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Autism Agenda

**Linn Benton Lincoln ESD-Cascade Regional Autism Program**

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.

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.

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NEWLY IDENTIFIED WITH AUTISM CONTINUED....

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: https://iancommunity.org/cs/newly_diagnosed. (Then you can access the links below from their website.)

[About Autism Spectrum Disorders](#)

[Challenging Behaviors](#)

[Therapies & Treatments](#)

[All About Research](#)

[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.

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NEWLY IDENTIFIED WITH AUTISM CONTINUED....

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](#) to participate.

If you have any questions, please contact us at researchteam@ianresearch.org.

This article is from the following website: https://iancommunity.org/cs/newly_diagnosed

IPAD APPS

11 Expert-Recommended Autism Apps for Kids By parenting.com

These apps are designed to support the emotional and social needs of kids with Autism Spectrum Disorder.

1. First-Then Visual Schedule
2. iPrompts
3. Autism Track
4. Learn with Rufus
5. E-Mintza
6. Stories2Learn
7. Model Me Going Places 2
8. The Social Express
9. Cognoa
10. Pictello
11. Dreampad

All apps are suggested by LBL-ESD and not required. For additional information go to <http://www.parenting.com/gallery/autism-apps>

CHILDSHOULD Motherhood, Autism, and Shoulding All Over Myself

Diagnosis Week, Diagnosis Weak

August 23, 2016 by [Katie Read](#)

I am picking up Mikey at his preschool.

As always, it's chaotic: the crunch of parents, the long sign-out line, backpacks and cubbies and standing-room only in the small office.

Today, though, is harder than usual. Drop off and pick all week have been harder than usual, because I am barely hanging on.

As Sam, my one-year-old, kicks and struggles in my arms to get down, I half-realize that the preschool director is looking at me. She is regal in a way that's unusual for this bland suburb: South African accent, tweed jacket and brooch—sharp contrast to my cheap T-shirt and jeans.

I flash her the quick half-smile you give people you don't know that well. Normally she would just nod politely back. Today, though, she keeps looking for a long moment over her bifocals. I rack my brain to remember if we'd paid tuition last week.

"We're thinking about you," she says, approaching. "That's hard. That's tough stuff."

I blink hard and look away. I wasn't expecting this. Her words pierce right through me, the way unexpected kindness always slices the onion when you're trying not to cry.

And "d.....", here are the tears. Hiding my feelings has never been a feature on my resume.

"Thank you," I say, faking a little *I'm fine* shrug as I try to force them back down.

I had failed miserably in the doctor's office a week ago, when the doctor with so many letters behind her name said the words I knew were coming: *moderate autism*. The office had jostled and spun for a moment, like the whole world tripped and fell to the left but I was the only one who noticed.

And I had cried.

I cried the forty minutes home from the doctor.

I cried the rest of that day, and into the night. And then the next. The crying came and went in waves I had no control over. I cried eating cereal. I cried drinking water. I woke, crying, from sleep.

I began filling out paperwork on Sam, just twelve months old, and cried, knowing deep down that he, too, would be diagnosed.

For a week straight, fear and grief throttled me. Clamped down and would not let up.

You have no idea what you're doing! the fear screamed. *All your instincts are useless here. This is a new ballgame and you have no training. You can't mother these children! You're too weak for this!*

And all the work of getting services came down like an avalanche. I had three emails from the insurance company on diagnosis day. Countless more that week. Calls to state services. Calls to the school district. Fresh reams of paperwork. And as we told friends and family, the articles, the endless advice people sent and tagged us in and told us we should read.

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PARENT VIEW OF AUTISM DIAGNOSIS CONTINUED...

And through all of it, there was little Mikey, needing comfort and play and nonstop attention, and Sam still up crying five times each night.

So here I was at preschool pickup, but barely.

And the preschool director, as I fought my tears, started talking. *Temple Grandin...research with nutrition...ABA...breakthroughs all the time...*

And her words started blurring together and all at once the too-muchness of the week was on top of me.

Someone else could mother these boys better.

Someone unselfish.

Someone who had her own life figured out.

Someone more grounded, less emotional.

Someone really good at being a grown up, who didn't want to blot out the world with cookies and wine and Real Housewives.



