

What Autism Parents Wish You Knew

A episode to share with extended family and friends

One of the biggest issues autism parents bring up in session with me is that their extended family and friends don't "get it." Autism and neurodiversity in a family really tends to shake things up. And often, well-meaning in-laws, siblings and friends do more harm than good when interacting with us.

There are several reasons for this, so I want to break it down.

What this feels like for us

I think it's really important for our friends and family to know how hard this is for us. Let's just be real for a second; yes your child is still an amazing human being with tons of potential. Yes, there are profound moments that you wouldn't trade for the world. And yes, there is so much you can do to help your child be the best they can be. But for now I want to focus on the pain of the experience because it's what we don't talk about. Why? Because we don't want pity. we want support. But it's hard to ask for what you want when you're grieving.

So we don't talk about the sleepless nights, the chronic health issues our kids have, the difficulty they have with language, making friends, managing big emotions. We often don't mention how much money, time and resources raising a child on the spectrum takes. How it takes a toll on our relationships, our marriages, and our homes. How we fear for their safety and worry about their future. How we feel like we can't die because we won't be here to care for them. Every moment of every day is taken up by needing to consider these things. Every decision we make is with the consideration of how it will affect our special needs child. Everything must be re-evaluated.

I've had parents describe for me what it feels like when they receive a diagnosis, and this is usually regardless of the age of their child.

"A punch in the gut"

"My heart literally hurt"

“I got nauseated and the room started spinning, as if this wasn’t really happening”

“ It was as if all me hopes dreams and plans for my child disappeared”

“I had no idea where to go from here”

These are all examples of profound grief. And all parents experience some level of grief when dealing with a life-changing diagnosis of their child. So when people in our lives say things like, “He looks so normal,” “Maybe you just need to discipline her more,” or even deny the diagnosis with “I don’t think he has autism,” these only compound our grief.

First, I want to address the reasons why they may not get it. I’ll share how you, the parent of the child, can make these interactions better, and lastly I’ll provide some guidance for extended family members so you can share this with them.

Reasons your family and friends may not “get it”:

1. They have no experience with special needs communities

Often people don’t know what they don’t know. Think about how hard it was for you when your child was first diagnosed; I don’t know about you but I remember feeling a combination of heartbroken, confused, scared and unprepared; and I was a special education teacher at the time.

So having some patience with the people in your life who are trying to wrap their heads around this will be crucial. And as a parent, you will quickly find out who can handle this and who can’t.

I’ve seen grandparents who just need time to digest what’s happening, and end up being a special families best advocate, and sadly, I’ve seen others who insist on making their opinions known no matter what the consequences or impact.

These are people I want you to have limited contact with- even if they are related to you. You’ll also want to be cautious about what you share with them so that you can keep your peace of mind.

2. They have an outdated view of autism, or perhaps no understanding of it at all.

Autism has changed over the decades and I can tell you first hand, the autism I was trying to help my son navigate was viewed very differently a decade ago than it is today. And rightfully so.

When my son was diagnosed in 2001, there were very few resources, a great deal of misinformation and a bunch of very angry parents who wanted answers and felt a need to “cure” their children. It was very much a death sentence as far as their future was concerned and the answers seemed very black and white; either he is autistic and his skills are compromised, or he’s overcome it and can function like a neurotypical person.

Now, I view autism as more of a neurological difference and disability that affects each person differently. I no longer want to “cure” my child, but rather ensure that he can have the best life possible while having autism. For many of our kids, autism is part of who they are and they wouldn’t have it any other way.

Now, autism is viewed as a diagnosis that impacts a person’s life but is certainly not an indicator of what that child will become. Supports and accommodations are more the norm, rather than trying to make the person appear more “normal.”

So if extended family and friends have taken their view of autism from TV and movies, I’m afraid they will have an unrealistic view. It is important that they get to know how autism affects YOUR child, which means you as the parent will need to gain a better understanding of how your own child is effected. And that can take time, and will most likely change as they grow.

Encourage your loved ones to check out people online who have autism and listen to what they say about their experiences. Some of my favorites are Temple Grandin, Stephen Shore, and Naoki Higashida. In addition, experts like Barry Prizant, who wrote the book, “Uniquely Human,” and has a podcast of the same name, has helped shape the new landscape of autism. The National Autism Association is an excellent resource if you’re looking for a reliable organization to pass along.

3. They feel they are entitled to give you unsolicited advice because they are your mom, dad, sibling, best friend, etc.

This is more a boundary issue than an autism issue. I have witnessed family members who feel it is their job to guide their adult children who now are raising

their grandchildren. The ethnic background of a family will often have a great deal to do with this issue. Many ethnicities value the wisdom of elders more than others, so be aware if this dynamic exists in your family.

Remember that you have the right as a person, so decide if you want this guidance or not. Often telling a well-meaning family member, “Thank you for trying to help, I will consider that point,” will go a lot farther than accusing them of giving unsolicited advice.

However,, once in awhile you may need to set a firmer boundary by saying, “I really don’t want solutions right now, I just need a listening ear.”

The responses from people confronted by your boundary will tell you all you need to know about their ability or inability to be there for you.

4. They are afraid to ask questions for fear of upsetting you

I remember being in my early 20’s when a close friend was diagnosed with cancer. It was really hard to navigate what to say and how to say it, without being very aware that I might say something wrong. But I found it helpful to talk about that elephant in the room, so to speak, by telling her I had no idea what to say, but that I was there for her.

When I think back on the people who I was closest to when my son was diagnosed, I can only think of ONE friend who did that with me. And I remember it being very comforting and freeing- much more so that the people who thought they had to say the right thing, and ended up doing the opposite. Because most of the time what they said was not helpful at all. When we fear upsetting someone, we are more likely to distance ourselves and do damage to that relationship.

