# Explaining Autism to Kids

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- 1. Should I tell my child they're autistic?
- 2. When is the right time?
- 3. How do I tell them?

These are the questions I hear most often from parents after an autism diagnosis. They are worried about stigma, their child's self-esteem, and the challenges that lie ahead.



As a society, we've become more **aware** of autism, but we are still learning to **accept** and **appreciate** autism as an important difference in brain wiring, rather than a deficit or disease.

#### Helping a child understand autism is about helping them understand their identity.

Too often, autistic children are taught to be different – to be more "typical." As we hear more from autistic individuals themselves, it is clear that trying to fit an autistic brain into a neurotypical ideal is simply not possible...nor helpful. In fact, it is excruciating and often damaging to the person who is trying to fit in.

Helping a child understand autism is not just about knowing how their brain works, it's about helping them understand a part of their identity.

And with this identity comes a huge community waiting to welcome them, celebrate them, and help them figure out how to navigate a neurotypical world without sacrificing their amazing autistic selves.

So to answer the above questions about talking to a child about autism:

- 1. Yes!
- 2. Now!
- 3. Read on!

# Autism: Redefined

First, it's important to learn more about how autistic people describe autism.

The DSM-5 outlines the criteria for autism as a list of deficits. In truth, there are many challenges autistic individuals face in a world designed for the neurotypical brain. However, this is not the whole story.

<u>Matt Lowry, LPP</u>, an autistic practitioner and parent of an autistic child, has brilliantly rewritten the DSM-5 criteria to reflect a different lens on what autism means.

Here are a few examples (abbreviated for the sake of space). For the full rewrite, <u>click here</u>.

DSM-5 CRITERIA VERSUS STRENGTHS-BASED C/O MATT LOWRY, MS, EDS, LPP	
Abnormal social approach and failure of back and forth conversation	Tendency to talk passionately about certain topics and not engage in small talk
Deficits in nonverbal communicative behaviors used for social interactions	Differences in nonverbal communication, including stimming while talking, looking elsewhere, or being bored
Deficits in developing, maintaining, and understanding relationships	Due to difference in communication, autistics tend to be shunned by neurotypicals
Insistence on sameness, inflexible adherence to routines	Security in routines. Autistic people do not have a sensory filter, so the world is in a constant state of chaos. Routines offer comfort
Highly restricted, fixated interests that are abnormal in intensity or focus	Due to hyperconnected brains, autistic people feel more passionately about what we love, so when we have a special interest we tend to fawn over and fixate on it

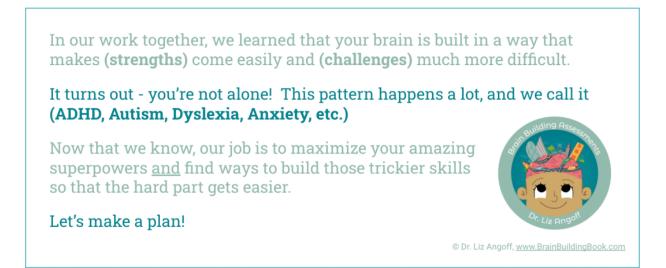
This critical reframing has been extremely helpful for me in thinking about ways to help kids find and advocate for the right environment, rather than trying to mold them into an environment that doesn't work.

#### 5 Steps to Explaining Autism

Explaining autism to a child is a conversation that unfolds over time.

As with any diagnosis, there is no "big reveal," but rather layers presented piece by piece so that the word autism becomes a way of describing what the child already understands about themselves.

The following sentence frame provides the basic structure that has been helpful to me in explaining learning or developmental differences one piece at a time:



When we break it down, there are 5 parts to this sentence frame:

- 1. Identifying Strengths
- 2. Naming Challenges
- 3. Defining the Diagnosis
- 4. You're Not Alone!
- 5. Let's Make a Plan

Here's what it might look like for autism.

# Identifying Autistic Strengths

Autistic brains are built differently than neurotypical brains. This different construction gives autistic individuals unique strengths, especially when the environment is a good match for their brain.

Using the "brain-building" metaphor I reference most, explaining autism begins with identifying these strengths, or "highways." This may sound something like:



*"We learned that your brain is built in a way that makes a lot of things come easily! These are like the super-fast highways in your brain."* 

Building on Lowry's description above, here are some of the "highways" that may be true for your child:

- Deep and passionate interests
- Very knowledgeable
- Truthful and trustworthy
- Thriving with routines and consistency
- Hyperfocus
- Feeling feelings very deeply
- Enjoying movement or other sensory experiences
- Noticing sounds, sights, textures, tastes, and sensations that others may not
- Using movement or rhythm to help stay calm in stressful times
- Finding unique ways of communicating

This language is especially helpful for parents to explain to teachers, coaches, or other parents what may be most helpful to their child. There's a big difference between "My child can't handle changes" and "My child thrives with routines."

For the child, this language is important for understanding that their strengths are not separate from their diagnosis or "in spite of" being autistic. They are the **benefits** of being autistic.

