# NONVISIBLE PART OF THE AUTISM SPECTRUM

Could You Be a "Little Bit Autistic"?

David William Plummer

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# **Dedication**

This book is lovingly dedicated to my wife, Nicole, with whom I've shared 35 remarkable years. You accepted me for who I was long ago and made me who I am today. You've been the steadfast compass in our journey through the uncharted waters of life with autism. Before we even knew its name, you navigated its challenges with an unwavering patience and grace that has been the anchor of our marriage's success. Your constant encouragement is the force behind most of what I do; your resilience is a silent testament to the strength of your character.

For every morning that you've greeted me with that radiant smile that resets my world anew, I am eternally thankful. This is for you, the unsung muse behind so many drafts, revisions, and random ideas along the way. Thanks for being the sunshine that brightens my world and the safe harbor where I can weather life's storms!

# Introduction

# Who This Book Is For

Have you ever wondered if you might be somewhere on the autism spectrum? Or do you find yourself in the company of those who are? If so, this book is for you. It's a companion for the curious, the ones who wonder whether certain quirks and qualities might be threads in the larger tapestry of the spectrum.

For those a generation removed from autism proper — perhaps as a parent, sibling, or child of someone who walks this path — you too may recognize echoes of these traits. As genetics play a significant role, you likely share some of them. May these pages offer kinship, insight, and a map to navigate the complexities of being, living with, loving, or understanding someone who perceives the world through a very different lens.

# **How This Book is Structured**

The first section of this book discusses the most common characteristics of the autism spectrum, how to identify them, and how they manifest in people on the spectrum. The second section provides tips, techniques, and strategies for living with and leveraging those characteristics. It's everything I know now about living a successful life on the spectrum that I wish I'd known long ago.

# "A Little Bit Autistic"

I always knew I was different, especially from the other kids. I spent most of my childhood feeling like an outsider looking in. In school, I was either hyper-focused on a topic or completely disinterested. I struggled socially and usually didn't "get" what others said or thought. In groups, I never knew when it was my turn to talk, and I took a lot of verbal – and sometimes worse – abuse for being different. It would be many years before I learned that millions of people were "similarly different."

By adulthood, I would eventually catch up to my peers in most ways and find acceptance from a small group of close friends and, soon enough, a loving wife and family. I was still different, but by then, we all figured I was just "Dave." Being Dave simply meant that I had some idiosyncrasies and needed a few accommodations.

I needed order and routine and got flustered by inconvenient changes. Sarcasm was hard for me: I took everything literally and often personally. I truly only had two interests: cars and computers. I had to cut the scratchy tags from my shirts and shower right after haircuts. I was uncomfortable with hugging people. I was never sure when it was my turn to talk; when it was, I never knew quite where to look when talking to people. I was great with stressful situations that I had the skill to solve but terrible with things outside my control.

Despite taking seven years off and on to finish high school, I did very well in college, where I could focus on subjects that I

was good at. By the end, I was clever, persistent, and fortunate enough to make it from Saskatchewan to Microsoft, starting as a software engineer on MS-DOS in the early 90s. After my stint in MS-DOS, I moved to Windows, where I was privileged to work on several other memorable features. If you've ever used Task Manager, opened a Zip file, played Pinball, formatted a disk, or used the Start Menu, you're using some of my code to this day.

A few years ago, my alma mater invited me back to deliver a lecture on my life and career. By now, I was self-aware enough to make a few oblique references in the lecture to having some telling characteristics, such as:

"There may be a whole spectrum of reasons I am who I am."

"I may not be on the spectrum, but you can see it from here."

"I could be on the spectrum, but if I am, it's the nonvisible part of the spectrum!"

A trusted friend and mentor, the very person who had hired me at Microsoft, happened to see the lecture. His adult daughter had recently been diagnosed with autism spectrum disorder (ASD), and that had sent him on a journey of self-education on all matters related to autism. He knew me well enough that he had begun to wonder if *I* had ASD as well. After seeing me

refer to the autism spectrum in the lecture, he reached out and took me for lunch, where he explained his reasoning. He followed up with the kind of email that really makes you sit up and pay attention:

"Maybe you should get yourself tested."

Taking his suggestion to heart, I contacted the autism center at the University of Washington, which, in turn, referred me to a top local neurologist who specializes in neurodevelopmental conditions. I learned it would involve twelve hours of intensive testing over several days: IQ tests, coordination assessments, personality inventories, etc.

As I told friends of this upcoming testing, I had been expecting to hear a chorus of "What, you? Autistic? That's silly!"

Instead, to my substantial surprise, I was met with knowing looks accompanied by comments such as "Fascinating... Let us know what you find out!"

In the meantime, I did what I did most afternoons – I stopped by a local auto/machine shop to have a coffee with Jim, a close friend who owned the place. He was about seventy now, a Vietnam combat veteran, a lifelong resident of my small town, and an absolute genius when it came to any car made before 1975.

Jim had lost an eye to cancer just a few months back. It was a melanoma that he ultimately wouldn't survive. He didn't warn me, and one day, I just walked in to find him terminally ill and missing an eye. As with many highly emotional moments, I

was stoic and measured in the moment... until I had a meltdown that night.

But on that day, when I told him I was being tested to see if I was a little bit autistic, he looked up from the carburetor he was working on, gave me a wry smile, and said, "Just a little, huh?" I guess sometimes you really are the last to know.

When the assigned day came, I began the testing. I found it challenging and exciting. There was one test, however, that I found highly annoying. It was an audio tape where a narrator read a sequence of random numbers. It's your job to sum up the last two you've heard and say the result aloud, all while listening, and it speeds up as it goes. The audio quality was terrible. It was some worn old cassette tape with scratchy sounds and hiss, and the volume was too low. There were also occasional background sounds that complicated my hearing of what they were saying. I did my best but became increasingly annoyed and bothered that the test quality would unjustly impact my score. When it was complete, I took it up with the examiner running the tests, and she said:

"Yes, I know. That's part of the test: We also use it to check for anger disorders."

- Test Examiner

I was looking forward to the IQ testing to get the results. I'd been tested as a teen and wondered if my new score would be significantly different. Ultimately, it was within a few points of my old score, which was reassuring. While I do well on such

tests, I'm also painfully slow. I tend to get the correct answer quite reliably, but I get there my own way at my own speed. Officially, I was diagnosed with "slow processing speed," a bit ironic for a computer programmer. It turns out to be a frequent feature of the inattentive style of attention deficit disorder (ADD) that I was also diagnosed with that day.

I asked my wife to accompany me to get the rest of the results, and as the doctor led us through the paper copy of the report, we eventually reached the section on social interactions. My wife spoke up:

"Well, at least the numbers are good here, far above average!"

But the doctor quickly corrected her:

"No, no... higher is worse!"

And so, the big news finally came at last: I have autism spectrum disorder. And not "just a little."

### **Traditional Levels of Autism Spectrum Disorder**

(Terminology in quotes may be deprecated)



<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>
"High Functioning" Autism or "Asperger's"	Autism	"Severe" Autism
<ul> <li>Requires         accommodations.</li> <li>Difficulties in social         situations</li> <li>Inflexible behaviors</li> <li>Problems with focus,         switching tasks,         organization.</li> <li>Obsession with         details over big         picture</li> </ul>	<ul> <li>Requires significant support.</li> <li>Significant social difficulties</li> <li>Inflexible behaviors</li> <li>Difficulty or upset coping with stress or change.</li> <li>Repetitive behaviors</li> </ul>	<ul> <li>Requires         substantial support         and assistance.</li> <li>Severe social         difficulties</li> <li>Significant         communication         difficulties</li> <li>Extreme difficulties         with stress and         change</li> <li>Repetitive         behaviors interfere         with daily life</li> </ul>

The doctor gave me a dual diagnosis: "Asperger's Syndrome if evaluated per DSM-IV, Autism Spectrum Disorder if by DSM V." More on that distinction and why the term Asperger's is now deprecated can be found in the appendix.

This "autism scale" is likely not intended to be a fractional one, but if we pretend for a moment that it could be, I'd be placed around a 1.75 on such a scale.

Now, if we're accepting fractional values on the spectrum, doesn't that beg the question of whether you could find yourself somewhere between zero and one?

Which is to say, could you be "a little bit autistic?"

That, in turn, depends on what we mean by "autism" and "autistic." If the word autism is just shorthand for ASD, I would then argue that you either meet the clinical definition for autism spectrum disorder or you do not - in the sense that you can't have ASD without the disorder. You can't be a little bit pregnant. And so, you can't be a little bit ASD. It's not just a cluster of symptoms: it must rise to the level of a specific diagnosed disorder before being ASD.

If, however, we accept the word "autism" to mean the neurodevelopmental condition itself rather than the formal disorder, then it stands to reason that you could have "just a little" of whatever autism characteristics impact you. Yet, they may not rise to the level of an actual disorder.

I believe that you certainly can, and many people absolutely do, have some set of symptoms or characteristics of autism that wind up placing them in this 0 to 1.0 region: the area I call the "Nonvisible Part of the Spectrum." They will likely never be diagnosed with ASD, but they experience *some* of the characteristics and symptoms typically associated with autism.

# Why Did I Write This Book?

I feel that I'm far enough "into" the autism spectrum that I can clearly see and understand the unique autism thought process and perspective while also being conversant enough to report back what I see. I know how it *feels* to have autism, and I do my best to explain it.

After being diagnosed with autism spectrum disorder, I've spent the last several years studying, speaking, and writing about it, focusing on helping people understand, manage, and accommodate the demands of their own autism.

While none of my children have been diagnosed with ASD, each of them experiences a unique mix of autism spectrum characteristics (ASCs), a fact perhaps not surprising for something so rooted in genetics. However, the advice I'd give to them is markedly different than what I would offer to someone with ASD, and that's a large part of why this book exists: for them. It is advice and understanding for people who have certain characteristics of autism but that do not rise to the level of a medical disorder.

# Part I: Autism Beyond the Labels

# The Spectrum

The widely accepted notion that autism is best described as a spectrum has been a mixed blessing. On the one hand, it speaks to the wide degree of neurodiversity that defines "the spectrum." And yet, the spectrum is not a linear path from one extreme to another; it's a multidimensional space where everyone occupies their own unique and distinct position. The notion of a linear spectrum implies a progression from 'less autistic' to 'more autistic,' a misleading and overly simplistic view. Autism is not a one-size-fits-all label but a complex interplay of characteristics that vary widely from person to person.

# "If you know one person on the spectrum, you know one person on the spectrum."

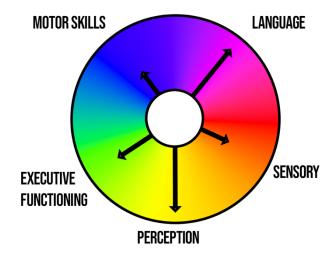
In other words, the point where an individual finds themselves on the autism spectrum is not a simple measure of "more" and "less" autistic because Autism Spectrum Characteristics (ASCs) are not limited to a single attribute or characteristic — the effects, whether positive or negative, are spread across many axes. How your own mix of ASCs impacts your language, motor skills, social skills, executive functioning, perception, and sensory processing are just a few of the factors involved, each

defining where you land on the spectrum. Absent some complex geometry like a 4D hypercube, perhaps it can be best described as a set of concentric rings divided into sections, one for each characteristic, like a pie. One's distance from the center within that slice could indicate the degree of impact from that

# What People Think the Spectrum Looks Like



# What the Spectrum Actually Looks Like



characteristic. The spectrum, then, could be represented as follows.

This portrayal only considers five core characteristics for simplicity, but the spectrum comprises many more.

Consider the case of an introspective individual who finds solace in the world of numbers and patterns. Their affinity for mathematics may be as intrinsic to them as an artist's flair for color and form. Or consider the quiet observer, whose rich inner world is often overshadowed by their anxious struggle to navigate social conventions. Their silence is not a lack of thought but a galaxy of unspoken words waiting for the right moment to align with the external world.

And yet, the spectrum isn't solely defined by its challenges. It's equally about the strengths and abilities that arise from a different way of processing the world. For some, it's an exceptional memory or acute sensory perception. For others, it's a remarkable focus and depth in a particular area of interest or the ability to think in unconventional, innovative ways.

You could write a book on the various ways in which I've been able to leverage the unique combination of gift and burden that autism has given me. In fact, it's the subject of my *last* book!\* My ability to obsessively persevere in problem-solving through challenges and adversity is undoubtedly an aspect of my autism, as is the unique perspective I bring to whatever the

<sup>\*</sup> Secrets of the Autistic Millionaire, https://amzn.to/3OA8c9b

problem is. I have a complete visual history of snapshots of my life on file in my brain that I can search as if they were Google Images. Almost every piece of factual knowledge I have in my head includes metadata about where I was when I learned it and how likely it is to be true. My internal fascination with how specific numbers "feel" helps me remember and process essential data while catching errors. My seemingly insatiable need to know what's inside everything has been the foundation of my engineering abilities.

Some of my kids experience synesthesia, where numbers and letters have their own unique mental colors, but I do not. I sense that each numeric digit and many multidigit patterns have a "feel," but it's not linked to any other sense in my case. For example, for the 1969 model year, full-size Pontiac cars were built with 427 cubic-inch engines in Canada and 428 cubic-inch engines in the United States. They sound very similar on paper, but I could *never* confuse those two or get them backward, as 428 has an entirely different "mental feel" than 427. Perhaps I can best explain it by equating it to the "feel" of days of the week. Sunday has a "feel" quite different from Friday. For me, each digit and many multidigit patterns have their own unique feel in the same way. Whether these feelings are innate or built by association, they are strong nonetheless.

It would be a cop-out to dismiss the autism spectrum as too diverse to characterize accurately, so let's take a moment to consider the core similarities among individuals on the spectrum.

# **An Autism Primer**

To ensure we're all on the same literal and metaphorical page regarding the primary autism spectrum characteristics, let's take a quick tour of the top five right now. Although the following are the most common symptoms, this is still by no means an all-inclusive list:

- Social Communication Challenges: Individuals with ASD might struggle with verbal and nonverbal communication. These can include challenges in understanding and using gestures, making eye contact, knowing where to look when speaking, having backand-forth conversations, knowing when to speak, and interpreting the tone of voice or facial expressions.
- Restricted, Repetitive Patterns of Behavior, Interests, or Activities: People on the autism spectrum may exhibit repetitive body movements (like rocking, flapping, spinning, snapping, etc.), rigid routines, or deep, intense interests in specific subjects.
- Sensory Sensitivity: Many individuals with ASD may be hyper- or hypo-sensitive to sensory input, which can manifest as adverse reactions to certain sounds, textures, tastes, smells, or visual stimuli. They might seek out specific sensory experiences while strongly disliking others.
- **Difficulty with Change:** Changes in routine or the environment may be challenging for people on the

autism spectrum. They might also be particularly insistent on sameness and can have a hard time with transitions or changes in routine.

 Motor Skills: Individuals with ASD may take longer to reach milestones like walking and may, over their lifetimes, face problems with motor skills and coordination. These deficits can complicate things as diverse as handwriting and competitive sports.

There are others, of course, but these five are generally common to some extent amongst most individuals on the autism spectrum.

# Beyond the Labels

A strong desire to categorize and systematize is common amongst those on the spectrum, but all people do it to some extent, and the labels we all use are a natural outgrowth of that. They offer us a semblance of understanding, a way to make sense of behaviors and traits that might deviate from the norm. But what happens when we step beyond these simple labels? What new understanding can we gain when we look at individuals on the spectrum not just as a collection of symptoms but as unique individuals with their own stories, challenges, and triumphs?

"My autism isn't what makes me stand out; it's what makes me unique"
- Rachel B.

Consider the label "high-functioning autism." It implies a certain level of capability or adaptability, yet it fails to capture the internal struggles and challenges that individuals such as me might face. The outward appearance of "functioning well" in society can mask difficulties with sensory processing, emotional regulation, social communication, and more.



Since my masking is well-practiced and because I have a sufficiently high IQ, many would label me as "high functioning." I find the label 'high functioning' in relation to autism problematic because it subtly implies a

comparison to older and sometimes offensive measures of intelligence. It overlooks the diverse challenges and strengths individuals on the spectrum may have, reducing their experiences to a misleading and simplistic metric. We should strive for language that respects the complexity of autistic experiences without resorting to comparisons that can demean their abilities and value.

Claiming that I am "high functioning" also overlooks some significant issues with sensory, emotional, and behavioral matters that I contend with regardless of my masking ability or intellect. I've seen Internet comments that describe my autism

as a "very mild form," but making assumptions about the impact of the disorder on my life based on my ability to host a YouTube video is misleading at best. And that is why, at least in part, I try to steer clear of such labels: even those with generally positive connotations can be needlessly dismissive and limiting.

# Autism Spectrum Characteristics (ASCs)

A common misconception about autism is that there is some definitive checklist of symptoms on which one can calculate a score to make a diagnosis. Any list of Autism Spectrum Characteristics (ASCs), including the one I presented earlier, is merely a generalization of the most common characteristics experienced by people on the spectrum and should not be mistaken as a diagnostic tool.

The symptoms of autism are many and varied, and no two individuals on the spectrum will have the same "mix" of symptoms. One may suffer profoundly from deficits in social communication and interaction, while another may be more troubled by repetitive behaviors or poor executive function. It is essential to keep in mind when talking about ASCs that the impact of each specific characteristic can vary widely, ranging from profound to none.

### ASC vs. ASD

ASCs refer to a set of behavioral and social characteristics that are like those seen in individuals with autism spectrum disorder (ASD). These symptoms may include challenges with social communication, such as difficulty with eye contact or understanding nonverbal cues, repetitive behaviors or routines, becoming emotionally overwhelmed, and sensory sensitivities or aversions. Autism-like symptoms can occur in a variety of different conditions or situations, including in individuals who have not been diagnosed with ASD.

ASD, on the other hand, is a specific neurodevelopmental disorder. It should be noted that the symptoms of ASD must be present in early childhood and have a significant impact on an individual's daily functioning to meet the diagnostic criteria: they do not manifest suddenly or later in life. Oddly, I feel at times that I've become more autistic as I've aged, but I think that's primarily a function of (a) being self-aware about my own autism and (b) getting more set in my own ways as I age. Functionally, such as in social situations, I've only improved over time thanks to the understanding that getting a diagnosis brought with it.

# Social Communication Difficulties

Those with autism often experience difficulties with social communication and interaction. They may struggle to initiate and maintain conversations, understand social cues, or show interest in others. They may have difficulty interpreting facial expressions, tone of voice, and body language and may find it hard to infer the thoughts, feelings, or intentions of others.

One of the core deficits in social communication for individuals with this ASC is difficulty in using language to communicate and understand social information. They may have problems initiating and sustaining conversations and may not be able to follow the typical turn-taking pattern of a conversation. They may need help to recognize when it is their turn to speak and, thus, have trouble jumping into a group conversation.

I remember being terrified of the "reading circle" in first grade, where each child took turns reading sections from a book. I could read well enough, but I had no idea when the previous speaker was finished. It appears my wiring in the circuit that flags the "and now *you* speak" moment doesn't quite work.

Once they do get their turn, people on the spectrum may also tend to talk at length about their interests without noticing whether the other person is interested. If you're on the spectrum and you're into computers, trains, dinosaurs, space programs, or video games, it's essential to remember that most others will not share your passion for the topic.

I recall experiencing several instances, particularly during my childhood, where I was reprimanded for interrupting adult conversations or for talking excessively about a topic of interest to me that was not related to the ongoing discussion. While this behavior may have made me appear impolite on occasion, it was most likely a manifestation of my ASD. Individuals with this ASC may find it challenging to understand and use nonverbal communication, such as facial expressions, gestures, and body language, to convey emotions, intentions, and social meaning. They may not recognize subtle social cues, such as changes in tone of voice, that typically convey emotion and may interpret language too literally. This can lead to difficulties in understanding jokes, sarcasm, and other forms of humor.



