A Parent's Guide to

# AUTISM AND ADHD

axis

"Because of their neurological challenges, people with autism face tremendous obstacles of three kinds: trusting their body, trusting the world around them, and—most challenging of all—trusting other people."

#### Uniquely Human: A Different Way of Seeing Autism by Barry M. Prizant

"Living with ADHD is like being locked in a room with 100 Televisions and 100 Radios all playing. None of them have power buttons so you can turn them off and the door is locked from the outside."

#### — Sarah Young

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### **Table of Contents**

Everything Everywhere All at Once	1	
What is autism?	5 7	
How is autism portrayed in pop culture?		
What is ADHD? How is it portrayed in our culture?		
What kind of care do teens with autism and ADHD need?		
Seen and KnownCall to Generosity		
		Sources

#### This guide will help you discuss the following questions:

- ✓ What are autism and ADHD?
- ✓ How does social media impact people with autism and ADHD?
- ✓ How have cultural perceptions of autism and ADHD changed?
- ✓ What do autistic and ADHD teens need from the people who love them?
- ✓ What does parenting a teen with autism or ADHD look like?
- ✓ What encouragement is in Scripture for parents of teens with autism and ADHD?

### **Everything Everywhere All at Once**

"My favorite question on the autism diagnosis form is: would you rather go to the theater or a museum?" begins a TikTok video by user <u>@rubyofmyeye</u>, before continuing to explain her amusement; "because I get overstimulated at a theater, and understimulated at a museum, so, neither."

Ruby, whose screen name and bio identify her as an autistic blogger, adds the hashtag #actuallyautistic to her videos. The tag suggests, theoretically, a person with diagnosed autism sharing their experiences, making jokes, or giving advice. The hashtag #actuallyADHD is popular too, and the tags often appear on the same video, along with the hashtag #neurodivergent. "Neurodivergence" is a non-medical term used to refer to a broad variety of mental health issues, disorders, and disabilities. In popular culture, however, it is most often used to refer to autism and ADHD, which have many similar characteristics, as well as high comorbidity.

Clearly, these TikTok videos—and the Instagram posts, Tweets, and YouTube videos of a similar ilk—identify a community that has formed around these experiences, and that community is ever-growing: over the last several years there has been a huge increase in the number of people diagnosed with ADHD and/or autism. The CDC reports that in 2003, roughly 4.4 million children aged 3-17 were diagnosed with ADHD. As of 2019, that number has jumped to 6 million. 1 in 150 children of the same age were diagnosed with autism in 2000; by 2020 that number was 1 in 36.

Those numbers are clearly significant, but in pop culture autism and ADHD are still accompanied by certain stigmas and stereotypes that can make it difficult to understand what a person with either disorder might experience in their day to day life. We at Axis are not specialists in autism or ADHD, and we want to recognize that not every perspective or experience of living with or caring for those with autism or ADHD will be represented in this guide. Our goal is to highlight the ways that autism and ADHD are often represented in culture, especially on social media, and to share some helpful information on what parenting a teen with autism or ADHD might look like. Above all, whether you're parenting a child diagnosed with one of these disorders or you simply want to know more, we want to encourage you to trust God and ask Him to develop greater love, empathy, and wisdom in you.

### What is autism?

Autism spectrum disorder, commonly referred to simply as autism, is defined by the <u>American Psychiatric Association</u> as, "...a complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behavior. While autism is considered a lifelong disorder, the degree of impairment in functioning because of these challenges varies between individuals with autism."

While there is not yet any definitive answer for what causes autism, the current scientific opinion is that autism has a genetic component, and has been linked to factors like <u>certain medications</u> taken during pregnancy and pregnancy occurring later in the parents' lives. Things that have not been linked to a child's likelihood of being diagnosed with autism include <u>vaccination</u>, socioeconomic status, race, or ethnicity.

Autism was not recognized as a disorder until its inclusion in the DSM-3 (the Diagnostic and Statistical Manual, which is the official handbook used by psychologists) in 1980. It had previously been considered a result of a lack of emotionality from mothers and was not taken seriously as its own unique diagnosis. It wasn't until 2013 that the DSM-5 defined Autism Spectrum Disorder as something that continued into adulthood. Until its publication, the common assumption was that most people "grew out" of their autism. As a result, teens and adults with high-functioning autism rarely received diagnoses and therefore rarely received the accommodations they needed to be successful.

**Reflection**: What kind of narratives about autism have you heard from culture or other parents? What's one question you've had about autism?