And as she was talking—the first in-person kindness all week that wasn't a call or a text but a real live human being—I suddenly wanted the world to stop, to tip sideways again so I could crawl into her lap, this older woman, and cry there, let her stroke my head and mother me instead of me trying to mother these two boys. I wanted someone else to take the reigns, to be stronger and know more and have perfect intuition to guide us through this alien landscape.

I wanted what I've never wanted—to be told, moment by moment, what to do next. I wanted the pressure of knowing what's best to be anyone's pressure but mine.

As she spoke, Mikey relentlessly tugged my arm: *Mommy, Mommy, Mommy, Mommy...*

I managed to thank her and leave before I became a gaping, sobbing wound in the sea of happy parents.

I looked down at Mike.

"Do you like it?" he asked, holding up a little triangle lightly traced in pencil. With his motor delays, he still used an upside-down baby grasp at four.

This triangle was a hard-won victory.

"I love it so much, baby," I said.

His life might be a study in hard-won victories.

In simple tasks mastered late, or maybe not at all.

His life might not be any of the things I dreamed for him when he was in the womb. Or it might be the best life anyone has ever lived. Right now, everything is a tall, daunting question mark.

But we are walking to the car. We will go home. He will crawl into my lap and need me to mother him. He will need me to take the reigns. To be stronger and know more and have the intuition to guide him through this alien landscape.

And if I can get quieter, much quieter than the tall, daunting question marks, he will tell me, moment by moment, what to do next.

Website link: <http://www.childshould.com/diagnosis-week-diagnosis-week/> (Explicative was removed and noted as ".....")

The Mighty

How Getting an Autism Diagnosis as an Adult Opened Up a New World for Me

By Siobhan Ronan

I never knew why, but I knew I didn't fit in.

Other people seemed to recognize it as well. I struggled throughout my childhood — trying to make friends and then maintain those friendships proved mostly impossible. I gathered a handful of friends over the years who thankfully liked me for exactly who I was, even if I was a bit of an oddball at times.

I spent my childhood trying to figure out a world that didn't make sense to me. Everyone seemed to know a secret innate language that I could never quite translate. This left me outside of most social groups, and led to a lot of [anxiety](#) and self-hatred. I couldn't understand what was wrong with me. Why was I rarely invited to birthday parties? Why was everyone else more likable than me? Despite this, I managed to pass as being on the weird side of "normal," and neither my parents or teachers realized what was going on.

Fast forward to my teenage years, and my coping mechanisms stopped working effectively. I was constantly overwhelmed and stressed by the increasing expectations placed upon me socially, emotionally, and academically at school. Friendships became more complicated, I started having romantic relationships, I was taking more advanced classes and I just couldn't keep up with everything anymore.

Trying to "pass" as being just like everyone else really took a toll on my mental health, and I started to use self-destructive coping mechanisms, including [self-harm](#). I managed to hide my growing mental health problem until I was 19, when my dad died and I spiraled out of control.

I had a crisis at 19, and that was when I first stumbled across autism online. It seemed to link everything I'd ever experienced together. I made an appointment to speak to my doctor, but unfortunately he laughed at me, exclaimed there was no way I could be autistic, and sent me on my way with a referral to the mental health team.

I tried to push the idea of being autistic to the back of my mind, and after an assessment I ended up with the diagnosis of [borderline personality disorder](#). While this didn't explain everything, I accepted the diagnosis and went to the suggested therapy group. It did nothing. At that point I started to reassess the likelihood of being autistic, and I changed doctors and got my referral.

The waiting and assessment was stressful, but I finally had it on paper that I was autistic. The assessors even commented on how there was no evidence of me having borderline personality disorder. Getting this diagnosis opened up a new world for me — not only could I access more support if I needed it, but it explained why I had struggled with so many things throughout my life. It explained why I view the world differently than my peers, and why I understand things and feel things in a different way.

Mostly, getting my autism diagnosis freed me. I could finally forgive that sad little girl who hated herself so much because everyone else seemed to.

