/cs/challenging_behavior/)
* [Therapies & Treatments](https://iancommunity.org/cs/therapies_treatments/)
* [All About Research](https://iancommunity.org/cs/all_about_research/)
* [About IAN](https://iancommunity.org/cs/about_ian/)

The more you learn, the more empowered you will be to make wise decisions, educate others and advocate for your child and your family.

Please keep in mind, as you take on this task, that you cannot possibly learn everything all at once. Take your time, and recognize that there are many varied opinions about what causes ASD and how to treat them. There are also many unknowns. In fact, part of becoming informed about ASD entails knowing the limitations of our current knowledge and learning to cope with ambiguity until research provides us with more definitive answers.

**ASD SUPPORT AND ADVOCACY GROUPS**

Advocacy organizations and support groups address families' needs, and finding one that is the right fit for you is essential. Support groups can be great sources of information that can help you tackle everyday situations, like handling temper tantrums, sleep problems, family outings, etc. They also provide resources on important transitions in life for your child, such as starting school, planning for college and work, independent living, and much more.

Other members in these groups can also share information about getting care services for your child. What role is the school district going to play, and how do you draw up an Individualized Education Program (IEP)? What private and public programs are available in your area? Where can your child get social skills training? Is speech, occupational, or physical therapy recommended? What financial resources are available?

Get involved in your local autism advocacy group to exchange information about these issues.

**BECOMING YOUR CHILD'S ADVOCATE**

As the parent of a child with an ASD, you will deal with many systems involved in his/her care-- school districts, doctor's offices, insurance companies and clinics. Armed with your knowledge of your child, and of ASDs in general, you will become your child's best advocate.

Keep thorough records of test results, medical issues and educational plans. You will be asked for details and you would need to access information for many years to come. Organizing yourself will reduce your stress and increase your ability to advocate for your child.

**CARING FOR YOURSELF**

When your child is diagnosed with ASD, it is rarely a complete surprise. It is a parent's unease, after all, which usually leads to appointments with experts and a formal diagnosis.

You'd think that would lessen the impact of hearing someone official declare that your child has an ASD, but it rarely does. Something about that official declaration makes it all real, dashing faint hopes that your suspicions about your child were wrong. It is natural to feel grief, denial, anger, despair, and fear-- all at once, and by turns. Relief may be mixed in, if you have been fighting to get someone to acknowledge that something is wrong, and have been unable to get needed services until they do.

Whatever the case, you have to find a way to care for yourself during this time. Your child's needs seem urgent, and the tendency is to try to get every intervention in place, running until you drop. Ultimately, however, that just leads to a parent with a nervous breakdown-- something that will definitely not help your child.

Alternate having "time off" with your partner, or find someone who can hold down the fort a couple of hours at a time. Turn to old sources of support — friends, family, your religious institution or your therapist — and seek new ones if the old ones are simply not enough. Support groups for parents of children with ASD can be very helpful, especially during this "newly diagnosed" period.

Whatever you are doing on behalf of your child, make sure you also give yourself time to find your balance again. You will need your strength to fight the good fight for your child and your family.

**PARTICIPATING IN RESEARCH: BEING PART OF THE LONG-TERM SOLUTION**

As you learn more about ASD, you will find that there are far too many questions without answers. Research is desperately needed.

One way you can be involved in the long-term solution is by taking part in autism research studies. There are scientists who are committed to finding answers, but cannot proceed without data. Believe it or not, data is what you've got! Your individual story, when combined with others, permits autism researchers to investigate patterns and trends, causes and treatments.

To learn more, read about IAN Research and consider participating. From your own home, via the internet, you can answer a series of questions about your child's ASD. Those answers will become part of a large data set scientists from all over the world will be able to access in order to make new discoveries. In addition, scientists looking for research participants for even more in depth studies will be able to find them through IAN. (These researchers are not given your personal information; we pass research participation opportunities on to you, which you can pursue or not, as you wish.)

If you're ready to get involved right now, you can go directly to the [IAN Research site](https://www.ianresearch.org/) to participate.

If you have any questions, please contact us at [researchteam@ianresearch.org](mailto:researchteam@ianresearch.org).

**ADDITIONAL RESOURCES**

* See our articles, [The Importance of Record-Keeping](https://iancommunity.org/cs/articles/the_importance_of_record_keeping) and [Good News for Late Talkers](https://iancommunity.org/cs/simons_simplex_community/speech_onset_study).
* Autism Speaks' [Autism Response Team](https://www.autismspeaks.org/family-services/autism-response-team), [100 Day Kit](http://www.autismspeaks.org/family-services/tool-kits/100-day-kit) and [100 Day Kit for School Age Children](https://www.autismspeaks.org/family-services/tool-kits/100-day-kit-school-age). The 100 Day Kit includes information for families on what to focus on in the first 100 days following their diagnosis.
* [FAQs about an ASD diagnosis](http://www.iancommunity.org/cs/articles/frequently_asked_questions_about_autism_spectrum_diagnoses): This section has several articles about how autism and Asperger's were diagnosed in the past, as well as changes that occurred in 2013 with the publication of a new psychiatric diagnosis manual.
* [Very late diagnosis of Asperger Syndrome](http://www.iancommunity.org/cs/articles/very_late_diagnosis_of_asperger_syndrome) — Professor Simon Baron-Cohen and his colleagues discuss the "lost generation" — those with Asperger's who grew up before the diagnosis existed. They describe a unique program designed to help diagnose and assist these adults, helping them understand themselves and equipping them to access services and support.