# How is autism portrayed in pop culture?

While autism is not a new condition, it has been getting a lot of attention in our culture of late. The ongoing TV show *The Good Doctor* was recently criticized (and memed to death) for its reductive portrayal of an autistic surgeon as genius-level brilliant but inherently childish and not to be taken seriously. Another example was in the 2021 film Music, directed by the popular musician Sia (who is known for mega-hit songs like "Chandelier" and "Elastic Heart"). The plot is about a non-verbal autistic girl. But the film faced immense backlash from the autistic community for a number of reasons. For one, the lead actress was not autistic, and much of her performance seemed to be based on caricatures of autistic people, such as exaggerated facial expressions and body movements. For the production of the film, Sia also partnered with the controversial autismadvocacy group Autism Speaks, which has a history of portraying autistic people as dangerous (such as this ad run by the group which portrays autism as a boogeyman who will "fight to take away your hope... [and] plot to rob you of your children."), as well as supporting therapy which, as autistic adult and advocate Tori Morales writes, encourages therapists to "withhold things as punishment (toys, playtime) or in some cases spray water in the child's face -still unhelpful and possibly abusive practices for autistic children." Though Autism Speaks has changed some over the years, the criticism continued when they supported *Music*'s depiction of physical restraint as a healthy way to deal with a person having an "autism meltdown," in which they become overstimulated or upset and are unable to articulate themselves clearly, sometimes leading to emotional outbursts and violent movement. This kind of restraint has contributed to the deaths and serious harm of many autistic people who could not communicate that they were being hurt. Regardless of the ways that Autism Speaks and Sia attempted to support and destigmatize autism, the whole endeavor had the opposite effect.

Having said that, the reaction that *Music* sparked helped to bring a spotlight to autistic self-advocates and what they had to say about their experiences. Though the film itself misrepresented autism, it provided a platform for autistic people to combat harmful stereotypes and share information on what does and does not help them live happily and comfortably in a society that is often overwhelming for them.

The sharp increase in attention paid to autism, especially on social media, created a cultural conversation that has only become more complex. As autistic people began describing their experiences on TikTok, Twitter, and Instagram, many others found themselves relating to the content. Several symptoms of autism—such as intense fixation on certain things, self-soothing

or energy-releasing physical movements called "stims" (like jittering legs or tapping fingers), as well as general discomfort in social situations—are, in fact, fairly common to the human experience. Though autistic people tried to make it clear that these symptoms are much more significant to them than they would be to someone without autism (so much so that efforts to avoid a certain sensory experience or social situation can lead to real disruptions in their daily lives), posts like these were already creating an opportunity for others to start self-diagnosing.

There is also the issue of autism being "aestheticized" on social media—that is, made palatable and even appealing by content creators looking for engagement. If the portrayal of autism found online encourages people to think of it as manageable and interesting, then people who experience severe, painful, or very obvious symptoms may end up feeling more ostracized than they already do. Autistic people who are nonverbal, developmentally handicapped, or whose symptoms are simply more visible still face the same amount of bullying and isolation (or perhaps even more) than they did before self-diagnoses on social media became popular.

Worth mentioning alongside this is the overlap between the autistic community and the LGBTQ+ community. According to a <u>University of Cambridge</u> study, autistic youth and adults are eight times more likely to identify as something other than heterosexual than their non-autistic peers. There are a number of possible reasons for this, but one possibility is that many <u>autistic people don't intuitively connect</u> to social expectations for gender, sexuality, romance, and attraction. This may cause them to question whether their lack of understanding of cultural norms (like heterosexuality) is actually indicative of them being outside that norm. Add this to an online culture that already converts real, valid, and valuable minority experiences into social currency and turns people's lives into platforms (everyone wants to be an influencer, but a *nonbinary*, *lesbian*, *autistic*, *POC*, *disabled* influencer will get more traction), and it seems that it would be difficult for a teen who "only" has autism not to feel left out.

Many people who experience and express symptoms of autism, whose lives are deeply affected by it, and who want to help educate others about what living with autism is really like are doubly impacted by non-autistic people making content about autism. On the one hand, people looking for a diagnosis that makes them feel better about their quirks may find the genuine struggles of autism off-putting in light of the more aestheticized content they've seen; on the other hand, social media users who are rightly wary of this kind of content may end up dismissing actually autistic people along with those who only claim to be.

Reflection questions: What's one thing that has been surprising to you about autism and the way our culture portrays it? How have you seen autism portrayed in media?