As a young child, I watched with interest as my grandfather built a shelf in the kitchen for one of my mom's creeping vine plants. He built it with two large angle brackets, but I still wasn't sure: would it be strong enough to hold the

large potted plant? When I asked my grandfather that question, he confidently answered, "It'll be strong enough to hold a horse!" I was pretty confused as to why you would try to put a horse on it and how you'd get a big horse into our kitchen in the first place. I took almost everything quite literally.

In my marriage, it took decades for my wife to accept that when she said something, and I took it literally, I wasn't being facetious: I really do usually assume the literal interpretation, often resulting in protests of "but you know what I *meant*!"

Individuals with autism may also avoid eye contact, which others can interpret as a lack of interest or engagement. However, this is not necessarily an indication that they are not paying attention, as maintaining eye contact can be intense or uncomfortable for them. They may be fully engaged in a conversation with another person, yet they may not follow the

regular eye contact dance that neurotypical people generally do.

In my own case, I've practiced this enough that I know to look the speaker in the eye... but not for too long. Because that would be weird, and particularly if the person I'm speaking to is a woman, they might mistake lingering eye contact as aggressive or worse. Thus, regardless of whom I am talking with, I try to do the dance of direct eye contact for a few moments, then look aside to think, and so on.

I often get into a state of not knowing where on the person's face to look when a person is speaking. Do you watch the mouth? The eyes? Which eye? Each one in turn, perhaps? Just as you might get a feeling that a word you know is spelled correctly, yet it just doesn't "feel" right somehow, that's how I often experience where to look: nothing feels "right," no matter where I look.

Yesterday, my wife and I were sitting in an airport lounge talking about our flights, and I got into that state where nothing felt right – no matter where I looked, it "felt" wrong. I resorted to a manual cadence: look her in the eye for a few seconds, then look away to consider my thought, then back... the full dance. As my wife started to crack a knowing smile, I said, "Sorry, I was having some eye contact issues," and she burst forth with knowing laughter – "But you were doing so well!" It still takes practice.

# Repetitive Behaviors and Restricted Interests

Repetitive behaviors are common in individuals with autism and may include hand-flapping, finger-snapping, or rocking back and forth. To those who do not understand that these actions are part of the way an individual's brain is wired, they may appear unusual or even strange. Being categorized as "weird" can unduly increase social pressures or even lead to the individual with autism being excluded from certain social situations.

I'm a finger snapper. Even today, if I don't catch myself, I'll snap my fingers loudly as I move down a hallway or across our kitchen. Over the years, I've learned to recognize this as a "stim," a repeated movement or tic that the person on the spectrum does for reassurance or comfort. I've noticed that the more novel the environment I walk in, the more likely I will start snapping.

I've also noted that many people on the spectrum seem to have the habit of running a hand down the wall as they walk in a corridor. Whether it is snapping or the tactile feedback of the wall rushing by, perhaps the stim provides the touchstone of a familiar sensation as we navigate the sensory experience of a new hallway.

I've learned to suppress this behavior in most public places, but the urge is strong, so I often replace it with "finger tapping," a silent but largely adequate substitute I use in spaces where I'd like to remain low-key.

# Sensory Processing Differences

Sensory processing differences are common among individuals on the spectrum. Individuals who experience these challenges may be over- or under-sensitive to various sensory stimuli such as noise, touch, taste, or smell, which can significantly impact their behavior and reactions to different environments.



Sensory information he can overwhelming for over-sensitive individuals, leading discomfort to or For distress. example, they may have difficulty crowded or noisy environments or be sensitive to certain

textures, sounds, or smells. This can cause anxiety, withdrawal, and avoidance of certain situations. They may also experience physical discomfort or pain in response to sensory stimuli that are not typically perceived as painful.

My mother-in-law used to love buying balloons for my kids when we visited. Now, I have nothing against balloons, but if I'm quietly reading, having one go off like a gunshot behind me sends so much adrenaline through my system that it can take several minutes to recover. And even if none pop, the sound of balloons rubbing against each other is highly annoying – almost

as bad as Styrofoam blocks. It's not that these sounds are merely distasteful to me, but rather that they cause significant discomfort.

On the other hand, under-sensitive individuals may seek out intense sensory experiences to stimulate their senses. They may not perceive certain sensory information, such as pain or temperature, which can lead to a lack of awareness of their surroundings and an increased risk of injury.

Sensory processing differences can also affect an individual's behavior and social interactions. For example, when I am startled by a loud noise in a novel environment, such as a tray of dishes crashing to the ground in a busy restaurant, I instinctively cover my ears and duck, which to most people looks like an overreaction. It's a reaction that happens faster than I can use my conscious mind, so I can't modulate this behavior.

A person who is over-sensitive to certain sounds may appear agitated in a noisy environment, which could be interpreted as disruptive behavior. An individual who is under-sensitive to social cues, such as tone of voice or body language, may struggle with social communication and interaction.

Some individuals on the spectrum may experience multiple sensory processing differences, while others may not. In some cases, the sensory processing differences may be identified and addressed through sensory integration therapy, which is designed to help individuals regulate their responses to sensory information.



I keep a pair of Bose noisecanceling headphones next to my bed, and some nights—but not all—I need them to fall asleep. The sound of the furnace warming up, the water heater clicking, or a toilet running all serve as stark distractions in my attempt to fall asleep.

On occasion, I've gone to put my headset on, only to have my wife ask why I'd need it – it's not loud, is it? To which I might answer, "No, it's not loud. But the kids are still playing in the media room, and I can hear their TV, the furnace is running, and the dog is snoring." These might all be trivial to a neurotypical person and cause no concern, but for me, they're like that scratchy tag in a new shirt: impossible to ignore.

# **Executive Functioning Challenges**

Executive functioning is a broad term for cognitive processes involved in planning, organizing, and executing tasks. These processes include working memory, attention, self-control, problem-solving, and decision-making. Difficulties with executive functioning are common among individuals on the spectrum.



Individuals with autism often struggle to plan, organize, and execute tasks effectively. They have difficulty may initiating tasks, prioritizing activities, and staying focused on tasks for extended periods. For example,

they may have trouble starting a task such as homework and may become distracted by other activities, such as playing video games or surfing YouTube or TikTok.

They may also have difficulty with problem-solving and decision-making. They may rely on routine and struggle to adapt to changes in their environment or daily routines, and may also have trouble understanding cause and effect, making it challenging to understand the consequences of their actions.

Another common difficulty for individuals with autism is the ability to control their impulses and emotions. They may struggle with regulating their behavior and become overwhelmed or frustrated in situations that do not follow their expectations or routines. This can result in outbursts or other challenging behaviors that can be difficult for others to understand.

#### Difficulty with Change

Difficulty with changes in routine or unexpected events is one of the key components of my own ASD. If, for example, my wife and I go for lunch every Tuesday, I will come to adopt that as part of my routine, and I might become frustrated if a lastminute change in plans is necessary.

While a change in lunch plans might cause only minor annoyance, more significant changes are much more challenging. I vividly remember how, as a college intern at the local telephone company, I had settled into a comfortable routine of what I did and how and when I did it. My desk was organized the way I liked it, and I had grown attached to the scenic view out my window.

One day, I was unceremoniously moved to a shared, open-plan desk facing a wall in a room lit only by fluorescent lights. This was a bit traumatic until I gradually adjusted to the new location and routine. The unfamiliarity with the new location caused me significant stress and discomfort disproportionate to the actual hardship. Indeed, it was a less desirable location, but hardly the end of the world. In the moment, though, it felt a lot like it.

Individuals with autism tend to need predictability and routine in their daily lives. They may develop rigid routines and rituals they feel comfortable following repetitively. Changes in routine or unexpected events can cause distress, confusion, and anxiety for them because they rely on predictability and stability to feel safe and secure in their environment.

A significant change in the schedule or a new activity can be very challenging for individuals on the spectrum. They may struggle to adapt to a new routine or understand what is expected of them in a new situation. This can lead to anxiety, confusion, and frustration. Some individuals with autism may try to resist the change or even have a meltdown as a result.

Additionally, unexpected events can be challenging for individuals on the spectrum. These can include plan changes, sudden loud noises, or unanticipated social interactions. They may find it difficult to anticipate what will happen next or understand how to respond appropriately.

#### Delayed Speech or Language Development

Language development can be delayed in individuals with autism even if their cognitive abilities are not adversely impacted. It is affected by a range of factors, including social communication and interaction difficulties, sensory processing differences, and cognitive inflexibility.

One of the hallmark features of autism is difficulty with social communication and interaction, which can impact language development. For example, individuals with autism may struggle to engage in reciprocal conversation, initiate or sustain conversations, or understand and use nonverbal cues. These difficulties can impede the development of language skills such as vocabulary acquisition, sentence structure, and comprehension.

While profound language deficits *may* be accompanied by cognitive challenges in some individuals with ASD, the lack of language processing is not an indication of intellectual ability, and many people with autism who are otherwise nonverbal or minimally verbal can write fluently and eloquently.

For such individuals, writing or typing can be an effective alternative means of communication. This can include traditional writing tools, keyboards, specialized communication devices, or software applications designed for augmentative and alternative communication (AAC). Such tools and methods can help those with autism communicate their thoughts, needs, and ideas more effectively than they might be able to verbally.

The disparity between speaking abilities and writing abilities in some individuals with autism can perhaps be attributed to the different demands these tasks place on the brain. Speaking is a complex, real-time process requiring cognitive, linguistic, and motor coordination, which can be challenging for some individuals with autism. Writing or typing, on the other hand, allows for more time to process thoughts, structure sentences, and express oneself without the immediate pressures of verbal communication.

I've often wondered if the coordination difficulties that can accompany autism might also contribute to speech problems. Perhaps in the same way that a complicated dance or sports move can be very challenging (if not impossible) for me to learn, the complex interaction between tongue, larynx, lungs, lips, and jaw may make learning to vocalize through speech difficult, even while language processing in the brain remains unaffected.

For others with autism, language itself is impacted to the extent that neither written nor verbal communication is possible. This may be because of differences in the language-processing part of the brain, which may also result from other aspects of autism. For example, learning language is both a social process and one that requires sensory processing, and since autism can impact both, it follows that language development may also be negatively affected.

Finally, cognitive inflexibility, a common characteristic among those with autism, can also impact language development. Such individuals may struggle with abstract thinking, problemsolving, and adapting to new situations. These difficulties can make it challenging for them to understand and use language flexibly and adaptively.

#### Intellectual and Cognitive Differences

Individuals with autism may have cognitive differences impacting their learning and problem-solving abilities. These cognitive differences can vary significantly between individuals on the spectrum, including differences in processing speed, working memory, or problem-solving skills.

I personally experience reduced processing speed, which refers to the rate at which an individual can take in and process certain information. It can affect my ability to keep up with the pace of information presented in academic or social settings, at least in areas outside of my special interests. I may need additional time to process information, and I sometimes struggle with multitasking or rapidly switching between tasks.

Working memory is the ability to hold information in one's mind while processing or manipulating it. Individuals with autism may have differences in working memory, making it challenging to remember instructions, follow complex procedures, or mentally juggle multiple pieces of information simultaneously.

People with autism may have differences in their problemsolving abilities, which can, in turn, affect their ability to navigate novel or challenging situations. They may struggle with abstract reasoning or conceptualizing multiple potential solutions. As always, no two individuals are the same.

It is important to note that individuals with autism can also have exceptional skills and strengths in other areas. In years past, someone with outstanding ability in music or mathematics might have been labeled a "savant." Today, those skills are often called "islets of ability" or "splinter skills." For example, individuals with autism may have a prodigious memory for specific facts or excel in areas requiring visual-spatial reasoning. It's certainly true in my own case; these attributes have been beneficial throughout my life.

These areas of exceptional ability can be harnessed and nurtured to support individuals on the spectrum in academic and professional settings. Additionally, understanding the specific cognitive differences and areas of strength among individuals can help inform appropriate interventions, accommodations, and support strategies tailored to their unique needs and abilities.

#### **Motor Coordination Challenges**

Some people on the spectrum have difficulty with fine or gross motor skills, affecting their ability to perform tasks such as writing, tying shoes, or riding a bike. This difficulty can be related to a neurological disorder known as dyspraxia, also sometimes known as Developmental Coordination Disorder (DCD). It is characterized by a lack of ability to coordinate physical movements with intent, and it is thought to be related to messages in the brain not being accurately transmitted to the body.

Dyspraxia is a condition that affects an individual's ability to plan and coordinate physical movements. Individuals with this condition may have difficulty with gross motor skills, such as running or jumping, and fine motor skills, such as manipulating small objects. It may impact their ability to perform everyday tasks, such as dressing, brushing their teeth, or using utensils.

I have trouble mirroring movements: if my trainer places me in an odd stretch position, for example, and then asks me to reverse it, I struggle and often must have him show me or explain it again until I get it right.

As a toddler, I recall my dad becoming quite frustrated with my inability to learn to tie a shoe. Now, in my defense, my dad was well-meaning, but he tied his shoes in some weird way that I will only describe as "the wrong and complicated way." But that wasn't the problem. I could picture how the loops and ends twisted and turned. I vividly recall knowing precisely what had to be done, but getting my hands to do it for me was another matter entirely.

For individuals with autism, motor difficulties may be related to various factors, including sensory processing differences, poor motor planning and coordination, and difficulty with motor sequencing.

Sensory processing differences can make it difficult for individuals with autism to process and integrate sensory information, affecting their ability to coordinate movements. Poor motor planning and coordination can also make performing complex or coordinated movements challenging. Finally, difficulty with motor sequencing can impact an



individual's ability to organize and execute a series of movements in the correct order.

I was a terrible athlete. I've never worn a sports uniform, and the only team I've ever played on was a no-cut sandlot baseball team when I was six or seven years old. I was so far behind the other kids that I was relegated to right field and only allowed to play for three innings per game. Fortunately, my dad was the coach, having volunteered to ensure I would receive at least that much time on the field: practice *does* help over time!

As an adult, I took up recreational racquetball and was initially terrible at it. But I stuck with it, eventually becoming competitive with some better local players. For that reason, I believe that the dyspraxia that may accompany autism is not a hard cap on ability, but it can make acquiring such abilities a much steeper climb. It does not always preclude those with autism from competence with precise movements. Still, it can result in significant extra time, practice, and repetition required to reach mastery more easily achieved by their neurotypical peers.

For the last eight to ten years, I've worked out with a personal trainer named Jon. He's a former NFL cornerback and receiver with a 4.31 forty-yard dash and a vertical jump of just over forty inches. He's in his forties now, but it looks as though he could still turn in similar numbers. The contrast between how a "natural athlete" does something and how someone on the spectrum does it can be stark.

There have been few, if any, major league sports stars diagnosed with autism. From my own experience with dyspraxia, I feel that the three positions that would be most accessible to athletes with autism would be baseball pitcher, football kicker, and golfer. Each is a position customarily constrained to a few types of movements, and where "general athletic ability" is not the critical success factor. They are examples of how mastery of a particular kind of movement can bring success and where the essential physical aspects of the position can be practiced repeatedly and mastered at an independent pace. Perhaps one day, when testing for ASD is more common and more people who have it are aware of it, we will see kickers, pitchers, golfers, and even other positions occupied by athletes assuredly on the autism spectrum.

Because it takes me longer to figure out anything quasi-athletic, or perhaps because I took so much derision for it as a kid, I've never been comfortable learning athletic activities in front of crowds. I worked out an arrangement where I went to Jon's gym before regular business hours; thus, we had the entire location to ourselves.

However, I still require a lot of extra time to perfect movements. I like to challenge myself periodically by learning decidedly tricky things, such as the seemingly simple task of juggling three balls. Or how to put my socks on without sitting down or leaning against anything. Even these simple feats took weeks (if not months) to perfect, but such persistence is usually rewarded. It's as though it takes me many more successful repetitions of a movement before I "get it." It doesn't feel "natural" until much, much later.

The amount of dyspraxia experienced by those with autism varies widely, and some may experience more severe motor coordination impairments than others. However, it is crucial to recognize that these difficulties can significantly impact an individual's daily life and overall well-being. Early identification and intervention can help individuals with autism who experience such challenges develop compensatory strategies and improve their overall quality of life.

I was slower to ride a bike or roll on a skateboard. Until the "cool" kids disabused me of it, I had a bouncing gait when walking that seems familiar among kids with ASD. There's a tendency to walk on "tip toes" at times.

Occupational therapy is one intervention that can help individuals with dyspraxia and motor difficulties develop strategies to improve their motor skills and physical coordination. It may involve exercises to improve strength and coordination and methods to improve sensory processing and motor planning. By addressing motor difficulties early on, individuals with autism can improve their ability to perform daily tasks and participate in social and recreational activities.

Ironically, kids on the spectrum benefit significantly from practice, yet many wind up avoiding the opportunity to do so because of ridicule in the school or on the playground. They may also not be welcome to play with their age-appropriate peers. The very kids that need the most practice encounter the highest barriers to engaging in it.

Any opportunity that affords such a child to play and learn a new athletic skill in an environment where they are encouraged to learn confidently at their own pace is valuable.

#### Difficulty with Transitions

Individuals with autism often prefer sameness and predictability in their environment and routine. This can make it challenging for them to move from one activity to another, mainly when it involves leaving a preferred activity or environment.

Transitions can be particularly difficult for individuals with autism because they often involve a change in routine, a shift in attention, and a new set of social expectations. For example, transitioning from playing alone to participating in a group activity may require changing focus, social skills, and communication.

People with autism may react with considerable frustration when forced to disengage from an activity or process they were intensely focused on and may seem to resent whatever the new distraction is.

Structured routines can help support such individuals during transitions. This may involve setting up a predictable sequence of activities or using visual supports, such as schedules or picture cues, to help prepare them for the change. Visual supports can be particularly effective in helping individuals with autism understand what is happening next and what is expected of them.

When I was a kid, we lived only a block from the school, and since we were so close, I would head home each day for lunch. For my entire childhood, the local TV affiliate ran "The Flintstones" every day at noon, like clockwork, and from the opening song to the closing credits, it defined the rhythm of my lunches. As the show drew to a close each day, I knew it was time to get my jacket and shoes and return to school. Because it was such a familiar and regular pattern, it did not cause me any angst, and I was always back at school on time.

Had I simply been left to play on my own after eating, however, each day would have been a stressful cycle of me not knowing when it was time to wrap things up and head on back. I would likely be distressed when whatever fun thing I was now focused on had to be interrupted so that I could return to school. I would never know on my own that it was time to disengage from one activity and begin another, and I would likely be late. Structure and clear signals can make a huge difference for someone on the spectrum.

This is why providing ample warning and preparation time for transitions is also essential. Helping individuals with autism prepare for the change may involve verbal cues, visual supports, or a countdown system. For example, a visual timer can show how much time is left for an activity, or a countdown chart can show the steps involved in the transition. Being able to anticipate and prepare for the change can make it less disruptive.

In my own case, having a visual calendar of commitments during the week helps immensely, as I will mentally block off space in advance for them. This, in turn, means they are not unexpected and, therefore, less troublesome.

Going back to our earlier "Tuesday Lunch" routine, if my wife has made plans with a girlfriend that conflict with our regular lunch date, she knows to give me as much notice as possible rather than springing the change on me at the last moment. It's not that I'm somehow entitled to extra notice, but the reality is it makes it easier for everyone involved, so it's simply pragmatic to accommodate such needs where practical.

Additionally, it can be helpful to offer choices or incentives to encourage individuals with autism to transition. For example, offering a preferred activity or reward after the transition can help motivate them to move on from the current activity or environment.

#### **Related Conditions**

Autism is often co-morbid with other neurological conditions, such as:

#### Intellectual Disability

Some individuals with autism also have intellectual disabilities that affect their cognitive and adaptive functioning.

#### ADD / ADHD

Individuals with autism may have symptoms of hyperactivity, impulsivity, and inattention that meet the criteria for attention deficit hyperactivity disorder (ADHD).

#### Anxiety and Depression

Individuals with autism may experience anxiety and depression due to social difficulties, sensory sensitivities, difficulty with change, stress from frustration, and other challenges associated with the condition.