Website: <https://themighty.com/2016/08/getting-an-autism-diagnosis-as-an-adult/>



10 Things I'd Tell Myself About Our Autism Diagnosis If I Could Go Back in Time

By April Shaw

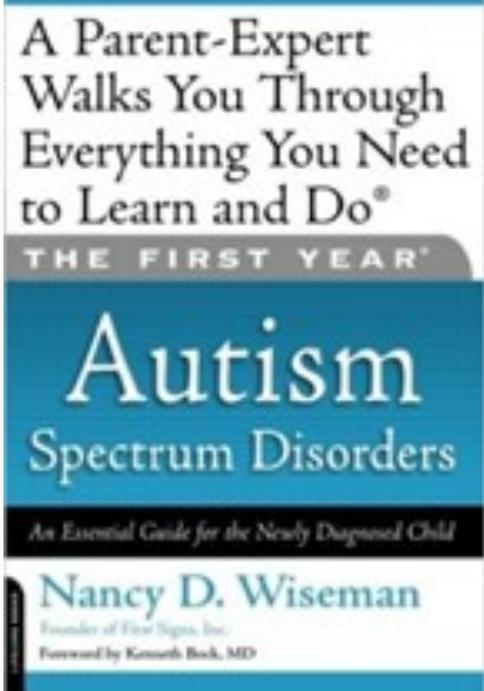
Recently a friend of mine asked me to lunch to get some advice about concerns regarding a family member's child — concerns this child may be showing signs of autism. I gave this person as much advice as I could and went about my day. I left that lunch contemplating what would I tell myself if I could go back four years to shortly after my son was diagnosed.

I thought long and hard, and one of the first things I would tell myself is “**Do not** cut your hair! You will not look like Posh Spice! Don't do it!” The second thing I'd probably say is, “Step away from the pie! You're just going to gain a bunch of weight, which as you approach 40, will be incredibly hard to get off. And the constant pie eating isn't going to make you feel any better anyway. Put the fork down. Now, before the lightning strikes the clock tower, and I have to get back in my DeLorean and travel back to 2014, I've got some real important “stuff” to tell ya, so listen up!”

10 Things I'd Tell Myself

1. **Stop blaming.** It doesn't matter how or what caused his autism. You've got more important things to focus on than the blame game. Above *all* else, don't you *dare*, for one more second, blame yourself. It's nothing you did, did not do, should've, would've or could've done. *You are not* the cause. All this mentality will do is drain you down to nothing but a shell of a resemblance of what might be left of a human being. Right now he needs you — all of you. He needs that precious energy, and so do you. He's on the autism spectrum. Move on.
2. **Quit spending countless hours on the internet chasing down that next new treatment/therapy** in Timbuktu, which may or may not have worked in 2 percent of kids with autism. Go with your doctor's recommendations. Listen to the professionals. But above all that, listen to your gut.
3. **Pray.** Pray a lot. Pray in the car. Pray in the store. Pray before you go into the store. Pray in the parking lot. The prayers don't have to be an ode to Jesus. They can be as simple as “God, I need you! We need you. I can't do this without you.” Short and sweet. Just pray. Prayer was, is, and always will be, in my opinion, the most powerful weapon in your arsenal.
4. **Laugh.** Learn to laugh quickly. Laugh a lot. Laugh at as much of it as you can. It sure beats the “h...” out of crying. And truth be told, crying won't change a “d...” thing anyway. Laughter will be the second greatest weapon in your arsenal.
5. **Quit waiting for it to get easier.** It's not going to. You'll get stronger. You'll even surprise yourself. You're a “b.....”. You just don't know it yet.
6. **Quit, quit, quit trying to fix him! He is not broken.** Focus on helping him to evolve. Help him, teach him and work with him towards evolving into the person God created him to be. Accept that he (just like “typical” children in this sense) will be *who he is*. Not some ideal of a picture you had in mind. He is special. He is unique. He is one of a kind. He is who he is. He just needs a little (sometimes a lot) more help along the way.
7. **Be patient.** Be patient a lot. Be patient in the car. Be patient in the parking lot. Be patient in the store. Learn patience quickly. And I don't mean just with him. Be patient with yourself, too. You're not perfect, and you don't need to have this all figured out. No one expects you too. And you know what else? No one else has it all figured out either! In the end, we're all just winging it.
8. **Avoid Autism Tunnel Vision.** Do *not* make it all about autism *all* the time. Quit with the “If he didn't have autism he would/wouldn't do blah, blah, blah.” While sometimes that may be true, sometimes it's not. Sometimes he's naked because he's a little boy. Sometimes he's stinky because he's a little boy. Sometimes he's cranky because he's a little boy. He'll have some good days, and he'll have some bad days. And sometimes that will have absolutely *nothing* to do with autism. Repeat after me: “He's still a little boy.”
9. **“_____” those ridiculous spreadsheets of what he should be doing by what age his “typical” peers are doing at that age.** I firmly believe beyond the diagnosis stage, this is a pointless piece of paper that does *nothing* but torture your mental wellbeing. Ignore them. Throw them in the trash. He will progress at his *own* rate — not when Timmy, Tommy, Jimmy or Johnny does. And he sure as “h...” won't do it based on what some crap piece of paper says.