#### Naming Autistic Challenges



Being autistic in a neurotypical world also presents a number of challenges. These are the child's "construction zones," or the skills they may be working to build.

What we identify as a construction zone for autistic youth is very important for how they understand themselves.

Specifically, many autistic children (and their parents) are taught that they need to learn how to interact with the world in

more "typical" ways. This is extremely problematic for a number of reasons I will not address here.

However, an easy example is teaching kids to "look people in the eye." Many autistic adults describe the experience of looking others in the eye as so intense, it makes it challenging to communicate. Looking away helps reduce the intensity, and allows them to engage *more* in the conversation.

In other words, "eye contact" is not a construction zone. "Listening to others" is a construction zone, but the way we "build" that skill may look a little different.

Helping others understand what it looks like for the child to "listen" is just as important as teaching the child to be an attentive listener.

When talking to the child about challenges, I might say something like:

*"We also learned that some things can be tricky. These are your construction zones, or the skills your brain is working to build."* 

Here are some of the construction zones I've identified with my autistic clients:

- Finding friends I can connect with
- Writing down my big ideas
- Knowing what to do when things change or are unpredictable
- Navigating the crazy hallways during passing period
- Knowing if my peers are joking or not
- Focusing on things I'm not interested in
- Letting a teacher know when I need a break

As we help children work on their "construction zones," it will be just as important to think about what environmental changes will help, as well as what the child might do differently. "Finding friends" is not about being more typical, but rather opening up spaces where this child can be more themselves.

### Defining Autism for Your Child

Autism is multi-dimensional, and no two autistic people are alike. It's common to hear: "If you've met one autistic person, you've met one autistic person."

With a diagnosis so complex, how do we define it for a young child?

I find it most helpful to define autism by the child's experience. This may look like bringing together their highways and construction zones, so that there are "no surprises." Rather, it is about putting a name to what the child already knows about themselves.

This may sound like:



*"It turns out, many people have highways and construction zones just like yours. You're not alone! When we see this pattern, we call it autism."* 

Here are a few ways I've described autism to the kids I work with. I often begin with, "For you, autism means..."

- "Your brain is built in a way that notices many sights, sounds, smells, and textures that others may not. Sometimes, this can get overwhelming and you may need some tools to filter out the sensations you don't want."
- "You have a superpower for focusing on the things you love! It may also be challenging to find others who love those things as much as you do."
- "Your brain enjoys routines and rules, but your brain may have a hard time when those routines or rules change."
- "You may communicate differently than your neurotypical peers. Sometimes they might not understand you, and you might not understand them. That's okay! We all have a lot to learn."
- "You process information in unique and creative ways, though it may be difficult to understand how non-autistic people are seeing the world."
- "Your brain is wired to focus with an uncommon intensity, though it may be hard to get stuff done that you're not interested in."

### You're Not Alone!

Autistic kids often feel isolated and "othered," but there is a huge community waiting with open arms to welcome them in!

Introducing children (and their parents) to this community is such an important part of this process.



I find it helpful to show kids examples of other individuals who have made autism their superpower. Here are a few resources that may resonate with your child. Click the links below or scan the QR code for the <u>complete list</u>.

- <u>Welcome to the Autistic Community</u>, an affirming, positive welcome to children (or adults) with a new autism diagnosis
- <u>Meet Julia</u>, an autistic character on Sesame Street, created with the autistic community and puppeted by the parent of an autistic child
- <u>Famous Autistic Individuals</u>, from surfers to singers to actors to Einstein, this page includes videos to bring each person to life!
- <u>Amazing Things Happen</u>, a short video about autism that is helpful for siblings and family members to develop an affirming understanding of the different experiences of autistic people
- Everything You Know About Autism is Wrong, a TEDx talk by Jac den Houting, research psychologist and autistic activist, explains how being diagnosed with autism was the best day of her life
- <u>OurTism</u> and <u>AANE</u>, providing groups and programming for teens, young adults, and parents

#### Let's Make a Plan!

Finally, the child and I come up with a list of tools and strategies that will be helpful for maximizing their strengths and building new skills.
This includes skills they will learn, as well as changes to their environment that will help maximize their amazing brainpower.

• "You'll have a computer or tablet with you at all times so you can type or voice record your assignments."

For example:





- "You're going to start working with the Speech Therapist to help figure out those tricky social situations you mentioned."
- "Your teacher will review the schedule with you each morning and let you know about any changes. You can let her know if there's anything that you think might be hard so you can make a plan."
- "Let's talk about who is easiest to work with for group work, and what they can do to help you feel most included."
- "Let's put together a box of sensory tools you can use when things are too loud, bright, or if you need help focusing. Your teacher may get a class set of some of these things since you're not the only one who could use them!"
- "The art teacher is starting an anime club. We need an expert to help create it!"

Again, it's important to keep in mind the supports the child needs, **and** the ways the environment can change to be a better match. This is a key step for going beyond **awareness**, and making strides towards **appreciation** and **acceptance**.

I hope this has been helpful to you and your autistic child! For more helpful articles like this, please visit <u>www.BrainBuildingBook.com/Parents</u>