#### Obsessive-Compulsive Disorder (OCD)

Some people with autism may have obsessive and repetitive thoughts or behaviors that meet the criteria for OCD.

#### **Epilepsy**

Individuals with autism may have a higher risk of developing epilepsy or seizures compared to the general population.

#### Gastrointestinal (GI) Problems

Studies have found that individuals with autism have a higher prevalence of gastrointestinal (GI) symptoms, including diarrhea, constipation, and abdominal pain. Some studies have also found a higher prevalence of certain GI disorders, including inflammatory bowel disease (IBD), in individuals with ASD compared to the general population. In my own case, I was diagnosed with Ulcerative Colitis some 40 years before I was diagnosed with ASD.

One theory<sup>i</sup> is that the gut and the brain are connected through the gut-brain axis, and disturbances in the gut may affect brain function and contribute to the development of ASD. Under this theory, inflammatory processes in the gut, such as those associated with IBD, may trigger changes in the gut microbiome or the immune system, leading to differences in brain function.

# **Neurodiversity and Autism**

# The Concept of Neurodiversity

Neurodiversity is a concept that recognizes that people have naturally occurring variations in the way their brains function and process information. It acknowledges that these differences, like differences in race, ethnicity, gender, and sexual orientation, are a regular and valuable part of human diversity.

When it comes to autism, neurodiversity refers to the recognition that autism is a natural variation in the way some people's brains are wired. It is not a disease or disorder that needs to be fixed or otherwise "cured"; instead, it is a different way of processing information and experiencing the world. The neurodiversity perspective asserts that people on the autism spectrum should be celebrated and accommodated for their unique strengths and abilities rather than being pathologized or stigmatized for their differences.

"Different. Not less." - Dr. Temple Grandin

The concept of neurodiversity has led to a shift in the way we think about autism: from a medical model that focuses on deficits and impairments to a more positive and inclusive model that recognizes the strengths and potential of people on the spectrum. This has led to a greater emphasis on creating inclusive environments that accommodate the needs and preferences of neurodiverse individuals rather than always trying to make them fit into neurotypical (non-autistic) norms.

There are certainly cases of autism where the pathological impacts of the disorder are severe enough that one might wish they could be improved. It is important to acknowledge that autism may be accompanied by challenges and difficulties that can impact an individual's quality of life and make it harder for them to navigate certain aspects of the world. For some individuals and their families, these challenges may be significant enough to seek support and interventions to help alleviate symptoms and improve functioning.

The concept of neurodiversity means that we should strive to view autism as a natural variation and approach support and interventions in a way that acknowledges and respects this variability.

In the context of autism, this might mean focusing on developing interventions and accommodations tailored to the individual's specific strengths and challenges rather than trying to make them fit into a one-size-fits-all approach.

Ultimately, the goal of the neurodiversity perspective is to promote acceptance, understanding, and accommodation for people on the autism spectrum while also acknowledging and addressing the challenges and difficulties that can come with the condition. It is possible to do both and support individuals and families in a way that honors their unique experiences and needs while preserving the idea that autism is a natural and valuable part of human diversity.

#### Autism as a Natural Human Variation

Our bodies and minds have characteristics and capacities that vary significantly from individual to individual. This is true not only within a population but even between siblings. They might differ substantially in height, weight, intelligence, and other factors. Over many eons, these variations have been the human race's superpower, allowing us to adapt to a wildly diverse set of environments and circumstances. In one environment, darker skin may offer superior protection from sun damage. In contrast, in another, the tendency to store body fat near the surface may provide superior insulation against a cold climate. As a population's territorial range gradually moved from one region to another, or as the environment slowly changed over the generations, these variations have allowed humans as a species to adapt.

Humans have long been social animals, living in groups. Because of this tribal nature, natural selection operates on at least three levels: the gene level, the individual level, and the group level.

At the gene level, natural selection is driven by gene variation affecting an organism's traits. Genes that provide a survival or reproductive advantage are more likely to be passed on to the next generation, whereas genes that give a disadvantage are more likely to be lost over time. The gene is not subjectively "better" or "worse," but it successfully propagates by

improving the odds that the organism born to it survives and reproduces.

At the individual level, natural selection operates on the traits of individual organisms. Organisms with traits better adapted to their environment are more likely to survive and reproduce, passing their advantageous traits to their offspring. This process changes the frequency of traits within a population over time. Patently essential or deleterious traits are retained or eliminated over time, but selection will stabilize at or oscillate around some balance point for traits with benefits and tradeoffs.

At the group level, natural selection operates on the traits of groups of organisms. Groups with traits better adapted to their environment are more likely to survive and reproduce than groups with less advantageous traits. This is also true for how group traits and characteristics are distributed. For a tribe to be successful in a particular environment, it must have the right mix of individuals.

Consider a tribe that leads a hunter-gatherer lifestyle. Let's imagine for a moment that some are natural-born hunters while others are better suited to local harvesting. There will be some ratio of one to the other that is "best" for the tribe as a whole. Whatever that ratio is, the tribes that most closely reflect it will have a competitive survival advantage. Over time, and with all other things held constant, environmental pressures will select from the natural variations that occur to "fine-tune" the population for the best chance of survival in their environment.

It is possible that the variations in characteristics that form the autism spectrum are also a "tunable variation" in a population. Perhaps a singularly-focused autistic mind is better suited to being a successful hunter, while the food harvester is better served by superior executive function. If so, the variation in autism spectrum characteristics from one individual to the next may be nature's way of adjusting a population to have the "right" mix of ASCs for their environment throughout numerous generations.

#### The Ten-Second Autism Test

In my first book on autism, I somewhat facetiously proposed a simple test question:

"Which do you believe is more important for the success of society, creativity or cooperation?"

I contended that those who find themselves solidly on the autism spectrum would typically select creativity, while those who did not would choose cooperation. And while this may even be broadly true, the more perceptive answer would be "both." Assuming no one person can be all things in all cases, an effective society would have some number of creative individuals who provide things such as technology. It would also have a perhaps more extensive set of individuals who were equally well-adapted to coordinating and cooperating in the employment of those technologies. Some have speculated that autism may be thought of as "the technology genes"; writer and professor Dr. Temple Grandin has mused that without the

genes that are responsible for autism, we might all still be socializing around campfires.

To steal an Apple slogan, we don't all need to "Think Different," but we're far better off if a few of us do.

# ASCs vs the Broader Autism Spectrum

In general, individuals who exhibit some of the features or behaviors associated with autism spectrum disorder (ASD), but who do not meet the criteria for a diagnosis of ASD are said to have autism spectrum characteristics (ASCs). But where do these people fit in relative to the broader autism spectrum?

While there is no clear consensus on how to categorize or define ASCs, some researchers and clinicians use the term "broad autism phenotype" (BAP) to describe individuals who exhibit mild or subclinical symptoms of ASD. BAP is considered a spectrum of autism-related characteristics that fall below the threshold for diagnosis but still represent a continuum of autism-related traits.

Some examples of ASCs/BAP may include difficulties with social communication and interaction, repetitive or restricted behaviors and interests, sensory sensitivities, and other traits associated with ASD. Individuals with ASCs/BAP may exhibit various abilities and strengths, and their experiences and needs may vary significantly.

Overall, the concept of ASCs/BAP highlights the idea that the autism spectrum is not a dichotomy of "autistic" and "non-autistic" but rather a continuum of diverse characteristics that

exist in the general population. The recognition of ASCs/BAP may help to increase awareness and understanding of the broader spectrum of autism-related traits and needs. It may also lead to appropriate support and accommodations for individuals who may not meet the diagnostic criteria for ASD but who still experience challenges related to autism spectrum characteristics.

# Summary of the Neurodiversity Perspective

Neurodiversity recognizes that differences in how people's brains function and process information are a regular and valuable part of human diversity. The concept of neurodiversity has led to a more positive and inclusive model of autism that acknowledges the strengths and potential of people on the spectrum. The goal of the neurodiversity movement is to promote acceptance, understanding, and accommodation for people on the autism spectrum while also acknowledging and addressing the challenges and difficulties that can come with the condition. Where an individual finds themselves on the autism spectrum is not a simple measure of "more" and "less" in a single dimension. Rather, it is a complex mixture of characteristics with varying degrees of impact in different areas of life.

# Part II: Managing Autism-Like Symptoms

### **Mindblindness**

Mindblindness in autism refers to the challenge individuals with autism often face in understanding and interpreting the thoughts, feelings, and intentions of others. This concept is closely related to the Theory of Mind, which is the ability to recognize that other people have perspectives, beliefs, and emotions that are distinct from one's own.

The theory of mind has been perhaps one of the largest blind spots in my life. It's not that I'm intellectually unaware that other people bring their own perspectives, context, and history to the table. The problems begin when I try to intuit what the other person is thinking or feeling. I make my analysis based on what my mind would likely think in their position, using my own set of preconceived notions and biases, which are necessarily different from their own.

Any interaction with another person, from a simple social encounter to a heated disagreement, can be complicated by the person with autism's inability to accurately formulate a version of what is going on in the other person's mind. Why is this?

Individuals with autism might struggle to interpret facial expressions, tone of voice, and body language, making it hard to gauge others' emotions. They may be oblivious to social nuances like sarcasm, jokes, or indirect language which can be confusing, leading to misunderstandings in communication.

People on the spectrum often interpret language very literally and may have difficulty understanding that others have their own viewpoints or knowledge. They may miss certain nuances of communication that cause them to build faulty mental models of the other person's process.

Due to these social difficulties, forming and maintaining social relationships can be challenging, as can participating in social activities that require an intuitive understanding of others' behavior.

The back-and-forth flow of natural conversation may be hard to achieve, as individuals with mindblindness might not readily pick up on cues to listen, respond, or change the topic sensitively.

# Big "T" Truth

The "Big T Truth" concept refers to absolute, universal truths that are unchanging and constant across time and cultures. These truths are often contrasted with "small t truths," which are more subjective, personal, or context-dependent. Big T Truths might encompass fundamental principles or facts about the universe, existence, morality, or human nature that are seen as holding universally, regardless of individual beliefs or experiences.

## Relational Frame Theory

Relational Frame Theory, or RFT, suggests that the meanings of words, concepts, or truths are not inherent or fixed but are given by their context and the relational frames\* we use to understand them. From an RFT standpoint, truths (including "Big T" Truths) are understood and interpreted through relational frames, essentially networks of associations between concepts built through our interactions with the environment and influenced by our history, culture, and personal experiences.

The person with autism may make an overarching assumption that their version of reality is the authentic Big T Truth.

# Implementing the Changes

After some counseling and introspection, I came to realize that when I was confident that I was right, I was erroneously awarding "Big T" truth status to my own version of things. Perspectives that really should have been held as my own "Small T" truths were granted universal truth status in my head unless and until someone could successfully disabuse me of it, at which point I would update my mental model with the new information and then repeat the same mistake again!

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Views on that table.

<sup>\*</sup> For the other computer folks out there, the Big T Truth is the underlying table in the database, and relational frames are like

Much of my life was spent presuming that, as an intelligent individual, my version of the world was the right one and that all I had to do was sufficiently educate, convince, and cajole the other person until they "got" my version.

It has only been in recent years that I have paid *genuine* attention to the fact that others have their own "small-T" truth perspectives. I begrudgingly accept that they are likely as valid as my own (something I still struggle with in the moment)!

Accepting that multiple views of reality can be valid simultaneously has made a great deal of difference in my life, and many relationships and interactions are now much easier.

The mindblindness that can accompany autism can reinforce an outsider's perspective that the individual's empathy is somehow impaired, but in most cases, this is a function of the communication difficulties that we just enumerated. They may impair the individual's ability to get a complete and accurate understanding of the situation from the other person's perspective.

These manifestations can vary widely among individuals with autism, with some showing remarkable skills in certain areas while facing more significant challenges in others.

# Monotropism

Imagine you are in a crowded auditorium. Suddenly, an announcement comes over the loudspeakers:

"Ladies and gentlemen, we need to evacuate the theater immediately. Please do not panic and proceed to the nearest marked exit in an orderly fashion."

For the next few minutes, as you proceed to make your way out of the theater only to discover several hundred people queued before you, your mind will be dedicated to a single task: locating the best exit and determining the fastest way to get through it successfully.

As you do so, you will be oblivious to all the superfluous details of the scene – the ornate interior architecture of the theater, the perfume of the woman in line in front of you, and the show that brought you to this theater in the first place. You won't think about your busy schedule or your unpaid taxes. Your mind will, during those few moments, work very much like an autistic mind.

When an emergency like the one you're imagining happens, everyone, regardless of neurology, can experience a form of monotropism because the brain prioritizes the most vital task—safety in this case—over all other thoughts and stimuli. This intense focus allows for rapid response to the immediate and pressing need to evacuate, putting less critical observations and thoughts into the background.

This kind of situation forces the mind to filter out extraneous information and focus solely on the most pressing goal, not unlike how an person with autism might focus on a particular interest or task. It's a helpful comparison for understanding

how different circumstances can shape our cognitive processes and how they vary from person to person.

What you are experiencing in this situation is something akin to monotropism, which is the leading theory of thought that underpins our understanding of autism.

Monotropism is the primary method of thinking for people who experience autism. In Monotropism, the attention tunnel is very narrow: it can focus intensely on a single interest at the cost of a lack of awareness of things outside the tunnel. The following image contrasts the way that neurotypical people are said to view the world versus how those of us with monotropic thought view it.





Figure 1 – Monotropism and a narrow attention funnel

This illustration doesn't mean I can't visually see the fence and field – just that they don't affect my decision-making. I don't see the "big picture." Instead, I focus on the one thing that seems most important right now.

In a monotropic thinking style, an individual strongly focuses on a limited number of interests, activities, or topics of conversation. These interests may be highly specific or specialized and can be pursued with intense concentration and a depth of knowledge that can exceed that of most neurotypical people. This intense focus often leads to excluding other stimuli or interests, making it difficult to shift attention to other tasks or social cues.

Metaphorically, if some people cannot see the forest for the trees, those with monotropic thinking may sometimes become fixated on a particular branch or even the leaves. They may perseverate over the details while missing the big picture.

I have a significant issue with over-prioritizing the importance of whatever the current challenge I'm facing might be. If it's a personal situation or argument, I might perseverate relentlessly over some "new normal" that I cannot accept. If it's a technical challenge, I might be in a bad mood at lunch because I'm annoyed by my failure to solve it. It's as if something of great importance depends on it, even if nothing truly does. I can't stop thinking about it; if I try, my mind will return to it promptly. And yet, if enough time passes, or even better – if I solve the problem – that import will fade. Looking back at the issue from the perspective of a few hours (or perhaps days) later, it will be a surprise to even myself how disproportionally critical the issue felt in retrospect.

Like so many things about the autism spectrum, this nearobsessive thinking is both a blessing and a curse. While Monotropism can cause people to miss things outside their attention tunnel, it can also bring an intense level of focus, known as hyperfocus, to the things that fall within it. This hyperfocus can lead to intense concentration, a distorted sense of time, and a profound sense of being in the present moment only. This is often referred to as a "flow state," a term that describes a person's experience of being wholly focused on and engaged in performing some activity. The process feels very rewarding and is usually accompanied by the knowledge that a solution to the situation is possible, which becomes the ultimate goal to the exclusion of almost everything else.

While in a state of hyperfocus most other needs become superfluous; people in this state may fail to eat regularly or even delay a long-needed trip to the restroom until it becomes imperative.

Even though sensory stimuli ranging from a scratchy neck tag to flickering lights can be disruptive to many on the spectrum, once in a state of hyperfocus, they are often finally able to filter out unwanted distractions. Many people with a monotropic mind can quite often suppress pain and other stimuli that do not serve to advance whatever challenge the hyperfocus state is being used to resolve. Such distractions can significantly impede getting *into* a state of hyperfocus, but then they fade.

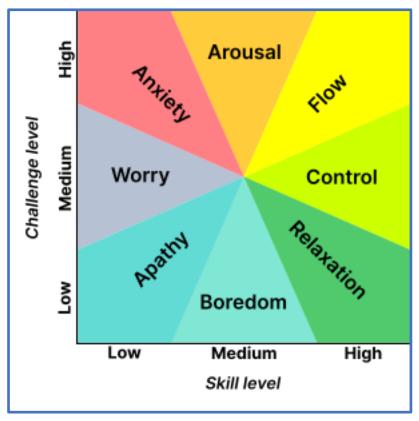


Figure 2 – A Flow state depicted on the challenge vs skill axes

The total amount of focus and attention that any human brain can exert is limited. It has been estimated that a typical person can process about 110 bits per second. Simply processing casual verbal input can take about 60 bits per second, so it's easy to see why someone who may already be spending 100+bits on whatever they are hyper-focused on can be hard to interrupt. Hyperfocus tends to consume all their available focus.

When a monotropic mind is engaged in hyperfocus, even if someone can temporarily grab their *apparent* attention, their mind's actual focus may remain on the challenge. This can result in the hyper-focused individual agreeing and nodding without actually hearing what was said, which can lead to future misunderstandings.



Figure 3 - Hyperfocus

Some of the keys to maintaining hyperfocus are that the activity must be rewarding, have a goal in mind, clear generate positive feedback on progress along the way, generally leverage the individual's strengths. Whether solving programming complex task or perfecting sonata, solving

problems while in such a flow state produces significant dopamine, the neurotransmitter most closely associated with the "reward" circuit in the brain.

Unfortunately, while it can be a powerful experience, hyperfocus is not without its costs. It can be challenging for the individual to redirect their attention to other matters, and any degree of multitasking is complicated. Students who experience hyperfocus or have monotropic thought patterns may have difficulty taking notes while listening to a lecture.

This inability to deal with multiple sensory inputs can often lead some with autism to avoid complex sensory environments.

In my own case, as a software engineer, it is almost impossible to distract or interrupt me in any helpful way once I am focused on a challenging task. I cannot listen to music with lyrics or other sources of verbal information when engaged in intense programming. I also have great difficulty switching my mind away from a task that I have been hyper-focused on. Suppose I am working in a flow state right before I go out with my wife, for example. In that case, she can find me distracted for the first thirty minutes because my mind keeps going back to the problem I was trying to solve, despite my attempts to make a clean break and to switch my context over to paying attention to the conversation. It is as though I have a great deal of "attention inertia," wherein it takes me some time to enter the flow state and, later, some time to exit it.

Experiencing a restricted and repetitive set of behaviors must be present for a diagnosis of ASD and is quite common among those on the spectrum. This can be complicated and compounded by the monotropic thought process, which makes it difficult to shift attention, leading to what can look like (or, in some cases, may genuinely be) an obsession with a singular topic.

Monotropic thinking differs from typical thinking styles in that the latter allows for a broader range of interests and more flexible shifts in attention. Monotropic thinking can create challenges for individuals in social situations, as they may struggle to engage in topics of conversation that are outside their areas of interest and find it hard to keep up with shifting social dynamics. It can also create challenges in academic or work environments if the individual's interests do not align with required coursework or job responsibilities.

# Multitasking

The flipside of monotropic thought is the inability to think about several things simultaneously. When I was a young kid, I was watching an episode of M\*A\*S\*H on TV with my parents. It featured one of the doctors, Major Winchester, scrubbing in for surgery and being somewhat perfectionist about the process. When the other surgeons begin to chide him for being too slow, he proclaims:

"Gentlemen, I do one thing at a time. I do it **very** well, and then I move on."

I had no idea why at the time, but I felt like he was speaking as if for me. It was precisely how I felt at the time and, indeed, very much how I've felt for my entire life.

People who experience monotropic thought usually face challenges with multitasking. Multitasking is the ability to perform multiple tasks at once and mentally track several important priorities at the same time. They may struggle with prioritizing tasks, focusing on multiple tasks simultaneously, switching between tasks, and managing their time efficiently.

Multiple priorities competing for my attention can be distressing, particularly when I know they are *all* important. It

can also initiate a form of mental paralysis where it becomes challenging to select what to do next.