# What is ADHD? How is it portrayed in our culture?

Attention deficit hyperactivity disorder, or ADHD, is the other type of neurodivergence often discussed alongside autism. The CDC describes ADHD as a disorder which impacts individuals' ability to focus, control impulsive behavior, remember and retain information, and which can make it difficult for them to move at a slow pace physically, emotionally, or mentally. Though many children exhibit behaviors common to ADHD like struggling to wait in line, daydreaming, or finding homework too unengaging, children with ADHD experience these symptoms much more severely and carry them into adulthood.

#### There are three ways ADHD can present:

- 1 People with inattentive presentation often struggle with detail, follow-through, and become easily overwhelmed by tasks that involve multiple steps or take place over a long period of time. Daily routines, drawn-out conversations, and complicated instructions can be difficult for people who experience this form of ADHD.
- 2 Hyperactive-impulsive presentation is the most visible presentation and is what most people likely associate with ADHD. People whose ADHD presents in this way often struggle with physical self-control, finding it nearly impossible to sit still or be quiet, and will often feel a need to move and fidget or talk a lot to express their fast-moving associative inner monologue. They often act before they think, which can cause them to appear disrespectful or thoughtless, when in reality their understanding of consequences simply has to catch up with their impulses.
- 3 The third way ADHD can present is in a combined presentation, where people experience symptoms of both inattentive and hyperactive-impulsive types.

Like autism, there are not yet any definitive answers for what causes ADHD, but that hasn't stopped common myths from springing up around what "gives" children ADHD, like eating too much sugar or playing too many video games. Unlike autism, ADHD can be treated with medication that can make symptoms more manageable and, in some cases, nearly unnoticeable. And, while ADHD can be debilitating, it doesn't necessarily cause developmental delays which keep children from experiencing certain aspects of adulthood, like a career, marriage, or children, which does often happen in people with severe autism.

Because of this, and the fact that ADHD is much more common than autism, people with ADHD are often taken less seriously. Using the phrase "I'm so ADHD" to describe being scatterbrained or forgetful is common, and <u>can contribute to the perception</u> that living with ADHD is mostly something to joke about.

Many of the same issues with social media and autism can also apply to ADHD. Self-diagnosis with ADHD, however, is significantly more common as technology use in young people becomes more ubiquitous. Excessive screen time can cause ADHD-like symptoms, like a shortened attention span, hyperactive physical movements, and difficulty with conversations and instructions. Social development taking place online rather than in person can also stunt a young person's ability to read social cues and understand relational nuance, something which can also be a symptom of ADHD. So, when an Instagram post describes a woman with ADHD as having "dyed hair be boredom" and "chipped nail polish forgot to remove," many young women might find themselves wondering if they have ADHD. The top comment on this particular post says, "Sooo if I check ALL of these boxes, then I have ADHD or most likely have it? So surprised by this!"

Unlike with autism, it is remarkably easy to get an ADHD diagnosis, and social media has encouraged more and more people to pursue treatment after self-diagnosing. While people with autism often struggle getting doctors to take them seriously, the widespread appearance of ADHD-like symptoms and the arguably simple treatment available through medication has led to a rapid increase in ADHD diagnoses and prescriptions for pharmaceutical drugs. During the COVID-19 pandemic, many people's interaction with medical professionals primarily happened virtually, and this has remained a common way for patients to seek treatment that is less expensive and quicker to access than in-person options. Despite the lack of face-to-face interactions, online health professionals are able to diagnose ADHD with a questionnaire, which makes it fairly simple to get a diagnosis and, subsequently, a pharmaceutical prescription. This has led to an ongoing nation-wide shortage of ADHD medication, meaning many people who rely on these prescriptions can't get them filled.

The combination of this phenomenon with all of the potential harms surrounding self-diagnosis and social media (which we mentioned above regarding autism, and which all apply to ADHD as well), have created a culture where many people who actually have ADHD are not receiving the care and accommodation they require to manage their symptoms and function to their fullest potential.

**Reflection questions:** What experiences do you have, either firsthand or secondhand, with ADHD? If a person told you they had ADHD, what would your response be? What would be some things you'd be curious about?

# What kind of care do teens with autism and ADHD need?

First and foremost, teens with autism and/or ADHD need the same things any teen needs: compassion, unconditional love, structure, investment of time and energy, and validation that their experiences matter and deserve understanding. However, teens with autism and ADHD might need some of these things in greater measure.

For one thing, we as parents may need to work on our understanding of empathy and sympathy. Though the terms are often used interchangeably, they actually mean different things. Empathy means feeling another's feelings, drawing on your own experiences to enter into their emotional or mental state. Sympathy is care for another person that doesn't arise from your own life or common feelings but from a love for them that seeks to understand what you haven't gone through. For parents or caring adults of kids with autism or ADHD, we can't always draw on empathy.