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The First Year: Autism Spectrum Disorders – An Essential Guide for the Newly Diagnosed Child

by Nancy D. Wiseman

When parents learn that their child has autism, the news can be devastating, even paralyzing. Meanwhile, the first 12 months after diagnosis are the most important when it comes to intervention. As a parent of a child with autism, Nancy D. Wiseman knows firsthand how difficult it can be to unravel complex issues, discover what questions to ask, and find effective treatments. In this landmark guide, Wiseman offers both compassionate insight and a wealth of information for diagnoses from Asperger's to classic autism.

While comprehensive, this book is informative without being overwhelming. In a time where there are more questions than answers about autism, and parents of newly diagnosed children are often presented with insistent “Do’s and Don’ts” from well meaning professionals and friends, this book serves as an anchor and island of sanity.

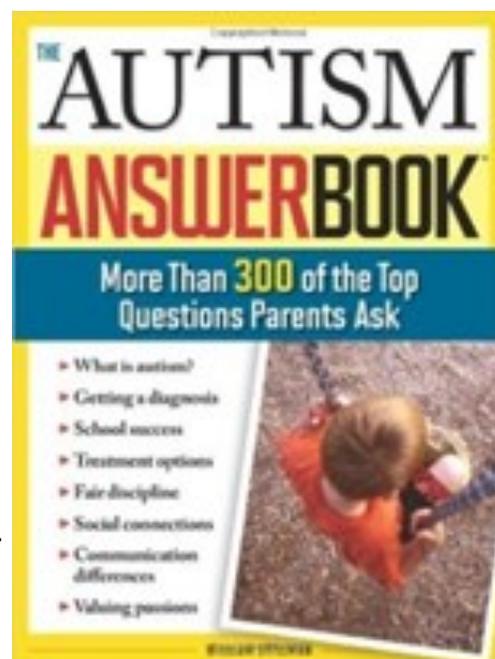
Day by day, week by week, month by month, *The First Year: Autism Spectrum Disorders* walks parents through a wide range of medical and lifestyle concerns, helps them navigate the healthcare, insurance, and educational systems, and ensures the best possible outcome for their child.

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The Autism Answer Book: More Than 300 of the Top Questions Parents Ask

by William Stillman

In a time when parents are overwhelmed with confusing, and often conflicting, information, *The Autism Answer Book* provides them clear and reassuring counsel by providing straightforward answers to their most pressing questions. *The Autism Answer Book* covers such topics as getting a diagnosis, explaining autism to others, social sensitivities, physical well-being, medical and educational interventions, school success, and more. Written in an easy-to-read Q&A format, *The Autism Answer Book* helps parents understand and accept their child and develop a plan for success.





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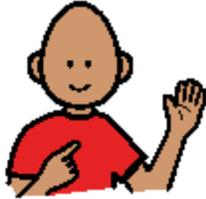
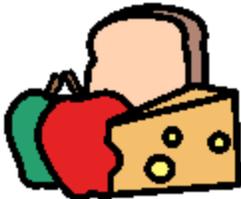
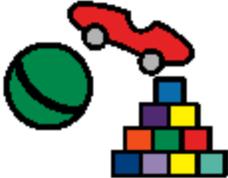
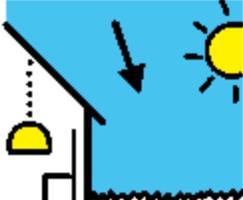
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VISUALS

<p>I want</p> 	<p>food</p> 	<p>juice</p> 	<p>water fountain</p> 
<p>milk</p> 	<p>snack foods</p> 	<p>water</p> 	<p>popcorn</p> 
<p>snack</p> 	<p>go to bathroom</p> 	<p>movie</p> 	<p>book</p> 
<p>toys</p> 	<p>outside</p> 	<p>I need help</p> 	<p>I want that</p> 