The following is a list of specific problems that someone with autism might face in trying to multitask among several important tasks. We have seen these symptoms before, but here they are particularly relevant to multitasking:

People with autism may find it hard to determine which task to focus on first or which requires more attention. This can lead to confusion and delay in completing tasks.

They are often more sensitive to sensory input than others. When presented with too many stimuli or distractions, they may become overwhelmed and find concentrating on the tasks at hand challenging.

They may struggle to quickly shift their focus from one task to another. This can cause a delay in completing tasks, leading to frustration and stress.

They may have a rigid way of thinking, making adapting to changes or unexpected events hard. This can hinder their ability to multitask and manage several important items simultaneously.

# **Difficulty Managing Change**

Many people on the spectrum have trouble managing ambiguity and randomness. They prefer to fully understand their environment and then have a concrete plan of action.

Once that plan is in place, it's a great relief and a reduction in stress for them. Should something change to suddenly invalidate that plan, it can cause a disproportionate amount of angst in the individual on the spectrum.

Imagine a flight to Disneyland with my wife and children (back when they were young). If our flight is at noon, connects at 3 PM, arrives at 6 PM, and we plan to watch the fireworks at 9 PM, I have a handle on my day and the structure it should follow. I'm ready for the trip.

If the departure flight is unexpectedly delayed, it represents a change. The delay changes my connection, which changes my ground transportation reservation and hotel check-in time, and we'll likely miss the fireworks. All this change happening all at once can feel overwhelming when the reality is that someone with better executive functioning will simply pick the next decision off the stack and make it – after all, there's little that can be done in Seattle at noon about tonight's fireworks at Disneyland, so why worry about all the possible outcomes now?



Most neurotypical people can look at their predicament from a bird's eye view and identify the next logical thing to do in terms of problem-solving. For me, however, a significant change in the plan can cause great stress and

confusion. When an unexpected storm upsets an integral part of my plan, sometimes I am rattled by it enough that it's hard to know what remaining parts of the plan are still valid. It can feel as though everything I knew and thought is now pointless, and I'm starting from scratch, even if that's far from the truth.

When a life change occurs that seriously troubles me, I can become consumed with refusing to accept this new normal, whether I have a choice in the matter or not. I cannot easily step back and survey the landscape of my life. If I could, I would often see that the change I'm upset about is only a tiny fraction of my life and that the rest is still excellent. At that moment, however, the only thing that seems important is the change itself. I can overlook most of the other positive context of my life amid the storm.

Perhaps this is a natural outgrowth of how I solve most technical problems: a relentless focus on the one thing that matters the most until I solve it, ignoring everything else. That might work in computer programming, but our lives are too capricious and variable to handle that way. What works in one domain does not work in all.

Much like changes in plans, changes in the environment can also be troubling.

People on the spectrum may also have sensory sensitivities that can make changes in their environment problematic. Some may only be troubled by more significant changes, such as moving to a new building, location, or office at work. Due to increased noise and distractions, others may have difficulty transferring from a private office to an "open" floor plan. For others, simply rearranging things on their desk may be enough to cause angst!

These issues may be further complicated by the fact that people on the spectrum may struggle to communicate their concerns or understand why things are changing.

As with a new habit, I've found it takes about two weeks to adapt to a new normal that you're not enthused about. So, whatever the inconvenience—a new job, a new college roommate, or whatever—give it two weeks and evaluate how you feel at that point. Odds are, you'll be in a far better position to make that evaluation.

## **Needing Time to Decompress**

I enjoy spending time with people, particularly those I know and love, such as friends and family. Doing so, however, takes a small toll on me, and after several hours, I may slip away to my shop or office just to be alone, decompress, and pay attention to other tasks and obligations that may have been accumulating in the back of my mind. But I mostly need to be away from people for a few minutes.

Being social, even at the most basic level of masking to appear part of the crowd, is work. It can be very taxing work, depending on how well you know the people involved and how "on" you must be. For example, a half-day job interview loop where one interview session leads directly into the next can be grueling. And weddings, where you might have to meet or entertain dozens of new people for many hours, are similarly arduous.

If I don't know the people in question or don't know them very well, the mental effort it takes to be "on" in a public way is much higher. Expending that energy at a higher rate causes the need for a break to come even sooner. If, for example, my wife and I are hosting an open house for the parents of all the kids on my daughter's soccer team, I will meet each of the several dozen parents. I will be unlikely to remember most of their names as I focus more on people's skills and what they do for a living than on the social relationships of "who knows who." I tend to categorize people in my mind by what they know how to do, presumably because it tells me more about how their minds work than knowing their social details.

On top of the social demands, add in the stress that results from having dozens of strangers wandering around my house, and I might only make it ninety minutes before needing to excuse myself at least briefly.

My wife was well aware of these needs long before I was even diagnosed with ASD. Perhaps one more helpful example can be found in our family trips to Disneyland with our children. After a morning of escorting the kids around the park, riding Dumbo, visiting the Haunted Mansion, and half a dozen other lines and rides, the sheer number of people at a location like Disney can be very draining. Knowing that I needed a respite but not even knowing what it was that I was trying to escape, I would say things like, "I need a break for a few minutes." My wife would look for a park bench for me to rest on, but that didn't help. It was not a physical rest I needed but rather a mental break.

As our budget began allowing it, we would try to stay at a hotel directly on or at least near the park property on subsequent trips. I could take my kids to the character breakfasts bright and early in the morning, jump on half a dozen rides with them, then run back to the hotel for an hour to relax, check my email, and so on. I'd then run back and rejoin the family, refreshed enough to manage the remainder of the afternoon easily. The flexibility to take a break mid-day made our trips much more enjoyable.

This feeling – that I only have so much reserve capacity for processing social demands – goes back as far as I can remember. When I was a toddler, my parents would take me on social calls to their friends' homes. Some of the homes had children to play with, others did not. Either way, though, within a few hours of

arriving, I was often mentally "spent" in a way that rendered me cranky, needy, or tired. I remember as a kid aching to be back home, not because I was homesick as much as I wanted to be away from the social demands of visiting.

In general, the more I must be "on," and the more change in my environment I am currently coping with, the more I need those periodic breaks.

### **Social Awkwardness**

Social awkwardness is a common symptom experienced by individuals on the spectrum. It manifests as difficulty interpreting social cues, understanding social norms, and initiating or maintaining conversations. This can make interactions with others challenging and may lead to feelings of isolation or anxiety.

I experienced a great deal of awkwardness as a youth simply because what was funny or exciting to me did not resonate with those around me. It could be as simple as quoting Monty Python instead of AC/DC, but whatever the case, being out of sync can make you stand out in ways that your peers may not reward at that age.

Because my autism impacted my coordination somewhat, I was sometimes labeled a "spaz" in the terminology of the day. In other words, as a kid, I was anything but "cool." This was only complicated by a lack of athletic ability and a "bouncy" gait as if walking on my toes at times. However, these challenges were

not insurmountable, and by the time I was an adult, I thought I had learned mainly to fit in and be accepted by others.

That was until I started my career at Microsoft, which, although populated by many people on the spectrum, still presented social challenges. My flat affect caused many who did not know me well to write me off as grumpy or unapproachable. Social situations at work were challenging because I didn't know what the expected response or action was most of the time. My natural responses or statements were viewed as quizzical by some and rude by others. I was always trying to improve such things, and I learned as I went, but being oblivious to the cause (i.e., my ASD) made it a slow process of refinement.

Exploring the underlying issues and developing strategies for overcoming them is essential to managing social awkwardness better and improving the quality of social experiences.

## **Understanding Social Cues**

One of the primary challenges individuals with autism face is the ability to interpret social cues accurately. People use subtle, non-verbal signals to communicate their thoughts and emotions. Examples of social cues include facial expressions, tone of voice, and body language. To improve the understanding of social cues, individuals with autism can benefit from studying and practicing recognizing these signals in a controlled environment, such as through therapy or social skills training programs.

## **Understanding Social Norms**

Social norms are the unwritten rules that govern social interactions. These norms can be complex and vary between different cultures and social groups. They are primarily learned behaviors, but those on the spectrum often struggle to learn them. Thus, for individuals with autism, learning and adhering to social norms can be challenging. It's helpful to break down the norms into smaller, more manageable components to overcome this. For example, learning about personal space, appropriate topics of conversation, and turn-taking in dialogue are all essential skills. By practicing these skills in various social settings, individuals with autism can build confidence and become more adept at navigating social situations.

# Initiating and Maintaining Conversations

Starting and sustaining a conversation can be especially difficult for individuals with autism, as they may struggle with knowing what to say, when to say it, and how to listen and respond appropriately. They may limit the scope of their conversation to things that interest them personally, whether they are of interest to the others present or not. Practicing conversation techniques such as open-ended questions, active listening, and empathetic responses is helpful to overcome this. Role-playing exercises can be beneficial for practicing these skills in a safe environment, allowing for repetition and feedback.

One of the hardest things for me to learn was that people often have problems for which they are seeking sympathy or empathy, not a solution. I'm a natural problem solver, so if presented with a statement such as "My dog is sick," I'm more likely to recommend a trusted veterinarian than to offer a consoling phrase. Sometimes, people just want to hear, "I'm sorry, that must be rough." They don't want a lecture on how to improve their situation.

## Tips for Managing Social Awkwardness

Anticipate potential conversation topics or icebreakers and rehearse responses to common questions, which can help to reduce anxiety and improve conversational flow.



When someone says, "How are you?" I learned from my stepfather that the correct answer is "Great!" generally regardless of how you're doing. The question is just a social convention, not a genuine invitation for a list of things that might be aggravating you at the time!

Develop a support network by surrounding yourself with understanding friends or family members who can provide guidance and support during social interactions. Ask those you trust to provide candid feedback on where you can most improve your social skills. Odds are that it's a mystery to you but not to them. Try not to take the feedback personally and resist the urge to debate other's impressions of you: use the information constructively.

Set realistic expectations. Recognize that social skills take time and practice to develop, and it's okay to make mistakes. It's taken me decades of trial and error to learn most of what I know, so allow yourself the grace to learn from these experiences and continue to grow a little at a time.

Observe and learn from others by paying attention to how they navigate social situations and trying to emulate their behaviors and strategies. People with autism are often susceptible to emulating or imitating those they interact with—pick good role models and try to behave as they do in the situations you struggle in.

While I'm sure it helps one to develop socially, I have a trait that can be a double-edged sword: I emulate the people I'm with. This is not surprising, as it simply means I'm adjusting my masking to fit the audience. I don't feel it compromises who I am, just how I am presented. As a junior software engineer, I had a friend named Andras who had recently escaped the Soviet Bloc. I was a recent transplant from Saskatchewan, meaning neither of us knew many people in the area yet, so we spent a fair bit of time together. I slowly started to pick up his accent – usually only in his presence. My accent would slowly grow thicker over time until I finally heard it myself and startled myself with the realization that he might think I was mocking him! From there forward, I've been much more careful about it, but the tendency persists.

As a little kid, I tended to emulate the protagonist of whatever cartoon I watched or read the most. Dennis the Menace might have been merely a precocious young troublemaker, but my own antics were not as kindly regarded if I acted like him. Perhaps a propensity for emulating those around you is beneficial when you don't have an intuitive sense of how to behave socially on your own.

Seek professional guidance. Consider working with a therapist, counselor, or social skills coach who can provide personalized advice and support for improving social skills.

Practice self-compassion. Remind yourself that social awkwardness is a common challenge for many people, not just those with autism. Be patient with yourself and acknowledge your progress along the way.

Engage in social activities that align with your interests. Join clubs or organizations that share your hobbies, as this can provide a natural starting point for conversations and a common ground for building connections.

I have a peer that I suspect may have autism. When he was a child, his mother may have suspected he faced specific challenges that his siblings did not, as she reserved certain onerous tasks just for him. Each was clearly a social exercise: he was required to act as an usher and greeter at his father's business events and eat family dinner – whatever they were having – at a different neighbor's home once weekly. His athleticism was challenged and honed at the family's annual summer games. And despite a few persistent deficits in his social abilities, this "training" has paid off handsomely for him over his lifetime.

If you can't rely on your mother to push you slightly out of your comfort zone as his did, you should do it yourself. I'm someone who doesn't even like to have my photo taken, but over the pandemic, I started a YouTube channel as a challenge to myself. Editing footage of yourself in high resolution 4K60 for hours at a time is quite the desensitization therapy! Even though the channel ("Dave's Garage") is quite technical, it's grown to over half a million subscribers. Things that were hard or seemed impossible initially are now second nature. Most discoveries happen in uncharted territory, so spend enough time there despite the mild discomfort that might accompany it.

Hopefully, by understanding the factors contributing to social awkwardness and actively working to develop social skills, individuals with autism can overcome many of the challenges they face and enjoy more fulfilling social interactions, mainly when dealing with neurotypical people.

## Hating the Telephone

If an eyebrow is raised quizzically in the forest, and no one is around to see it, does it make any noise? Not on the phone!

I avoid talking on the telephone. I dislike people calling me, and I'm uncomfortable calling most people. It's not much better when I know the person, either: even speaking to my wife on the phone feels somehow stilted, remote, and disconnected. In an emergency, if it were practical, I'd prefer to email 911.

I do pretty much everything by text or email, from purchasing my house to having my car restored to dealing with insurance agents or buying football tickets. If a phone call needs to be made, I'll often ask my wife to make it for me, and if she cannot or will not, a genuine fear of dread can come over me if it's going to be a complex call.

When I was at Microsoft, one of my earliest friends and managers, Mark Taylor (MarkTa), made a deal with me. He said that if we were ever talking on the phone and wanted to end the call, we could just say goodbye without fanfare or hurt feelings. It was just easier, he argued, than doing that dance that people can do at the end of most social phone calls. Lucky for me, I was terrible at that dance.

To this day, I'm not sure if the offer was for his benefit or mine!

People with autism may have difficulty using a telephone for several reasons, some of which may even seem paradoxical at first. For example, they may dislike using a phone because they find it overwhelming or stressful to initiate or accept a call on the telephone. Perhaps it is because they cannot see the person they are speaking with and have difficulty seeing nonverbal cues such as facial expressions and body language.

"It can take me several hours to work up the courage to make a simple call like a restaurant reservation."

- Riley P.

In my own case, because I'm never *quite* sure when it's my turn to talk, it can lead to poor conversation flow at best and create confusion at worst. As a contrived example, someone might make a statement as banal as:

"I believe in discount bus passes for war widows."

There is an implied social contract amongst the neurotypical whereby if someone makes such a statement that calls for a prompt response, they expect an immediate agreement such as "Yes, of course!" If, instead, *I'm* still waiting to see if the other person is actually done speaking and it is indeed my turn to answer, that added delay suddenly seems suspect. Maybe I'm secretly *against* such discounts for all they know. Such a mistake can create a misunderstanding, and someone with ASD might also have a hard time noticing the sudden discomfort in the other party, or if they sense it at all, they might be oblivious to the reason why it happened. These misunderstandings may

not occur during an in-person conversation because the listener with autism may get the prompt via the speaker's facial expressions or body language.

Where's the paradox? It lies in the fact that people with the most trouble reading out-of-band social communication channels, such as facial expressions and body language, seem to be at quite a disadvantage without those clues! If they can read them only poorly, why would they still create a marked deficit when absent?

Perhaps this all goes back to mindblindness and how difficult it can be for some people to construct their theory of the other, which is to say, what the other person is really thinking. On the telephone, there are numerous techniques that neurotypical people consistently use to communicate nonverbal cues in a telephone conversation, and they are only available partially or not at all to some people on the spectrum. The following are but a few examples:

#### Tone of Voice

A person's tone of voice is a critical aspect of communication that conveys a wide range of emotions, attitudes, and intentions. Studies have shown that the tone of voice can be more important than the words spoken in conveying meaning and emotion.

The speaker's tone of voice can convey a wide range of emotions, including happiness, sadness, anger, and excitement. For example, a cheerful tone of voice can express happiness or excitement, while a monotone voice can convey boredom or disinterest. Similarly, a harsh or angry tone of voice can convey anger or frustration, while a soft or gentle tone of voice can convey empathy or sympathy.

In addition to emotions, the tone of voice can convey nuances such as sarcasm. Sarcasm is a form of verbal irony that involves saying the opposite of what is meant, often with a mocking or satirical tone. This can be conveyed through the tone of voice, which may be exaggerated, mocking, or condescending.

The tone of voice can also convey subtle social cues, such as the speaker's confidence level or authority. For example, a confident tone of voice can convey authority and expertise, while a hesitant or uncertain tone of voice can convey insecurity or doubt.

For individuals with autism, interpreting the tone of voice can be challenging when considered alongside the absence of nonverbal cues such as facial expressions and body language. This can make it difficult for them to understand the speaker's emotions, intentions, or sarcasm. As a result, individuals with autism may benefit from explicit instruction and practice in understanding tone of voice, including role-playing exercises or social stories.

Changes in pitch, which might escape the person on the spectrum, can imply many emotions. They can also communicate the listener's base level of enthusiasm or boredom.

#### Volume

The volume with which a person speaks can convey a wide range of emotions and intentions. For example, a person who speaks loudly and enthusiastically can convey excitement and passion about the topic. On the other hand, a person who speaks in a low or quiet voice may be conveying a sense of sadness, uncertainty, or secrecy.

Similarly, someone who speaks loudly and forcefully may convey frustration, anger, or a sense of urgency. Conversely, a person who speaks in a calm, even tone may convey a sense of relaxation or ease.

The volume of a person's voice can also be used to emphasize a particular point or idea in a conversation. For example, a person may raise their voice to highlight a particularly important or surprising point or to get the listener's attention. This can effectively ensure the listener understands the speaker's message and engages in the conversation.

For individuals on the spectrum, interpreting the volume of a person's voice can be challenging. They may have difficulty reading nonverbal cues and understanding the emotional tone of the conversation. As a result, they may miss important information or misunderstand the speaker's intent.



#### Inflection

Changes in inflection, or the rise and fall of pitch and tone in a person's voice, can reveal much about the speaker's emotional state and intentions. For example, a rising inflection at the end of a sentence can indicate a question, while a falling inflection can indicate a statement or command. These cues are critical for understanding the intent behind the speaker's words and responding appropriately.

In addition to indicating the type of sentence being spoken, changes in inflection can also reveal the emotional state. For example, a rising inflection can convey surprise or excitement, while a falling inflection can convey anger or frustration. These emotional cues are essential to effective communication, as they allow listeners to understand the speaker's perspective better and respond appropriately.

For people with autism, interpreting changes in inflection can be challenging, given their difficulty reading nonverbal cues and understanding the emotional tone of the conversation. This can lead to misunderstandings and miscommunications, as they may miss crucial emotional cues or fail to recognize the intent behind the speaker's words.

To address this challenge, individuals with autism may benefit from explicit instruction and practice in understanding changes in inflection. This may involve role-playing exercises or social stories to practice recognizing and responding to different conversational intonations. Visual supports such as picture cues or written instructions may also be helpful in some cases.

#### **Pauses**

Pauses are a critical aspect of effective communication that convey a great deal of information about the speaker's intent and emotions. Pauses indicate hesitancy or uncertainty, such as when a person is searching for the right word or trying to convey a complex idea. In this context, pauses provide valuable time for the speaker to gather their thoughts and choose the most appropriate words to convey their message.

In addition to indicating hesitancy, pauses can emphasize certain words or ideas. By pausing before or after a particular word or phrase, a speaker draws attention to it and conveys its importance to the listener. This technique is particularly effective when the speaker tries to persuade or influence the listener, as it helps reinforce the argument's key points.

Pauses may convey incredulity or disbelief, such as when a person is surprised or skeptical about a particular idea or statement. In this context, pauses indicate that the speaker is processing the information and trying to make sense of it or that they are waiting for further clarification before responding.

Finally, as noted earlier, pauses can be used to seek confirmation of a statement or to encourage the listener to respond. By pausing at the end of a sentence or statement, the speaker can signal to the listener that they are open to feedback or response and can create a more collaborative and engaged conversation.