A few guidelines for family and friends

So if you are a parent, friend, sibling or other extended family member to an autism parent, there are a few guidelines to follow to ensure you are being as supportive as possible. These guidelines are taken from the hundreds of parents I have helped over the years and are based on what they want you to know, but have trouble telling you.

I know for most of you, your goal is to connect with the child and to support the parents of that child. So put aside a need to be right and let’s talk about what is actually going to help you achieve that goal.

1. Please don't tell us that our children are spoiled or need to be punished or spanked.

Here's the thing: autism is tricky because it appears like a behavioral disorder but it is NOT.

It is a neurological disorder/difference that *results* in behaviors that occur due to many factors; not being able to express oneself adequately, not being able to regulate emotions, sometimes it's due to sensory issues that can be overwhelming such as light or sound, maybe a texture against their skin that they don't like. Often it's due to physical discomfort such as a headache or tummy ache and many of our kiddos are not able to tell us what's wrong or where it hurts.

So if a child is having a meltdown in a grocery store for example, and you get angry with them for expressing their feelings in the only way they know how, it's equivalent of telling a child who can't walk that they need to get out of their wheelchair and climb those stairs or you'll spank them.

Now that may seem like an extreme analogy but I can tell you from talking with people on the autism spectrum that it is accurate. And the response they are given, when it's harsh and not compassionate and helpful, can do damage.

2. Don't take it personally when the child does not respond, needs alone time, or doesn't say please and thank you. This is not about you, it's part of their disability.

I can't tell you how many parents I work with who tell me that grandma or grandpa thinks the child is rude when in actuality the child is trying their hardest to cope with what is going on in that moment. Understandably, we want our kids to grow up with manners. But in the autism world, this is last on our list. We usually are trying to help them cope with the world around them which can be a very scary place when you can't always make your needs known effectively.

Many of our children have speech and language disorders as well that make it difficult for them to express themselves verbally. So a healthy respect of the form of communication that works best for the child as well as extra patience when they don't respond the way you would like, are beneficial both for the child and for their parent. I can promise you the child's parent is just as nervous about the way grandpa responds to the child as the child is.

This goes for physical affection as well. Children should never be made to hug or kiss someone they don't want to, and this is especially true for our kids on the spectrum. Bodily autonomy is so important as it is often the only thing children have actual control over.

For our neurodivergent* kids, hugs and kisses do not always carry the meaning they do for other people. We may see it as a form of affection, but some children may view it as a very uncomfortable sensory experience where they have no control.

(*Neurodivergent is a term used to encompass all the different learning styles including autism, ADHD, sensory processing disorder and the like)

3. When interacting with the child, take your lead from the parent (and the child).

Kids on the spectrum experience the world differently from others. Often they don't see the big picture or understand the meaning of some phrases. They may get lost in the details, which is why you may see a child having more fun spinning the wheels of a toy car rather than making the car drive.

When adults come along and correct a child for playing with a toy "inappropriately" and instead show them how it should be done, they've just create a divide in that relationship.

The message the child gets is not "Hey! I know how to play with this car now." Instead it's "This is not a safe person for me to be myself around."

So find out from their parent the best way to approach them. Every child is different. If you have interacted with other children on the autism spectrum, that doesn't not qualify you to know how to interact with this one.

Some kids need space and feel overwhelmed when people get too close. Others won't respond but still want others to say hello and talk to them. And still others may talk incessantly and might need a gentle reminder not to interrupt conversations. So allow the parent space to do the parenting and only give advice when asked.

Don't repeat yourself over and over or speak louder if the child didn't respond. Many children with language difficulty need more wait time when asked a question. Most kids on the spectrum are asked WAY too many questions just

because someone wants to interact with them. Often just being present and calm with them is enough.

Follow their lead and the lead of the parent.

4. Only offer support to the parents if you are willing to ask in what way they need to be supported.

One of the things I address with my autism parent clients is to help them identify where they need the most help. Most of them say they are afraid to ask for help or aren't even sure what it is they need.

Maybe it's as simple as ten minutes to take a shower without being interrupted. Maybe they need a listening ear and someone to just hug them when they cry. Whatever the need, you get to decide what you can provide, how often and when.

When my son was little, both my husband's mother and my parents could take turns babysitting. But as he grew bigger and started having some aggressive tendencies during puberty, it became increasingly clear that babysitting was much more difficult.

I absolutely adore my mother-in-law. And I am grateful she was able to express that she could no longer help with Ben, but made it a point to tell us what she **COULD** do. Among other things, she started making us dinner once a week and dropping it off at our house. She is an amazing cook and doing this was such an act of love and so helpful, that she still does it to this day.

When my parents got to the same point, my mom continued to make Ben's favorite muffins and delivered them to our house. All of the grandparents ask often if there is anything we need at the store.

These little things are huge to our family. and it is the support we truly need. So think outside the box a bit when you look at the family you love and think about what you could take off their plate. But please do this with a compassionate heart and not out of obligation. Resentment is never something our families should have to deal with, as we have already too much on our plates.

I'm sure there many other things we could add to this list, so please ask the family you love what they want you to know. Open the lines of communication

so that these necessary conversations can happen. Flexibility is necessary in the world of autism parenting and we need that from our family and friends as well.

It's challenging for autism parents to maintain relationships.

We cancel plans a lot.

We don't always return texts and phone calls.

We often don't get enough sleep.

We don't always reach out to those we love.

I'm so grateful for the friends I have who expect very little from me, and love me anyway. They are gems.

In closing, I want to say thank you to the grandparents, sibs and extended family members and friends who have been there for our families, who are willing to make mistakes, who are willing to learn and also willing to pivot when needed.

We are so grateful for you.



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