Sympathy, however, gives us the ability to express our love for our children without having personally experienced what they go through. This is often exactly what people with a life-altering and potentially isolating disorder need to hear: that the people around them love them, and that even though they may not be able to personally understand their experiences, they are still willing to listen, learn, and help them in whatever way they can. Depending on the severity of a young person's autism or ADHD, this might mean anything from learning how to parent a forever child (a child whose disorder prevents them from fully developing emotionally or mentally into an adult and who will likely require lifelong care) to checking in with a teen who is managing their own symptoms, but who maybe needs to be reminded from time to time that you are still a safe person to share their needs with.

The importance of community—for both you and your teen—cannot be understated when walking through these difficulties. Care from a mental health professional who is trained in providing children and teens with skills and coping mechanisms (and is not emotionally involved with your child in a way that inhibits their patience or emotional bandwidth) can make a huge difference in your ability to help your teen. While social media can be a source of support and community, it may also be worth looking into professional-led support groups with other teens who have autism or ADHD, where your teen can find community with others who *can* empathize with them.

In addition to caring for your child, it's important for parents and caring adults who love kids with autism and ADHD to care for themselves too. Children with ADHD and autism are both prone to having difficulty regulating their emotions and behaviors. As a parent, as much as we may try to be understanding, there will inevitably be times when this is frustrating, and having patience with a child whose brain doesn't think the way yours does can be confusing and lead to anger and even hopelessness. In short, parenting a child with autism or ADHD always requires support, which could include seeking out your own mental healthcare from a professional who specializes in supporting parents of kids with these disorders, or maybe finding a group of other parents walking through the same things.

It also means being open with and leaning on the people who love you, be that friends, family, or your church. If you are married, it means that your marriage will likely require extra care and consideration, as unfortunately <u>divorce is much more common</u> among couples with children who have autism or ADHD. You and your spouse are both called to love and disciple any of your children with these disorders, as well as to keep one another accountable for the ways you may see each other falling into frustrations and reactionary behaviors.

Above all, loving and parenting a child with autism or ADHD requires moment-by-moment reliance on the grace and sufficiency of God. Zephaniah 3:17 says, "The Lord your God is in your midst, a mighty one who will save; he will rejoice over you with gladness; he will quiet you by his love; he will exult over you with loud singing." God promises His continuous presence with us in our pain, confusion, and hopelessness, as well as in our faithful work and desire to love and parent well. He is our Father, which means He understands and embodies *all* aspects of parenthood. He faces no difficulty in parenting every one of His children, no matter what our experiences have been or what we live with. He is perfectly patient, perfectly understanding, perfectly compassionate, and perfectly loving. He is never frustrated or dismissive, He is never at a loss or confused or annoyed. In drawing close to Him and trusting Him to hold us in His heart, we can draw on His perfect parenthood to guide and nourish us as we parent.

**Reflection questions**: If you parent a teen with autism or ADHD, what are some ways you've found support in that journey? How do you find yourself pressing into God as a parent, and what are some ways you can do that more intentionally?

### **Seen and Known**

In John 10:14-15, Jesus describes His relationship with us: "I am the good shepherd. I know my own and my own know me, just as the Father knows me and I know the Father; and I lay down my life for the sheep." Jesus says that we are familiar to Him, that He understands and sees us in the same way as He and the Father understand and see one another. The nature of the Trinity is that God the Father and God the Son are one being, in total unity and community and accord with one another, having no separation or distance or miscommunication with each other. That is the kind of relationship to which Jesus compares our relationship with Him.

As parents and caring adults who love kids with autism and ADHD, this can be a comfort on multiple levels. Not only does Jesus feel this way about us, but it's how He feels about our kids. Despite the challenges they face living with these disorders, Jesus understands and loves and knows them—doing so is not a challenge for Him. He is as present with them as He is with any of His other children. In the depths of their loneliness, to the edge of their frustration, throughout the whole breadth of their lives, Jesus walks perfectly in step with those for whom He lays down His life.

Reflection questions: Did you learn anything new about ADHD and autism from this Parent Guide? How do you hear your own teens talk about autism and ADHD, and how can you engage in conversations about these topics with them in a loving, interested way?

### **Call to Generosity**

If you like what you learned in this Parent Guide and want to help us continue to make great resources to serve parents like you, consider making a gift at <u>axis.org/give</u>. Thank you!

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