#### **Pacing**

The speed of speech is a crucial aspect of communication that can convey a wide range of emotions and intentions. A person's speech pace can indicate their excitement or enthusiasm level and the degree of urgency or importance they attach to the conversation. For example, fast speech can indicate excitement or urgency, while slow and methodical speech may convey calm or deliberation. Similarly, a sudden change in pace can indicate a shift in mood or focus and can be used to emphasize specific ideas or points.

However, for individuals with autism, interpreting changes in pace can be challenging. They may have difficulty reading nonverbal cues and understanding the emotional tone of the conversation. This can lead to misunderstandings and miscommunications, as they may miss critical emotional cues or fail to recognize the intent behind the speaker's words.

## Replaying the Day's Interactions

One quirk of folks who find themselves on the spectrum is that they will often look back upon social interactions they've had of late and replay them in their minds. Even if they're not keenly aware of what they are doing or why they are doing it, a common theme is that it is done with an eye towards better understanding whatever conversation or social dynamic was at play at the time: Why did the person I was speaking to say "X"? Why was their reaction something other than what I expected when I said "Y"? Did I leave them wanting more, or did I wear out my welcome with them?

The amount of time I spend doing so tracks linearly with the number of social interactions I've had and the complexity of When working full-time in an office those interactions. environment, complete with meetings, reviews, interviews, there was a lot of daily social effort available for my post-processing review. Now that I work primarily from home, there is understandably much less. I still do it, though, and it could be as simple as "Why didn't the checkout cashier smile at my 'Dad joke'? Was my timing off, or was the joke based on a reference that was too obscure, or could it have possibly caused offense? Was it the wrong time and place, or was she not in the mood then?" Figuring out why the client rejected a proposal that took weeks to prepare could be even more complex.

I will run these past events through a metal gauntlet of tests to determine if I may have committed some kind of social faux pas or where my masking or social skills could improve.

Looking back at conversations and interactions, I look for things I wish I *would* have said. I also look for things I regret having said or that I should have at least said differently. Sometimes, if things did not go well in some aspect and it's one that "I wish I could do over again," I'll obsess over it as I try to understand the root cause of a disagreement or uncomfortable moment.

I believe that many people on the spectrum post-process their social interactions in this way because the amount of social and emotional context that flows from a neurotypical person during these interactions is simply too much at once. For some people on the spectrum, it is of a higher bandwidth than their social abilities can process live. And so, they retreat later to process and review the extra information at their own pace. This allows them to spot nuances and details they might have overlooked entirely in real time. It also allows them to scrutinize their own "performance" in terms of actions, reactions, statements, and behaviors to improve them for next time.

# **Issues with Eye Contact**

Managing "proper" eye contact is one of people's most delicate social dances. Holding direct eye contact for too long can be perceived as aggressive, if not downright creepy. Too little can be mistaken for distraction, disinterest, or subservience. With neurotypical people they say the eyes are the windows to the soul. In autistic people, it's more complicated.

Owing in large part to the fact that our eyes are white and clearly visible, one human can tell where another is looking at a substantial distance, something presumably useful to prehistoric hunters coordinating their actions, among other things. At social distances, how a person manages their eye contact communicates much about everything, from their position in the dominance hierarchy to how confident they are or whether they are ashamed of something.



Some have asserted that those with Autism have *difficulty* looking people in the eye. It may be true for some. I can only speak to my own experience, but the problem is that no pressing need or imperative drives us to lock our gaze on the other person. If neurotypical people need to do so to feel "present" with the other person, I generally do not. If I am processing a visual memory, I might look up to the left, which almost reflexively allows me to picture it. In the same situation, a neurotypical person might look the listener directly in the eye to reinforce or underscore their point. The fact that I seem to be looking off into space at that moment likely does not make my argument more persuasive.

Similarly, a person on the spectrum might simply focus their gaze on the object of their attention. If that is local to the room,

like a map, whiteboard, or television show, there's a good chance that when talking about it, the person on the spectrum will direct their gaze there rather than to the other people in the room. Where the mind goes, so go the eyes.

People on the spectrum may not understand, appreciate, or be able to perform their eye contact in the conventional manner expected by neurotypical people. They dance their own dance, and it doesn't always take a partner into account.

I've noticed that people on the spectrum often do look the other person directly in the eye when unsure whether they are being heard and understood; perhaps this is done to confirm a look of comprehension.

There may be several reasons that eye contact is either challenging or unconventional for people on the spectrum. They may have difficulty interpreting the social cues of the speaker they are engaging with. They might also miss the meanings and implications of the other person's eye contact.

Some may find it overwhelming or distressing to lock eye contact with others.

Some may hold their gaze on the other person too long, which might be interpreted as aggressiveness. Others, whether by nature or because of previous stressful experiences, may have social anxiety, which can make maintaining eye contact uncomfortable.

## **Trouble Initiating New Tasks**

I confess that I may be conflating my ADD with my ASD, but I would still categorize the difficulty I face with initiating new tasks as an autism spectrum characteristic (ASC). It is not so much procrastination as a marked preference for doing either (a) that which I am already doing or (b) that I would rather be doing (i.e., my special interests). Between those two, it's hard to break off into new, less desirable, or tedious tasks that need doing.

It's not uncommon for individuals with autism to struggle with initiating tasks or staying focused. Here are some strategies to help you start and successfully clean your desk and workbench.

Break the task into smaller steps: Divide the cleaning process into smaller, more manageable tasks. Write a list of these steps, such as clearing clutter, organizing papers, and wiping down surfaces, all of which can make the project feel less overwhelming.

Set specific goals: Define clear goals for the cleaning process, like organizing your tools or creating a more functional workspace. This can help you stay focused and motivated.

Use a timer: Set a timer for short intervals, such as 10 or 15 minutes, and commit to working on the task for that period. This technique, known as the Pomodoro Technique, can help you overcome procrastination and maintain focus. If you ever need to eat an elephant, it's best done one bite at a time.

Create a structured routine: Set a specific time to clean and maintain your workspace daily or weekly. Creating a routine can help establish habits that make it easier to initiate tasks in the future. Soon enough, your brain knows what you "should" be doing at that time and place, and it comes more naturally.

Minimize distractions: Clear your work environment of distractions, such as turning off electronic devices or closing unnecessary browser tabs. Use "Focus" mode on your desktop and devices to minimize incoming text messages, emails, and other potential distractions.

Use visual cues: Place a reminder or motivational quote on your desk or workbench to inspire you to start cleaning.

When I was newly married, my wife and I were out driving around looking for apartments. We stumbled across a residential area with a corner house that constituted my dream house, at least at the time. Better yet, the owner was out front washing what appeared to be a new red Corvette. I stopped and grabbed a real estate flyer for the home, cut the picture out, and taped it to the edge of my monitor.

The photo frequently reminded me to get to work on the side projects that I hoped would one day fund our own dream house. If I found myself lingering too long on CompuServe,\* the

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<sup>\*</sup> Am I dating myself? CompuServe was an online service that was reached by modem in the years before the World Wide Web.

photo would often remind me to spend my time more wisely and to "get back to work."

Use a reward system: Plan a small reward for yourself after completing the task or each step. This can motivate you to finish the task and reinforce positive behavior.

I know the sinister side of this pattern all too well, however, in that I smoked cigarettes for decades. I would structure my working day around those much-anticipated breaks, making them the reward for an hour or so of hard programming. This pattern of reinforcement made the addiction all that much harder to kick when I finally did so. Addiction issues are beyond the scope of this book, but I've found the books by Allen Carr to be particularly useful and well-suited to the autistic mindset.

Create a conducive environment: Play calming music, use noise-canceling headphones, or ensure comfortable lighting to create an environment that supports focus and productivity.

Practice self-compassion: Remember that it's okay to struggle with initiating tasks. Be patient with yourself and acknowledge your efforts.

Seek support: If you continue struggling with starting tasks or staying focused, consider seeking support from a therapist or counselor specializing in ADD and Autism. They can provide additional guidance and strategies tailored to your specific needs.

Remember that everyone has different needs and preferences. Experiment with these strategies to find the ones that work best for you. Pushing yourself to do tasks other than your special interest is like exercising a muscle at the gym – the first few times, it might even hurt a little. But neurons adapt even faster than muscles, and I've found that two weeks is often enough to anchor a new habit (or to tolerate a difficult change).

### **Restricted Interests**

Restricted interests are a common ASC, characterized by an intense focus on specific topics or hobbies, often excluding other interests. This can make it difficult for individuals with autism to connect with others or engage in more diverse activities. To better manage restricted interests and promote a well-rounded life experience, exploring the underlying reasons for these interests and developing strategies for broadening one's horizons is important. Remember, having a special interest can be a sincere blessing; expanding your interests outside it can only serve to foster growth.

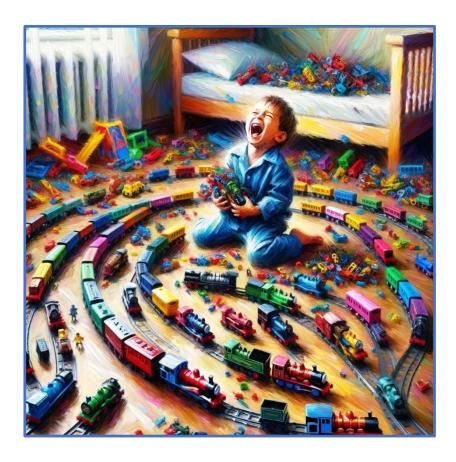
# Understanding the Appeal of Restricted Interests

For individuals with autism, restricted interests often provide comfort, predictability, and control in an otherwise confusing and unpredictable world. These interests can become a source of expertise and pride and may even serve as a coping mechanism for dealing with stress or anxiety. By understanding the reasons behind these intense interests, individuals can develop strategies for incorporating a more comprehensive range of activities into their lives while still maintaining their passion for their special interests.

In my own case, computer programming – and doing it well – provides intense personal satisfaction, sharpens my skills, enhances my reputation, and scratches the itch of complex problem-solving all at once. Debugging software is much like taking apart my mom's toaster to see what's inside, and it feels similarly rewarding.

As a child, I was fascinated by NASA and the space program. This is common amongst kids, particularly those of my vintage, so it's unsurprising. But I took it to another level. By the third grade, I was writing complete reports that documented every Soviet and American launch that had ever taken place. I knew every detail and, sometimes, could think of little else. It is difficult to say why it was so rewarding, particularly from a vantage point this far away in time.

However, the reasons behind your special interest might be clear or shrouded in mystery. Either way, it's worth exploring and understanding your own motivations, rewards, and incentives as best you can.



# Strategies for Expanding Interests:

Begin by setting small, attainable goals for exploring new activities or topics. This could include trying a new hobby, attending a group event, or learning about a new subject. Gradually increase the complexity and variety of these goals as you become more comfortable with the process.

After my autism diagnosis, I spent significant time and effort undertaking challenges that were new to me. In addition to the YouTube channel, I also wrote my first book. I hosted a large open house shop party for almost 100 people, many of whom I did not know very well. If you're not *too* far out of your comfort zone, it's the fastest way to learn new skills and build tolerance to doing things that do not come naturally to you. As with working out, these things take time – start small and build. You can't become physically fit on a single visit to the gym. The good news is that neurons respond faster than muscles.

Use your existing interests as a starting point for expanding your horizons. For example, if you are passionate about a specific historical period, consider learning about the art, music, or literature from that time to broaden your knowledge.

Engage in social activities related to your interests. Join clubs, organizations, or online communities that share your passions. This can allow you to connect with others, learn new perspectives, and discover related interests.

Cultivate a sense of curiosity about the world around you, and challenge yourself to explore new topics, activities, or experiences regularly. It shouldn't be a one-time thing; you should always push your envelope by immersing yourself in new (sometimes uncomfortable) situations and challenges. It's much easier to grow a little bit at a time than all at once.

Recognize that it's okay to shift your focus and explore new interests as your passions and priorities evolve. In my own case, my interests were pretty much limited to computers and working with cars. However, there have been plenty of opportunities to expand my horizons, even within the scope of those. Rather than just working on engines, I restored a classic

pickup involving every nut and bolt in the entire truck. I learned many new skills while still engaged in tasks that provided some comfort. Indeed, there can be frustration in doing something you're not good at initially, but it's worth the effort.

Share your goals for broadening your interests with friends, family, or a therapist who can encourage, hold you accountable, and provide guidance.

Celebrate progress by acknowledging and celebrating your achievements in exploring new interests, even minor ones. This can help build motivation and confidence in expanding your horizons.

Strive for balance by incorporating activities catering to your physical, emotional, social, and intellectual well-being.

By working to expand their interests and engage in a broader range of activities, individuals with autism can not only develop a more diverse skillset but also foster deeper connections with others who share their passions. This process may require patience and persistence, but with time and effort, it is possible to overcome the challenges associated with restricted interests and enjoy a richer and more fulfilling life.

## Masking

"When people say, "You don't look autistic," I often receive it with mixed emotions. While the intention behind the statement may be harmless, it's hard not to feel somewhat offended, as it

makes me wonder what their perception of someone with autism *should* look like. However, I mainly see this comment as a testament to how skillful I've become in the art of masking.

Masking, also called camouflaging, conceals one's genuine emotions and internal state from the world by adopting more socially acceptable behaviors, actions, and expressions. Essentially, it's a way for individuals with autism to blend in with neurotypical people, often so as not to stand out in the crowd. To achieve this, individuals with autism frequently rely on internal "social scripts" they've learned from observing others, starting from an early age. Those scripts can be learned from the people they interact with or the media they consume.

"Cast in this unlikely role
Ill-equipped to act
With insufficient tact
One must put up barriers
to keep oneself intact."

- Neil Peart, Rush

The motivations behind masking are diverse. Some individuals mask to better connect with friends in social settings, while others do so to secure a rewarding job or pursue a romantic interest. Masking occurs when a person's natural reactions must be suppressed and replaced with a more suitable and appealing facade.

Even subtle adjustments to one's behavior can be considered masking. For instance, if you must restrain yourself from bouncing your knee or sitting on your hands to avoid distracting others, you're masking—which may be appropriate and considerate in that context. Similarly, if you need to practice a few anecdotes outside of your area of interest and expertise to perform during a job interview, that's masking.

For those with autism whose speech patterns exhibit a flat affect, masking may involve summoning enthusiasm and friendliness to work in a customer service or retail sales position. Over time, you might develop an array of "scenes" to enact based on different situations, such as cheerfully guiding a customer through the returns process. Having spent my youth in retail, I have quite a repertoire, though it's generally only useful in hardware and home-improvement stores.

In my personal experience, I once received feedback during an annual employee review at Microsoft that a few new team members – who were not yet very familiar with me – perceived me as "grumpy." This was likely because they only saw me when I wasn't masking. People with autism may not always display the expected facial expressions; for example, I can feel content and happy without necessarily smiling. Conversely, negative emotions of almost any kind usually manifest on my face as apparent frustration or anger. Judging me solely by my facial expressions might give the impression that I am either happy or annoyed, with no room for anything in between. However, just like anyone else, I experience a wide range of emotions – they simply don't dictate my expressions in the same automatic way.

The primary objective of masking is to blend in with the crowd. When successful, this increases an individual's chances of success in social relationships, employment, and romance. Individuals with autism who are more adept at concealing their symptoms can more easily form friendships with neurotypical people, strengthen their social support networks, and perform better during job interviews.

## Masking is Hard Work

Masking is not a simple, effortless state that everyone with autism can quickly enter. Even when honed to perfection, masking requires considerable cognitive effort. One of the most frequently reported consequences of masking is exhaustion or mental fatigue resulting from prolonged performance periods. I need a break when I must be "on" for an extended time. Suppose I am "on" for three to four hours. In that case, I need a 30-minute to one-hour respite to decompress and momentarily free myself from constantly monitoring my every movement, word, silence, or thought for appropriateness. Quiet time without social or interpersonal demands is the ideal solution. The duration and frequency of breaks will vary for each individual and depend on the nature of the activity or interaction.

One of the most challenging situations is travel days, especially when I must journey across multiple connections and time zones to reach a remote destination like Saskatchewan. Upon arrival, I am expected to engage with friends and relatives for several hours. Maintaining my mask becomes incredibly taxing without a break between traveling and socializing. I simply

cannot sustain it for such an extended period. For years, no one understood why I needed a break upon reaching my destination, as it seemed illogical. My family could not understand why other families could fly into town, drop their bags at the hotel, and immediately head out for fun and socializing - In contrast, I needed a "break" to decompress and recharge from a full day of masking. Since this was prediagnosis, what we failed to consider was the fact that I had been "working" on my performance all day.

The more masking an individual with autism must perform, the more exhausting it becomes. Excessive masking can deplete one's resilience and increase the likelihood of experiencing a meltdown. In my case, many meltdowns appear to be related to these long travel days, which involve copious amounts of masking. It seems that this continuous effort significantly impacts the stress reserves.

## Masking and Mental Health

The cognitive and emotional effort required to constantly monitor and modify one's behavior, speech, and expressions can be extremely taxing. This mental fatigue can accumulate over time, leading to feelings of burnout and overall weariness. Individuals with autism who mask regularly may find that their energy reserves are depleted more quickly, leaving them with less capacity to handle the typical stressors of daily life.

Moreover, the pressure to maintain a facade can contribute to heightened anxiety levels. The constant worry about being "found out" or failing to meet neurotypical expectations can exacerbate existing anxiety disorders or even trigger new ones. This anxiety can manifest in various ways, such as social anxiety, generalized anxiety disorder, or panic attacks.

The ongoing suppression of one's true self can also lead to feelings of isolation and loneliness. Individuals who mask may feel disconnected from others, as they cannot express their authentic emotions, thoughts, and experiences. This lack of genuine connection can result in a sense of not belonging or feeling misunderstood by those around them, further exacerbating feelings of loneliness.

Depression is another mental health concern linked to masking. When individuals constantly suppress their natural tendencies and emotions, they may develop a sense of low self-esteem or self-worth. The internal message that their true selves are unacceptable or not valued by society can contribute to feelings of hopelessness and despair. Additionally, the strain of maintaining a facade may prevent individuals from seeking help or support, further isolating them and deepening their depressive symptoms.

Masking can also influence the development and severity of other mental health conditions, such as obsessive-compulsive disorder (OCD) or eating disorders. For instance, the compulsive need to maintain a neurotypical appearance may lead to rigid routines or rituals, which could evolve into OCD-like behaviors. Similarly, the stress and anxiety associated with masking may cause some individuals to seek control through disordered eating patterns or other self-destructive behaviors.

While masking can provide temporary relief and social acceptance for individuals with autism, it is crucial to acknowledge and address the potential mental health implications associated with the practice. Encouraging open dialogue about the challenges of masking, promoting self-acceptance, and providing appropriate mental health support can help mitigate the adverse effects on mental well-being.

#### Masking and Identity Development

Masking as a coping strategy can have significant implications for developing personal identity and pose risks to an individual's sense of self.

During the formative years of childhood and adolescence, individuals explore and solidify their self-concepts and identities. For individuals with autism who engage in masking, this period of identity development can be fraught with challenges. The constant suppression of their true selves in favor of a neurotypical facade may create a dissonance between their authentic identities and the personas they present to the world. Over time, this disconnect can hinder the development of a stable and cohesive sense of self.

The struggle to reconcile their true selves with the expectations of others can lead to confusion and uncertainty. Individuals with autism who mask may have difficulty understanding their own thoughts, emotions, and preferences, as they are constantly adapting to the perceived desires of those around them. This lack of self-awareness can make it challenging for them to make choices that align with their authentic interests

and values, potentially leading to unfulfilling or unsatisfying life paths.

Furthermore, the ongoing effort to maintain a neurotypical appearance can contribute to feelings of inauthenticity and internal conflict. Individuals may feel trapped between conforming to societal expectations and the desire to express their genuine selves. This tension can create a sense of alienation from others and oneself as the individual struggles to balance authenticity and acceptance.

In addition to these challenges, masking can harm an individual's self-worth and self-esteem. By constantly hiding their true selves, individuals may internalize the message that their authentic identities are not valuable or deserving of recognition. This can lead to a negative self-image and a belief that they are inherently flawed or inferior.

Unmasking or gradually revealing one's true self can be crucial in fostering a healthy sense of identity. By embracing and accepting their autistic traits, individuals with autism can begin to develop a more authentic and integrated sense of self. This journey towards self-acceptance may involve seeking support from understanding friends, family members, or professionals and engaging in self-exploration and self-reflection.

#### Facial Expressions vs Mood

Some individuals, many of whom I suspect might be on the autism spectrum, struggle with what is known as a "grumpy resting face." At least one famous actress has openly described herself as having a "resting bitch face," a term that has even earned its own Wikipedia entry. My father exhibited a similar



characteristic: could be entirely content, relaxed, and enjoying television, but when his face was at rest. particularly when thinking or concentrating, he often appeared angry or annoyed. As a child, I would frequently ask him,

"Dad, what's wrong?" with apprehension, trying to gauge the sincerity of his response when he assured me that everything was fine. In most cases, he was genuinely untroubled, and my concerns were merely a reaction to his neutral expression.

Aware of this issue long before I had any inkling about autism, I encouraged my own children to inquire as often as they needed to, reassuring them that unless I explicitly stated otherwise, I probably wasn't upset. I emphasized that they could ask me anytime, as I didn't want them to experience the same anxiety and distress that I had experienced when

wondering about my father's mood. Since I'm not the type to sulk without voicing my feelings, I assured them that if I were unhappy, it wouldn't be a secret – all they had to do was ask.

My wife and I bounce "you good?" off each other a few times per day at least to gauge each other's mood. My neurotypical wife isn't going to be able to replicate my thoughts and accurately determine my thoughts in each situation any better than I, as a person with autism, can read hers. There is a disconnect between the neurotypical and the autistic, a communication barrier where we do not readily know what the other is thinking. Because a flat affect can make it even harder to see, it rarely hurts to ask, whereas guessing can lead to complications.

Such an open exchange of reassurances wouldn't be feasible in a professional setting. For those who knew me well, my grumpy resting face wasn't an issue because my masking skills were refined enough that when interacting with me, I appeared normal and "happy" at most times. But I might look grumpy and frustrated from a distance or when observed sitting silently during a meeting. Remembering that my facial expression doesn't necessarily reflect my genuine emotions is essential.

#### Female Masking

Masking can be so effective in concealing the symptoms of autism that it has been cited as a contributing factor to delayed diagnoses, particularly among females. Some believe that girls might be more proficient at learning or mimicking "normal" neurotypical behaviors, which could result in a higher

likelihood of having undiagnosed autism symptoms. While males with autism are diagnosed at a rate approximately four times higher than females, this disparity raises the question of whether the actual prevalence of autism in females is lower or if it is due to their ability to mask diagnostic indicators more effectively.

True or not, it is conventional wisdom that girls are more attuned to social issues than boys are. If true, it would make sense that, as a generality, girls might be better at "appearing neurotypical" both in daily life and at the pediatrician's office. As a result, they might not attract the initial attention that leads to an evaluation or diagnosis.

It is, therefore, crucial to reevaluate and modify the screening and detection methods for autism to ensure that the process does not disproportionately identify or exclude individuals of a specific gender. To address this issue, several adjustments could be considered.

Increasing awareness among medical professionals, educators, and caregivers about the unique ways in which females may present with autism is essential. Providing comprehensive training on gender differences in autism symptoms and manifestations can help ensure that girls are not overlooked during evaluations.

Developing and employing diagnostic tools that take gender differences into account can help identify autism in females who may otherwise go undiagnosed due to their ability to mask. These tools should be designed to recognize the subtle variations in how girls with autism might present as compared to boys.

Empowering girls and women on the autism spectrum to understand and communicate their experiences can be valuable in securing a timely and accurate diagnosis. Supporting them in expressing their unique challenges, strengths, and needs can help professionals better understand their symptoms and tailor appropriate interventions.

Further research focusing on the unique experiences of females with autism is necessary to understand the condition's presentation better and develop more effective diagnostic processes. Investigating the impact of social and cultural factors on masking behaviors in girls and women can contribute to a more comprehensive understanding of gender differences in autism.

By addressing these issues and making the necessary changes in screening and diagnostic processes, the identification and support of girls and women with autism could be significantly improved, ultimately leading to better outcomes and a higher quality of life for those affected.

## Should those on the Spectrum Mask?

Out on the savanna, zebras have an interesting defense mechanism. Their bold contrasting stripes are apparent when looking at an individual zebra, but predators are at a loss in a circling herd of a hundred such animals. The stripes defend the entire herd, protecting its individual animals – as long as none stand out.

The concept of masking raises a valid question: Shouldn't we be able to express ourselves as individuals and be accepted for who we are without pretense? Ideally, yes. However, society is not a heterogeneous mix of vastly different individuals. Instead, people within a society are generally more similar than dissimilar, and it is these similarities that masking seeks to leverage.

In my personal experience, I adopt a more natural demeanor within the comfort of my own home, except during special occasions (birthdays, Christmas, etc.) or when hosting guests. In such situations, I am expected to be "on" with all the associated demands and time constraints. Naturally, I prefer to be myself, which doesn't imply being rude, dismissive, or disinterested; my family has described my behavior as "factual." That description still makes me chuckle!

I recognize that many people, including some friends and family members, might prefer that I always maintain my "on" persona. I might approve if it were a simple choice rather than a cognitively demanding performance. However, expecting someone to mask constantly is neither feasible nor fair.

Despite the limitations imposed by my own mindblindness, I am aware of when masking is most needed: when a new report card arrives, a new piece of artwork is displayed on the fridge, or after a performance in a play, for example. In these instances, the internal excitement and pride are as genuine as they are for any parent. Still, I must consciously express these emotions openly to ensure they are acknowledged and understood.

# **Repetitive Behaviors**

People on the spectrum often exhibit repetitive behaviors that may appear odd to others. These repetitive behaviors, also known as "stereotypies," are frequently one of the earliest signs of autism and can include a variety of actions such as hand flapping, rocking back and forth, lining up toys, or repeatedly saying certain words or phrases. As a toddler, I most enjoyed bouncing in my "Jolly Jumper" and stacking things like cans and blocks.

Physical behaviors that are repetitively engaged in are most likely a type of "stim" or self-stimulation. In a stim, the person experiencing this autism spectrum characteristic performs the behavior primarily because it energizes or comforts them.

I am no exception. At Microsoft, perhaps because there were so many other people also on the spectrum, it was not uncommon to be in a meeting where tensions were high or where thoughts were deep and find myself and a few others rocking in our chairs, often rubbing the knees and tops of the legs. Usually dismissed as just "something nerds seem to do," it is a prime example of repetitive behavior and likely a "stim" as well.

The exact cause of these behaviors in people with ASD is not fully understood. However, there are a few theories:

Repetitive behaviors may serve a self-stimulating function. They can provide sensory input, calm the individual, or help the person focus. In my own case, I like to snap my fingers when I walk. It provides some base level of enjoyment and comfort and is thus best characterized as a "stim." I also tend to rock when I am thinking and speaking. I often provide my own sound effects when walking around the house alone.

Repetitive behaviors can also provide a sense of control and predictability in a world that may often feel overwhelming and chaotic, thereby reducing anxiety. As noted earlier, a common behavior I observed in my friends on the spectrum while in high school was a tendency to run a hand down the wall as they walked a long hallway. Perhaps it provided a touchstone, a familiar stimulus to be experienced in favor of the ambiguities and unknowns that might accompany a walk down a high school hallway.

Individuals on the spectrum often resist change and may prefer routines and predictability, making any changes quite distressing. Repetitive behaviors can manifest this preference.

For those whose communication is impaired in some way, repetitive behaviors may be a nonverbal attempt to communicate needs or emotions. Hand-flapping, for example, most often occurs with happiness or excitement and may be a valuable communication device for some.

It's important to remember that a repetitive behavior, even one that causes embarrassment or angst, may simply be unavoidable. For my finger-snapping, I've adopted a silent finger-tapping approach that mostly scratches the itch, but even so, the internal pressure to snap my fingers as I stroll along can be immense.

### Sensitivity to Sensory Stimuli

People on the spectrum often perceive sensory information from the environment differently than neurotypical individuals. This phenomenon is known as sensory sensitivity or sensory processing disorder.

These differences in sensory experiences can be broadly classified into hypersensitivity (over-responsiveness) and hyposensitivity (under-responsiveness).

In the hypersensitivity case, individuals on the spectrum may be overly sensitive to certain sensory inputs. They may find sounds, lights, smells, tastes, or touch stimuli that are tolerable or even unnoticed by others to be overwhelming, distressing, or painful. For example, the hum of a refrigerator, which most people can ignore, might be distressing to someone with hypersensitivity. Similarly, the texture of certain fabrics might be unbearable, whereas another person might be unable to eat certain foods due to their texture.

On the other hand, individuals on the spectrum may also exhibit hyposensitivity to certain sensory inputs, where they seem not to notice sensory information that others do. They may not react to pain in ways that others would expect or might crave intense sensory input. For example, they might enjoy spinning or rocking, seeking out strong flavors or smells, or feeling certain textures.

Some people on the spectrum are under-sensitive to some sensory inputs. Such individuals might not perceive sensory information as intensely as others, which could lead to a lack of awareness of their surroundings and an increased risk of injury. They may also then seek intense sensory experiences to stimulate their senses.



Figure 4 - LED and Laser lighting on my shop.

My workshop and studio are filled with bright, flashing LED lighting features I have designed and programmed. I presume that the sea of bright colors takes most visitors to my shop by surprise, but it's an environment I love. My computer monitor is surrounded by other bright displays that show the audio spectrum of the music currently being played, as well as news, weather, and abstract designs. None of this is distracting to me in the slightest, but I imagine it might be for most other people.

I've loved this visual look since I was a child, admiring the brightly lit tree on Christmas Eve or playing with my Lite-Brite as a kid the following morning. Whether it means I am hyposensitive to bright colors or flashing, I cannot tell. But something is different.

It's also possible for an individual to experience both hypersensitivity and hyposensitivity, even within the same sensory system. For example, a person with autism might be overly sensitive to certain types of touch, like light touch or certain textures (hypersensitivity), but under-responsive to other aspects, such as not noticing pain or temperature as quickly as others might (hyposensitivity). Sensory sensitivities can have significant impacts on the daily lives of individuals with autism and their families. They may affect a person's behavior, communication, social interactions, and learning abilities.

I find myself firmly on the hypersensitive side of things regarding sound. Certain sounds, like Styrofoam rubbing on itself, are intolerable for reasons I cannot explain. I had assumed I would "mature out of" this at some point, but that has simply not come to pass. The same sounds that were troublesome in childhood remain so today.

I have a high pain tolerance, and yet I am *very* sensitive to light touch. This makes me very ticklish in some circumstances or deeply annoyed in others: a paper neck tag in a soft T-shirt will drive me to distraction until I cut it out (I used to just rip them out in frustration, but as my wife has repeatedly explained to me, that can leave a hole).

When it comes to music, I enjoy playing it loud at times, but novelty and volume seem to be a sour mix for me. In other words, if I know the song well, I don't mind it loud. But if the music is new to me and I don't know what's coming next, having it played at higher volumes can be stressful.

My oldest son is an aspiring music producer, so he is often eager to show me his latest tracks. I enjoy hearing his new work, but I often must ask him to turn the volume down – not because I don't enjoy the music, but because music that's new to me is bothersome at higher levels. Once I know the song well enough, "Rock on."

Managing these sensory sensitivities should involve a multifaceted approach, including occupational therapy. Occupational therapists can provide sensory integration therapy, which involves specific activities that help the individual become more accustomed to certain sensory stimuli.

Individuals with autism may wish to create their own "sensory-friendly environment." This might involve reducing exposure to distressing stimuli (like dimming lights or reducing noise) and providing opportunities for beneficial sensory input (like access to sensory toys).

Many facilities, such as airports and malls, are starting to offer "sensory booths," like phone booths, where a person overwhelmed by too much sensory input can go for a brief respite. They may even provide noise-canceling headphones to assist.

In terms of the most basic practical advice, odds are, if you are among those who find themselves overly sensitive, you already know what works: noise-canceling headphones for audio, sunglasses for bright lighting, a weighted blanket to provide calming pressure, and so on. Using whatever interventions and precautions benefit you without feeling odd about it is essential. If you *require* that accommodation in that circumstance, there should be zero shame in according yourself to it.

That said, there's also sometimes an argument to be made for being as subtle as possible when you prefer not to bring attention to yourself. While I like the performance of Bose (or similar) noise-canceling, over-the-ear headphones, I also carry a set of Apple Air Pods with similar noise cancellation. If my environment is too loud or distracting for too long, I can pop them in without looking inappropriate in most situations.

Loud sounds are paradoxical for me. I've been to my share of heavy metal concerts, fireworks shows, the gun range, and even nitro-burning top-fuel dragster events. But in those cases, I am an interested spectator and know what's coming. Sometimes, I can even paradoxically relish the temporary sensory overload of a casino, for example, with its loud and raucous atmosphere, garish carpets, and flashing LED displays. But even if I am enjoying it, it will still wear on me, and after a few hours I'll likely need to put my Air Pods in.

I think the fact that even things I love and enjoy can take their toll indicates that sensory sensitivities are often needs and not wants; they are not mere preferences for having things a certain way. It is a genuine need to avoid or alter certain sensory experiences.

These sensory processing differences can significantly influence an individual's behavior and interactions with those around them. For example, being startled by loud noises in unfamiliar settings can lead to what appears to be an overreaction but is an automatic response to sensory overload.

I remember a few years ago, I had just had disc surgery in my neck and was walking between two cars in a parking lot when a large dog popped his head out only inches from my ear and released a huge bark. Startled, I did what I do every time such a thing happens: I reflexively covered my ears and ducked. It does not look cool or suave; it happens before I even think. It was one of those cases where the body reacts before my autistic brain even forms a plan of action, and in this case, it was tough on my neck!

When the sensory situation becomes overwhelming, simply trying to grin and bear it is possible, but it comes at the cost of an accumulation of angst and stress that can make a person on the spectrum more prone to a meltdown.

If you have frequent episodes where the sensory situation can be overwhelming, you are likely already aware of your sensory triggers. If not, you may wish to keep a journal to record where you were and what you were doing/experiencing at the time.

Having a safe space to retreat to, like your own bedroom, den, or office, can be enormously valuable, but odds are you won't

always be able to retreat there when you need to! This is another case where noise-canceling headphones can be useful. For other sensory issues, you might consider a fidget spinner, chewable jewelry, or any other accessory or tool that helps you manage stress. Techniques such as deep breathing, meditation, or mindfulness can help manage the stress response to sensory overload.

Gradually expose yourself to sensory stimuli that cause discomfort in a controlled manner to build tolerance over time. This is often referred to as "desensitization therapy" and you might wish to consider working with an occupational therapist specializing in sensory integration therapy. This therapy can help you cope with sensory sensitivities.

Choose clothing that is comfortable and does not trigger sensory discomfort—avoid tags, rough textures, or tight-fitting clothes as needed.

Sometimes, visiting the venue in advance during a quieter time can be beneficial and reduce anxiety. Inform friends, family, and colleagues about your sensory sensitivities so they can support you in creating a suitable environment.

# **Difficulty with Change**

People on the spectrum can put a great deal of energy into avoiding change, in part because change can be overstimulating and anxiety-inducing. Changes also reduce the individual's resilience; if not managed well, too much change

can lead to a meltdown. But why? Fundamentally, what causes this resistance to change amongst people on the spectrum?

First, we should note that change comes in at least three forms: change in oneself, environment, and circumstance. Each type of change can cause significant stress, and some big life changes involve more than one at once.

The resistance to seemingly trivial environmental changes – such as losing a favorite place to sit – might seem silly or immature. The amount of mental effort invested by the person on the spectrum in "getting it right" in the first place is often unseen and unaccounted for. It is not that they get unduly worked up over a trivial change – it would be more precise to say the change is far from trivial for them and that they are reacting to their internal perception of the level of angst, hurt, or inconvenience inflicted upon them by the change in question.

The sometimes-intense resistance to changes in one's circumstance can be challenging for the neurotypical to understand. The most classic case might be the need to avoid separation from a loved one; perhaps it's as simple as the fact that emotional connections are tough for individuals with autism to build in the first place. Again, anything that jeopardizes them places a considerable amount of their invested effort in jeopardy. If emotional connections are difficult for them to establish, it makes sense that they might be even more precious.

Change also involves risk, and in my experience, those on the spectrum are not necessarily risk-averse per se; they often need to understand – and internally accept and agree to intellectually - the tradeoffs involved. Whatever their decision ultimately is, they prefer it to be an informed one. It can be maddening for them to be asked to accept an increased risk with no attendant benefit. After all, why would you willingly do such a thing?

"We need to know what it is we're calling for here... I got to know what I stand to win."

- Proprietor, No Country for Old Men

Consider the simple case of introducing an exotic new food to your diet. If the thought of consuming a snail causes you anxiety, you must weigh that against the potential benefit of how great it might taste. Between you and me, I highly doubt that escargot is so delicious that the risk of eating snails is worth it. So, I'd prefer raspberry yogurt or Sour Patch Kids. But maybe I'm just funny that way.

Perhaps one of the most fundamental reasons that people on the spectrum fear change is that they may operate in a rule-based fashion in certain areas of their lives. Because so much of human interaction fails to "come naturally" for them, they must instead build up a practiced repertoire of responses to various situations. Building this repertoire can take a lifetime, and "change" means that some percentage of what you know – your whole rules system – is now invalid. But which parts, and how do they get fixed? And how will you know how to predict

what happens next and what to do next if your underlying assumptions are no longer valid?

And finally, change can also simply mean annoyance and irritation.

In all these cases, the common denominator is anxiety – anxiety over losing invested effort to a capricious external change, anxiety over the unknown of personal change and growth, anxiety over lost emotional connections, and anxiety over risk without reward.

Much about modern social life can require extra effort from people with autism. Many aspects of it, such as the interplay of who looks where during conversation or who speaks next and at what point, are learned one at a time. They become rules or the individual with autism follows guidelines that prescriptively to fit in and "behave" like everyone else. To deviate from them causes anxiety because it means that the person is now operating outside known norms and must improvise, which they know from experience that they are not traditionally good at. Hence, the individual with autism becomes very adept at - and even dependent upon - following a set of prescriptive rules and quickly spotting any exception that lay outside them, whether committed by themselves or others.

Plainly stated, many people with autism rigidly adhere to rituals, behaviors, and circumstances because the alternative – accepting change – may cause them intense anxiety. To move forward, the person with autism may need to learn to accept

the annoyance and irritation associated with any *important or* unavoidable change. Together with any neurotypical partners involved, they must then work to face the anxiety and work through it.

#### **Change and Accommodations**

I believe the first response to any autism spectrum characteristic that has become pathological is to attempt to alleviate the symptom by accommodating the need. That which cannot be practically or reasonably accommodated should be modified, and that which can be neither modified nor accommodated forms the surface of a disorder. However, the first approach should always be one of simple accommodation.

As an example of accommodations that friends might make for a friend on the spectrum, one classic aspect of the character Sheldon on the television show *The Big Bang Theory* is that he has a particular place where he prefers to sit. He acts as though it is a significant hardship for him to sit anywhere else. When pressed, he carefully explains the reasons for his selection:

- In the winter, that seat is close enough to the radiator to remain warm but not so close as to cause perspiration.
- In the summer, it is directly in the path of a nice cross breeze because it is ideally located between three windows.
- The angle with which it faces the television is not so direct as to discourage conversation yet not so wide as to cause a parallax distortion in the view.
- And so on...

You might think Sheldon likes to sit in the same place all the time merely just because people on the spectrum often work so hard to avoid any and all change. Still, Sheldon's reluctance to move to another spot is *not* territorial or a petty request based on *habit*. He has invested a lot of mental energy into determining the best place to sit, and he does not want to lose those benefits without good cause needlessly. Unlike a neurotypical person, he would be painfully aware of every moment spent sitting in a less optimal spot. In other words, the moment he is forced to sit elsewhere, all he can think of is the improper temperature, lack of a breeze, lousy angle to the television, and so on... which all could have been avoided if they had listened to simple reason!

Even more frustrating would be for Sheldon to lose his spot and to have said spot not put to good use by someone because they failed to appreciate the subtle benefits. If someone could use it better, he might gladly give it up, but at least mentally, it can be a big deal for such things to go to waste. If the spot is available, and it's imperative to him and a trivial matter for others to accommodate that, then why not?

In this episode, which is early in the series, they effectively push Sheldon as far as they can until he ultimately can bend no further. He has a "television" version of a meltdown—strained facial expressions and an inability to speak. Perhaps there's not a lot of dignity in that portrayal, but it *is* a comedy and not a documentary! It at least doffs its cap toward reality.

I, too, have a favorite spot to sit on my sofa and have many reasons why it's the optimal spot for me. In discussing this topic with my wife, I also learned that our friends and her parents (my in-laws) had similarly accommodated me by letting me have the same spot in their homes – and here I thought they were just conveniently always free! This is a prime example of an accommodation people had learned to make for me without knowing why. It's not that I'd ever ask someone to move if they took "my" spot; it's just that they usually save it for me because, after many years, they finally sense how important it can be, even if for reasons they do not comprehend.

#### Some Tough Love

My life would be a lot less stressful, and I would rarely have to worry about anxiety or its various manifestations if only people would always do things the way I wish they would. Because I have autism and a set of loving family and friends, they often do accommodate my rather special needs. Whether I am "entitled" to such accommodations, I choose not to speculate; I believe they are effective when given and appreciated when I receive them.

Naturally, when I receive such accommodations, it reduces the level of frustration and stress that I experience. I think it's easy, following a lifetime of it, to come to expect people can or should accommodate *everything* that causes you frustration. This is unrealistic and would be unfair to those around you. You must be able to delineate things that frustrate you because you are wired differently from those you simply like or prefer. Try to think of it as need vs. want, demanding only the

accommodations you genuinely need. Or, put another way, pick your battles. You cannot, and should not, win them all.

# **Literal Thinking**

I take most of what I hear literally as if intended exactly as spoken. I say "most" because I can recognize an *obvious* joke and usually tolerate it well, even when it's made at my expense. But the more subtle ones can throw me. I presume there's a payload attached to the slight, and that's often a mistake.

Why? Of course, it's possible that whoever said whatever was said intended it as a veiled insult. But the reality is that I simply don't know. The problems arise when it was meant playfully but received maliciously, a mistake that's all too familiar because I'm terrible at accurately inferring other people's intent.

As with many similar situations, when I'm left to guess a person's intent, I do so by placing myself in the other person's position. And the only scenario in which I would say what I just heard would be if I were trying to cause hurt. Because no one likes to be hurt, I'll likely be defensive at best and angry at worst. Either way, it's a trap because the odds are that it was meant playfully. My conclusion that it could *only* be intended to hurt would require me to accurately read the other person's mind, which I am terrible at.

# **Problems with Playful Banter**

It is well known amongst my friends and loved ones that I'm simply a poor target for playful barbs and jabs. Even when I can detect that the intent is sarcastic or playful, on some level, I internalize what is said at face value anyway.

Some enjoy having these playful jousts passed their way—I do not. Those commercials, shows, and movies where loving couples jokingly insult each other? They're actually stressful for me to watch, and I can't easily participate in them.



Figure 5 – She takes his barb as an insult

I'm usually even in on it – I get it's a joke. But it's as if my mind processes both interpretations, both the literal and the implied,

at the same time. And I then feel both feelings – both the sting of the literal insult\* and the comedy with which it was intended. For some reason, however, I can't get past always processing the literal interpretation, even if I do my best to overlook it. The fact that it's a conscious process makes it akin to mental masking and is far from foolproof.

I've been able to modulate this response but have not mastered it. Those around me have grown to appreciate and understand that I'm not the appropriate target for a pointed barb, no matter how hilarious it might be. At the same time, I do my best to continue to look past the literal meaning and appreciate the intent... but I'm not good at it.

# **Difficulty with Empathy**

Empathy, in its simplest terms, is the capacity to comprehend and resonate with the feelings of others. Understanding empathy in individuals with autism requires dividing empathy into two separate abilities: first, the capacity to discern and comprehend the emotions that another individual is experiencing, and second, the capacity and readiness to partake in those emotions and act accordingly.

Individuals on the spectrum often have unique ways of processing and communicating emotions, which can make them feel different or even flawed compared to neurotypical individuals. This difference can cause them anxiety, and their

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<sup>\*</sup> A phenomenon I have dubbed the "Ha-ha.... ouch" moment.

parents as well, due to the fear that their ability to love and care — traits closely linked with empathy — might not be conventional.

Exploring empathy in people on the spectrum involves looking beyond societal stereotypes and understanding that being different does not equate to being less empathetic. Individuals on the autism spectrum may process and express emotions differently, but they still feel a wide array of emotions and can be caring and loving. The primary difference lies in their capacity to recognize, understand, and respond to complex emotional states in others, which can sometimes be challenging for them.



I'm confident that I have strong empathy, but with two caveats. First, I assume that the other person will feel as I might if I were

in their position. Second, I am sometimes entirely oblivious to more subtle emotional needs if they are not communicated in a way I can perceive and understand.

For example, I am reasonably tall at six foot two inches. My oldest son had long wanted to reach six feet but fell just shy of that mark when he'd stopped growing in his late teens. But then, at his annual physical in his early 20s, he was measured at just over six feet. When he came home and told me of this, my first thought was not that he'd reached an important personal milestone. I thought, "How is that possible at that age?" My response was to suggest that when our doctor recently moved offices, they likely mounted the measuring device to the wall at a subtly different height, enough just to push him over the edge of six feet.

Naturally, he left deflated because I did not understand or appreciate, and thus could not empathize with, his desire to be six feet tall. Next month, when it was time for my own physical, I measured a quarter inch shorter than I had before—so it wasn't the measuring device! When I later told him, he beamed.

The critical takeaway is that *I did not perceive this need and then ignore it* – I simply did not know better. When presented with a surprising situation, I looked for the most logical explanation rather than thinking about the emotional payload it carried for him. Had I *known* his feelings and what was important to him then, I would have fully empathized with his situation. But I did not.

These difficulties with intuiting and responding to others' emotional states are often mistaken as a lack of empathy. However, it's important to note that it's not about a lack of emotional depth but rather a difference in emotional communication and processing. Those on the spectrum often must relate others' emotions to their past experiences to fully comprehend and empathize with them. This differs from the emotional intuition that neurotypical individuals usually display, enabling them to understand and co-experience emotions with others, even if they have not personally experienced them.

However, relating emotions to personal experiences may not always provide a complete understanding, especially when the circumstances of others' experiences differ significantly from their own. As a result, individuals on the spectrum may occasionally struggle to empathize with another person's emotional state fully. Yet, it does not mean they do not care; instead, it reflects the distinct way their minds process emotions.

Such individuals might also struggle with appropriately responding to others' emotional states. For instance, they may unintentionally react to others' grief in a way that seems inappropriate to neurotypical individuals, not because they are not moved but because they relate the situation to their own emotional experience and response.

My wife lost both of her parents in the same month to unrelated medical causes, which was a traumatic time for her and our family. I had lost my own father almost twenty years ago, so I understood the pain. Except *my* pain had the distinction of having had twenty years to heal, whereas hers was fresh and visceral. As soon as I started worrying more about how she was feeling rather than how I would feel in her position, I could be of much more use.

The differences in empathy between autistic and neurotypical individuals could be linked to differences in their mirror neuron systems, which are believed to play a significant role in understanding others' emotions. In neurotypical individuals, this system helps intuit what another person is feeling. In contrast, in autistic individuals, this system works differently, and they may have to consciously process what the other person is feeling, relying heavily on past experiences to predict emotional responses.

This disconnect in empathy appears to exist in both directions between the neurotypical and those with autism. I attribute this phenomenon to both sides being unable to intuit and understand the emotional states of the other fully. I can empathize quickly and deeply with other autistic individuals when they relate their stories, much more so than when neurotypical people do. And that is because I understand, or believe I do, more precisely how they felt when they had the experience they described. When someone is on the spectrum, inferring the emotions behind the circumstance seems easier.

Just as I tend not to understand the emotional state of a neurotypical person intuitively, I've perceived by now that they usually do not understand my own, either. The disconnect is one of intuition and understanding, however, and not ability: once communication is established clearly enough that both parties understand one another's feelings, empathy can flow more freely.

To reiterate the point, individuals with autism do possess empathy, but it may present differently due to their unique emotional processing. They may struggle to intuit others' emotions without explicit cues and must draw from their own experiences to fully understand others' emotional states. However, their ability to love, care, and empathize should not be underestimated or undervalued. Both those on the autism spectrum and those around them need to understand and accept these differences, fostering a more inclusive and understanding society.

#### **Central Coherence**

Central coherence refers to one's ability to process information in context, synthesizing details to perceive overall meaning and patterns. This concept is often discussed in contrast to the cognitive style seen in many individuals on the autism spectrum, who may exhibit a detail-focused cognitive style sometimes referred to as "weak central coherence."

Central coherence involves the capacity to integrate details into a broader understanding or global view. It's about seeing the forest, not just the trees, enabling individuals to grasp the big picture in any given situation.

People with strong central coherence are adept at using context to make sense of specific elements. This skill is beneficial for understanding nuances in language, such as idioms, metaphors, or jokes, all of which require an appreciation of context beyond the literal meanings of words.

Central coherence allows for more flexible thinking and problem-solving. It helps in scenarios where it's necessary to reframe or reconsider information in light of new contexts or requirements.

While central coherence emphasizes a holistic approach, it doesn't exclude the importance of details. Instead, it involves a balance where both detailed and global processing inform one's understanding and actions.

Individuals on the autism spectrum often exhibit what is described as weak central coherence. This does not necessarily mean a deficit but rather a different cognitive style characterized by several potential strengths. For example, many autistic individuals have a remarkable ability to focus on details. They may excel in tasks that require detailed attention, such as spotting discrepancies in data, intricate artwork, or remembering specific facts.

The flip side can be difficulties in integrating these details into a broader context. This might make it hard to follow narratives or conversations where the integration of various elements is needed to understand the overall meaning.

Without strong central coherence, everyday expressions or abstract concepts can be misunderstood, and instructions or narratives can be interpreted more literally. To deal with these challenges, here are some tips that may be helpful.

Prioritize tasks by breaking down larger or daunting tasks into smaller, manageable steps. Sort them based on their importance and urgency.

Try to reduce distractions in the environment by finding a quiet workspace, turning off notifications on electronic devices, and wearing noise-canceling headphones.

Focus on one task at a time: Instead of trying to multitask, focus on one task and give it your full attention until it is completed. If that is not practical, work on one task until another becomes more important or you've reached a logical milestone with the first

It might sound silly initially, but visual aids like checklists, calendars, and reminders can be valuable tools to help individuals with this ASC manage their time and keep track of their tasks. My highest priority reminder – a yellow sticky note on my monitor edge – is reserved for things I must do ASAP, and I try to limit it to one or two at most so that I always take them seriously when present.

In our craft room, my wife maintains a color-coded whiteboard calendar that shows everyone's commitments and appointments for this month and the next. I process things well visually, so I can internalize my upcoming schedule once I've seen the board a few times. Soon enough, I'll be able to picture and remember that I have an appointment next Thursday. I

won't know the exact time, but I know I'm free until then, and it helps me compartmentalize my time.

If my wife is going to be out of town, on the fridge, she will post a list of the family's to-do items for the day. She highlights my items in yellow, like picking up one kid from their soccer game and taking another to their team photos. That way, I can see my day at a glance.

Naturally, it helps a great deal that I have an excellent partner in my wife who helps me with executive function, which is a definite weak spot for me.

Seeking support from a therapist or a coach who works with individuals on the autism spectrum can help them learn new strategies and coping techniques to manage multitasking challenges.

Monotropic thinking is one of the core characteristics of those on the autism spectrum, and it impacts the lives of those who find themselves on it to widely varying degrees.

# Perseverance, Perseveration, and Success

In an older episode of the TV drama "The Good Doctor," the main protagonist – a surgeon with autism – has been trying to work through a particularly vexing case. The patient is in dire straits for reasons that he cannot yet figure out, and he's afraid that the patient will die if he doesn't soon solve it. He spends hours obsessively thinking about it until finally, in the middle

of the night, he needs more information. He chooses to drive to the patient's home and wake their family to question them about some aspect of the patient's history, but the family member who answers the door protests that it's too late at night – he should come back tomorrow.

He cannot, he explains, for he will perseverate all night.

When referred to in the context of autism, perseveration embodies the intense and sometimes compulsive focus or repetition of a thought or idea. This characteristic, deeply rooted in the cognitive and behavioral aspects of individuals with autism, can be a powerful attribute if channeled appropriately.

> "I'm convinced that about half of what separates the successful entrepreneurs from the non-successful ones is pure perseverance."

> > - Steve Jobs

Individuals with autism may engage in perseveration in various forms—repetitive speech, enduring pursuit of interests, or relentless perfection of a craft or skill. The results can be remarkable when these behaviors are directed towards a productive goal. The ability to delve deeply into a subject can lead to exceptional expertise, often surpassing that of neurotypical individuals. It is not uncommon for people on the spectrum to become experts in their field, be it technology, art, music, or any other discipline they are passionate about. This

relentless drive can lead to innovation, the creation of detailed works, or the acquisition of encyclopedic knowledge in specific areas.

Moreover, the unwavering focus associated with perseveration may contribute to developing unique problem-solving approaches. An individual with autism's perspective can bring forth solutions or ideas that might elude others who have a broader but less intense focus. In employment, those who persevere can be invaluable assets, bringing dedication and thoroughness to their roles.

On the flip side, this trait can be limiting when the focus becomes too narrow, preventing individuals from adapting to change or engaging in social interactions effectively. In such cases, it is crucial to strike a balance—encouraging the individual to leverage their innate strengths while fostering flexibility and a range of interests.

In essence, the dichotomy of perseveration as both a gift and a challenge encapsulates the complex nature of autism. It's a nuanced attribute that can fuel one's ascent to greatness in a chosen domain while simultaneously posing interpersonal and adaptive challenges. The key lies in harnessing this intense focus, guiding it toward beneficial pursuits without allowing it to become an obstacle to one's overall well-being and personal growth.

When perseveration is unwanted, however, it can be a significant burden. If not managed well, perseveration can be a sure path to a meltdown, particularly in cases where it forms a

"perfect storm," such as a significant change in one's life that negatively impacts one's routines and normal.

# Interoception and Emotional Regulation

Emotional regulation refers to the processes by which individuals influence and control which emotions they have, when they have them, and how they experience and express these emotions. It is a crucial aspect of "emotional intelligence" that involves understanding and managing one's emotions effectively.

For people on the autism spectrum, achieving effective emotional regulation can often be challenging. This difficulty may be due to differences in processing social-emotional information, heightened sensitivity to sensory stimuli, or difficulties in identifying and expressing emotions. However, several strategies can help improve emotional regulation.

It can often be improved by rethinking a situation to alter its emotional impact (cognitive reappraisal). Simply looking at things a different way can help, or you can try to gauge is importance on a more cosmic scale by adopting a broader perspective.

Although not a good long-term strategy, sometimes willfully suppressing your emotions, or at least their expression, can help. To the extent you can rein things in, there are certainly times and places where you might wish to do so.

Learning to better recognize and label one's own emotions and the emotions of others can be a crucial step. This can involve therapy sessions focusing on understanding facial expressions, tone of voice, and other emotional information cues.

Cognitive Behavioral Therapy (CBT) can help modify the thought patterns that contribute to emotional distress. It's effective in helping individuals on the spectrum develop more adaptive responses to stressful situations. The beauty of CBT is that when it works for you, and you're *trying* to achieve some particular behavior – it starts to come naturally.

Practices such as mindfulness, meditation, deep breathing exercises, or progressive muscle relaxation can help manage anxiety and reduce emotional volatility. Standard stress reduction techniques are also generally useful if practiced. Tools like apps designed to teach emotional regulation or provide calming activities can also be beneficial.

By employing these strategies, individuals on the autism spectrum can work towards better emotional regulation, which can improve overall well-being and functioning in daily life.

Interoception, the sense of being aware of the physiological condition of the body, plays a crucial role in understanding and managing emotions, especially for individuals on the autism spectrum. Here's how someone on the spectrum can use interoception to better manage emotions:

Develop a greater awareness of bodily sensations. You can't begin to control things you aren't even aware of, so the first step

is to become more keenly aware of internal bodily sensations, such as heartbeat, hunger, thirst, and the feeling of breath in the lungs. Learn to recognize when you start to feel a rush of adrenaline and use that as a signal that it's time to pull back.

Learn to link sensations to emotions. Learning to connect what they feel physically with their emotions can help individuals on the spectrum identify what emotion they are experiencing. For example, a fast heartbeat or tightness in the chest might be associated with anxiety, but you might be able to catch it before it becomes serious if you're aware of the easy sensations.

# Prosopagnosia

Prosopagnosia, often referred to as "face blindness", is a neurological disorder characterized by the inability to recognize faces. In milder forms, like my own, it makes it difficult for the person to distinguish between similar-looking individuals.

In individuals with autism, prosopagnosia can manifest as part of broader challenges with social communication and sensory processing. Put simply, it makes it harder to recognize who a person is from just a visual image.

Individuals with autism who experience severe prosopagnosia may struggle to recognize even those faces they see regularly, such as family members or close friends. This can lead to social awkwardness or misunderstandings. I experience mild prosopagnosia. I cannot tell you how many times I've introduced myself to someone only to have them be surprised or hurt that I did not remember them. In most cases, I know fully well who the person is once I'm told (or once I figure it out on my own with time).



Figure 6 – A simulation of how eight similar but different faces might appear to someone with prosopagnosia. There is an increased reliance on identifying glasses, facial hair, skin tone, etc., over facial features.

It's not that you cannot see the facial features of the person in question, but rather, it's that you cannot see how they differ from others and distinguish the person. In my case, every heavyset middle-aged man with a beard that I don't know well

looks approximately the same to me. I group people into buckets that way, and sometimes, I cannot tell which person they are, only what bucket they fit into. I fit into the bucket illustrated above, and to be honest, I could be several of them myself!

These "buckets" are usually made up of collections of physical attributes, like height, weight, hair color, facial hair, eyeglasses, and so on.

As a child, I found it particularly troubling if a loved one got a new hairstyle or eyeglasses, as to me, it almost made them a completely new person!

I recently spent a solid 30 minutes wandering up and down the same rows of slot machines in a casino, trying to find where my wife was seated. I walked past her an unknown number of times because she had curled her hair for the evening, and I simply could not locate her in my scanning.

# Remembering Who's Who

My lack of facial recognition is compounded by my rather profound inability to remember people's names. While it's not clear to me that this is a common trait on the spectrum, I believe my autism is the likely cause. Rather than remembering people by their social relationship to me, I tend to remember people by what they know and what they can do.

Put another way, I'm unlikely to remember that Tom is Sally's cousin from Alabama, but if you tell me that Tom is an electrician, that I *will* remember.

One possible explanation is that individuals on the spectrum may process social information differently than neurotypical individuals. They might find it easier to recall concrete information, like their occupation or a specific skill they have, rather than abstract social connections.

This might be because occupations and skills are more directly observable and related to tangible outcomes or actions. These kinds of information can often be logically organized and are more predictable, which can be easier to remember than the complexities of social relationships, which are more abstract and can change over time. People on the spectrum love to systematize things; perhaps that's easier to do with vocations than relationships.

Many people on the spectrum have intense interests in specific topics, and they might be more likely to remember information related to these interests. If someone's job or skill aligns with one of these interests, it would naturally be more memorable to the individual.

#### **Meltdowns**

Meltdowns suck. Ask me how I know.

A meltdown occurs when an individual is pushed past their tolerance for sensory input, circumstance, or emotional challenge. It can result in an overwhelming response that manifests through a range of behaviors, from withdrawal and silence to verbal outbursts and physical expressions of distress. Once crossed, this threshold signifies a point where the

individual's usual coping mechanisms cannot effectively handle the sensory overload, emotional intensity, or complexity of the situation at hand. It is typical for individuals with autism to struggle with emotional regulation at the best of times, but during a meltdown, they largely lose control of at least one aspect of their behavior.

There is no value in a meltdown; I would never choose to have one nor allow myself to slip into one if I could avoid it. When having a meltdown, I appear angry, I am less articulate, less likely to convince, and less likely to get the actual outcome I prefer or need. Meltdowns are embarrassing, damaging to relationships, frighten children, take time to recover from, and weaken my resilience toward future episodes. And yet, they may be somewhat unavoidable.

Although anyone can have a meltdown, they are much more common among individuals on the spectrum as they appear to reach their tolerance limits sooner.

"On the brink of self-destruction
Widespread panic
Broken glass inside my head...
There's a plague inside of me
Eating at my disposition"
- Billie Joe Armstrong, Green Day

A meltdown, deeply rooted in the individual experiences of those on the autism spectrum, can take various forms and be expressed through a wide array of behaviors. Each is reflective of the person's attempt to navigate (or escape) overwhelming sensory input, emotional distress, or both. These manifestations can be broadly categorized into *externalized* and *internalized* behaviors, although the distinction is not always clear-cut, as individuals may exhibit characteristics of both depending on the situation and their coping mechanisms.

Verbal outbursts, including shouting, screaming, cursing, or crying, are common. The individual may express their distress through words or sounds that are louder and more intense than normal communication, sometimes involving phrases or sentences that are repeated multiple times. During a meltdown, the individual's judgment may be impaired, and they may say provocative things just to elicit a response or to cause upset, regretting it later.

Those experiencing a meltdown may act out physically. This can range from pacing and rocking to more intense physical expressions like hitting and throwing objects or self-injurious behaviors such as head-slapping or biting oneself. These actions are not intended to cause harm to others but are manifestations of the extreme stress the individual is experiencing.

Understanding neurodiversity helps us comprehend behaviors that might otherwise perplex us. Yet this understanding is not a carte blanche. While an individual might display physical reactions during a meltdown, these actions are not beyond scrutiny, especially if they breach personal boundaries. In these heightened instances, it is imperative to prioritize safety and professional guidance. Such measures ensure both the

individual's well-being and the integrity of the supportive environment around them.

My sense is that in this state, the individual with autism desperately wants to communicate the depth of their emotions but cannot express them conventionally. Sometimes, acting out may be a crude mechanism for showing others just how important the matter feels to them in the moment.

I wish I had great advice for you on how to modulate your behavior during a meltdown or advice for loved ones on how to help an autistic individual stay in emotional control during a meltdown. I wish I did, but I do not.

That is because even in my own case, when having a meltdown, I act in ways and say things that I wish I did not. Before my autism diagnosis, I did not know what these "episodes" were and assumed they were panic attacks. As time went by, I started to wonder if they were more serious than that.

A meltdown can be likened to an escalation of the flight response. When the situation cannot be escaped, and there is no option, the individual succumbs to what feels like insurmountable stress resulting from an unacceptable situation.

Once I had my diagnosis in hand, though, I better recognized my meltdowns for what they were and initially spent a long time wishing, hoping, and working on it so that the next time I had a meltdown, I would be a gentleman. That proved largely fruitless.

The frontal cortex, which is crucial for high-level functions such as reasoning, decision-making, and emotional regulation, may become less effective during a meltdown. Stress and emotional distress can impair the frontal cortex's ability to function optimally, making it harder to use reasoning and problem-solving skills. It can feel like the frontal cortex "shuts down".

Under the extreme stress of a meltdown, there's an increased activation of the more primal brain areas, such as the amygdala, which plays a role in emotional processing and the fight-or-flight response. This shift can lead to a more instinctual, survival-oriented behavior, which is less mediated by the higher brain functions of the frontal cortex.

Since controlling my emotions during a meltdown proved so difficult, I switched my focus to *preventing* the meltdown. Candidly, that's impossible for some people. For certain people on the spectrum, their sensitivities might be so high that meltdowns are, at least to some extent, a fact of life. I am confident that the frequency and perhaps duration can be substantially reduced with a cooperative effort from the individual on the spectrum and the support network around them. Meltdowns are destructive enough both for the individual and those around them that any reduction is a positive step.

It reminds me of the ancient joke:

Q: How many psychiatrists does it take to change a lightbulb?

# A: Just one, but the lightbulb must want to change! -Ancient Dad Joke

Hackneyed or not, it's a valid point: the first step to reducing meltdowns is for the individual who experiences them to *want* to reduce them both for their own sake and for the sake of the loved ones around them.

During a meltdown, there is an intense feeling of righteousness related to whatever the issue is. The person having the meltdown will be morally convinced that their position is the correct one, that their rights are inviolable, and that the situation could largely be resolved if the other person involved would simply relent or utter some specific sentiment, thereby fixing the whole thing. All of which goes back to the primary point: modulating behavior during the meltdown is hard, but reducing the frequency of meltdowns is eminently doable for most.

Managing meltdowns for individuals with autism can be challenging, but there are effective strategies that can help reduce their frequency and ideally, even their severity. Here are some steps that can be helpful:

First, you should attempt to identify the most common triggers. Understanding what triggers meltdowns is crucial. Triggers can vary widely but often include overwhelming sensory environments, unexpected changes in routine, or emotional stress. Keeping a diary to note when meltdowns occur and what happened immediately before can help identify patterns.

I kept a simple journal for a few years where I would score my overall emotional state for the day on a 0-5 scale, then "star" the dates where I experienced a meltdown. It became apparent that meltdowns could often come after a run of otherwise hard days.

Next, you should learn to recognize the "flooded" state, which also known as "the rumble stage". This is the point where the individual becomes overwhelmed by emotion but has not yet lost control of their behavior. It constitutes your last offramp before a full meltdown, and if you can catch yourself and modulate (or even suppress) your emotions for a moment, you might be able to save yourself form spiraling down further.

It may help to create a more predictable environment. Individuals with autism often benefit from routine and predictability. Try to establish a consistent daily schedule. If changes need to occur, prepare the individual in advance as much as possible. If changes are a major stressor that leads to meltdowns, taking steps to minimize such stress can only benefit the cause.

Skills such as deep breathing, counting to ten, or retreating to a quiet space can help manage emotions. These should be taught during calm periods so that the individual can learn to apply them when they start feeling overwhelmed. It's important not to withdraw simply to ruminate or perseverate over the real or imagined aggrievement: that will almost assuredly make it worse. Use the time to de-escalate your mood as much as possible.

Many with autism find visual aids like picture schedules, timers, and warning cards helpful in understanding what to expect throughout the day, which can reduce anxiety and help prevent meltdowns.

Quite a few emotional outbursts are rooted in sensory sensitivities. Working with an occupational therapist to develop sensory integration strategies, such as using weighted vests, noise-canceling headphones, or tactile toys can be beneficial. Even if each step you take provides only minor benefit, those benefits can be cumulative, so be sure to do *everything* that helps, even if only a little.

Difficulty in communication can lead to frustration and meltdowns. For youth on the spectrum, speech therapy can help improve communication skills. Additionally, for those with communication difficulties, teaching and using alternative communication methods such as sign language or picture exchange communication systems (PECS) can be helpful. Quite often the trigger for a meltdown can be found in the relationship between the individual with autism and a loved one, and that relationship could clearly benefit from clearer communication on *both* sides of the equation. Sometimes, clearing up or resolving a fundamental disagreement or misunderstanding can prevent *many* future meltdowns.

Ensure that family members, teachers, and caregivers understand the individual's triggers and know how to use calming techniques and strategies effectively. Training and workshops on autism can be very beneficial if they are conducted by knowledgeable groups or individuals.

Some individuals with autism may have food sensitivities that can affect their behavior, so a balanced diet tailored to their needs can be important.

Getting professional support can be a big deal. Regular consultations with professionals who specialize in autism, such as psychologists, psychiatrists, or behavioral therapists, can provide guidance tailored to individual needs and develop specific strategies to manage and reduce meltdowns.

In some cases, medication may be prescribed to help manage anxiety, depression, or other symptoms that could contribute to meltdowns. This should be considered carefully with healthcare providers. Both Abilify (aripiprazole) and Risperdal (risperidone) have been approved for the treatment of the irritability associated with autism.

And finally, it pains me to say it, given how much I personally hate exercising, but regular physical activity can truly help manage stress and improve overall well-being, resulting in fewer meltdowns.

# Frustration, Anxiety, and Depression

A life's journey on the spectrum is often a complex interplay of experiences and emotions. While it can foster resilience and grant unique perspectives, it can usher in stress and frustration. These feelings can stem from numerous sources, particularly when confronting the myriad daily challenges and misunderstandings that accompany life on the spectrum. A life

on the spectrum is one spent managing such frustrations. The escalation of these stressors can precipitate anxiety and depression for those on the spectrum.

In my own case, if I were to speculate, I seem to produce a baseline level of some brain chemical (perhaps serotonin) at a constant rate that lends the internal feeling of resilience and that all will be well. The rate at which life depletes this reserve can vary, depending on the amount of angst, stress, and frustration in my life over time. In the short term, acute instances of extreme stress can precipitate a meltdown. Over the longer term, chronic stress can precipitate depression.

Since I do not seem to be able to impact the baseline recovery rate, my two options then are to reduce stress or seek medical intervention. And sometimes, like with a death in the family or other severe psychological trauma, reducing stress may not be a practical option.

Numerous helpful (and even lifesaving) interventions are available through your family doctor and the specialists to whom they might refer you. Regardless of any preconceived notions or stigma you might associate with therapy, I encourage you to explore all the available options.

Following my diagnosis and mid-way through the disruption of a pandemic, I sought out counseling to help me understand both where my own blind spots were and where my assumptions about other people's mental models were lacking or flat-out wrong. The process was incredibly instructive and useful. After about nine months, I felt I had learned all I was

going to learn through it, which is just a reminder that therapy can be something you finish rather than something you do forever.



I also experimented with about six months of neurofeedback, wherein I would watch documentaries on Netflix twice a week while connected to a brain scanner. The scanner would assess my level of focus and attention, rewarding it with a

brighter and more saturated image. If my attention wandered, the image shrank, the colors faded, and the audio degraded. This served as a feedback tool to train my attention. Although one of the benefits touted by its advocates is emotional regulation, I was still surprised when I seemed to derive benefit in that regard, but it was measurable and real. I don't know how it works outside the attention cycle, and with a sample size of one, I can't earnestly explain why, but "it worked for me."

Other primary factors associated with the spectrum can magnify and amplify the risks for anxiety and depression, such as sustained periods of being subjected to sensory inputs that the individual finds troublesome. Overstimulation – be it bright lights, loud noises, or unexpected touch – can exceed their threshold for sensory input, leading to an overwhelming

sense of distress known as sensory overload, which often triggers the "flight" mechanism. This persistent state of discomfort can act as a catalyst for anxiety, as one may become apprehensive about encountering such stress-inducing environments.

Navigating the subtleties of social interactions also poses a significant challenge for many on the spectrum. Misunderstandings and social faux pas can lead to feelings of isolation and loneliness. There's often a profound sense of being "out of sync" with others, which can erode self-esteem and contribute to social anxiety and depression.

The inclination towards routine and predictability is another characteristic of the spectrum. Disruptions, even minor ones, can be profoundly disquieting, eliciting a stress response. When routines are disrupted without warning, it can trigger an acute stress reaction, breeding anxiety over potential future changes.

Similarly, tasks that require planning, organization, and multitasking can be daunting due to potential executive functioning impairments. The ensuing frustration from these challenges can engender feelings of inadequacy and contribute to a pervasive anxiety about one's ability to manage life's demands.

Expressing emotions and needs and interpreting others' communications can be daunting for someone on the spectrum. This barrier can lead to misunderstandings and conflict, which, over time, can sow the seeds of anxiety and a persistent fear of miscommunication.

Keep these major areas in mind as you build a map of your stressors. Being aware of these is often essential to correctly identifying where you can make the most dramatic improvements.

#### Self-Harm

The suicide rate among individuals with ASD is commonly reported to be higher than that of the general population. However, it's essential to note that the exact figures can vary depending on factors such as age, gender, level of functioning, and co-occurring conditions.

Several studies have indicated an increased risk of self-harm, including suicide, among individuals with autism compared to the general population. Factors such as social difficulties, bullying, isolation, depression, anxiety, and challenges in accessing appropriate mental health support can contribute to this heightened risk.

The exact suicide rate among individuals with autism is challenging to determine precisely due to factors such as underreporting, misdiagnosis, and variations in study methodologies. However, research suggests that the risk of suicidal ideation, attempts, and completion is markedly higher among individuals with ASD compared to neurotypical individuals.

Given the increased risk, it's crucial for individuals with autism to receive appropriate support, including mental health services tailored to their needs. Additionally, raising awareness about the mental health challenges faced by individuals with ASD and addressing stigma can help improve outcomes and reduce the risk of suicide.

It's critical that you reach out for professional help if you start to consider self-harm. In the United States, help is a close as dialing 988. Suicide means murdering someone your family loves, and it's a permanent solution to a temporary problem.

I suspect that people on the spectrum can fall prey to a monotropic fallacy: when you combine the single-minded thought process of autism with its poor central coherence, you get a person who sometimes feels that they cannot tolerate their "new normal". They can focus only on the problem and lose sight of the broader context of their life. Worse, they may falsely perceive every painful setback as being eternally unacceptable and insurmountable. These fallacies are made easier to believe by the way the autistic mind works and must be rejected.

It's important that you strive to recognize these failures in your own thought process. If you experience them, I strongly encourage you to contact a qualified professional promptly. Nothing is more important.

#### **Travel**

I love to travel but have always found it challenging in direct proportion to how complicated the journey is and how far it takes me out of my comfortable routines. Throughout my adult life, the initial days of any trip, be they for leisure or business, invariably stir a whirlwind of anxiety. In a few instances, this has escalated to panic, threatening to spiral into a full meltdown. Such experiences underscore the challenges that travel presents for some on the spectrum, turning what should be a joyful exploration into a test of endurance.

Travel can bring a host of challenges, as it is fraught with several aspects that can trigger anxiety and discomfort. Transitions can be hard for anyone on the spectrum, and a travel day is generally one of almost constant transition. Sometimes, you need to take a bus to catch a plane and then a shuttle to get to a boat, and it can be a bit much, particularly when multiple connections are involved or if flights are delayed or canceled.

This section of the book was added very late, after proofing had already begun, largely because I had almost forgotten about this aspect of my autism. That is, until this very morning when I was sitting in the St. Regis hotel in Rome with my wife, eating breakfast the morning after arriving. Aside from jet lag, things could barely have been more perfect, but I was on the edge of tears for no discernable reason.

The travel day had been long, and while everything went surprisingly well and according to plan, I still found it arduous. Getting from Seattle to Rome requires airport transfers, flight connections, layovers, taxis, and any number of other steps. I am in a novel environment, away from my "safe space," at the mercy of random chance, the capricious nature of various airline, security, and border personnel, and so on. It's a full day and not the kind of day I relish.

I've worked on this issue for years and have made significant strides, but as I sat looking at my breakfast, I could feel a certain angst rising. In years past, this would have escalated to at least serious anxiety, if not some panic. My self-awareness allowed me to recognize what was happening and "catch" it in the moment. Emotionally, I was spiraling down, but intellectually, I knew that all was well, and I was able to navigate the situation and recover quickly.

In years past, this would not have been true, and it likely would have required me to retreat to my hotel room and, in a few instances, experience a meltdown. Before my diagnosis, my family had, of course, noticed the difficulties I had with travel, but we all assumed it was simply some agoraphobia that I would have to work through.

I sense that it is not agoraphobia but rather an aspect of my autism. With its inherent unpredictability and need for constant adaptation, travel can significantly impact individuals on the autism spectrum, whose experiences are often characterized by a preference for routine and predictability. The sensory inputs and demands of a travel day—crowded airports, fluctuating schedules, unfamiliar settings, and continuous transitions—are not merely inconveniences; they can be profoundly disorienting and distressing.

There are several reasons why travel can be particularly challenging for those with autism. Travel environments are typically bustling with overwhelming noise, activity, and crowds. This sensory overload can be intensely uncomfortable and even painful for someone with sensory sensitivities, which

are common with autism. Travel is also full of the inconveniences of standing in line, waiting for luggage, delayed flights, uncomfortable seats, and any number of small factors that can conspire to make the day demanding.

Individuals with autism often rely on predictable routines to navigate daily life comfortably. Travel disrupts these routines extensively, introducing a degree of unpredictability that can induce anxiety and stress. Almost every routine you have will be disrupted to some extent during travel.

Traveling can create a sense of insecurity and discomfort, as it involves new environments, unfamiliar people, and unexpected changes. The unpredictability associated with travel—even including unfamiliar foods—can exacerbate this anxiety.

Travel often requires communicating with strangers. Navigating social interactions, understanding announcements in noisy places, and asking for help can be particularly challenging for those with autism, who may struggle with verbal communication and social cues. While a neurotypical person might get lost in a large airport and simply ask a staff member for directions, a person with autism might avoid asking in order to spare themselves the social challenges involved in asking a stranger for help.

Travel can also cause physical discomfort. Long periods of sitting and standing in lines and the physical act of traveling, like flying or riding in a car, can be uncomfortable and exacerbate stress. Airline and bus seats are generally not the

first choice as a comfortable place to spend half a day. It all adds up.

The cumulative effect of these factors can lead to heightened anxiety on the first few days of a trip as I adjust to the new environment and disruptions to my normal routine. In the earlier years, even if all went well, once we had finally reached our destination, such as our hotel room, the one thing I needed most was to establish a new "home" that would serve as a surrogate safe space, get organized, and then rest from the strain of the day. Contrast that with the neurotypical family members, who were generally eager and ready to head straight out and start socializing as soon as they could drop their bags off! By comparison, I was something of a wet blanket that first day, and none of us understood why.

Today, we know better and that everyone's interests will be best served by my taking time to decompress after travel, even if it means the others head straight out without me. Once I've set up my laptop and hacked the hotel thermostat (I like it cold!) I might simply "veg" for a few hours and then join the others.

This downtime is essential for me, and because we usually ensure I get this accommodation now, travel is much easier. The trip to Rome was a full day and half without comfortable downtime or restful sleep, and it proved to be just a bit too much for me. Awareness of what was happening was the only saving grace.

I'm much better off once I've established a new home base. And sometimes, to the occasional consternation of my family, I like to hang out there and do things such as write this chapter rather than lounging at the beach or pool. Of course, I still participate and spend time with the family, but it took years for all of us to understand that sometimes I'm happier doing my own thing, at least for part of the day. While we're all on the same page now, it could create problems in earlier years because the family wasn't aware that I was having fun – just my own kind. And I learned to grant that lying in the sun on a lawn chair in oppressive heat is a perfectly fine way to spend a day – for other people.

By now, we've achieved a guilt-free compromise system in which I might have breakfast with the family, check out a tourist excursion with them, have lunch... and then be on my own for several hours to do the things that I like to do with my leisure time while they frolic on the beach, or whatever neurotypical people like to do. It was many years before both sides understood that the other was having fun! I still make it my responsibility to do everything I can with them in exchange for the grace they extend me in letting me do my own thing for part of the day.

If you experience travel stress that is exacerbated by the symptoms of autism, there are a number of things you can do to help mitigate the stress of travel. The first step is to analyze what aspects of travel are the most problematic for you. Recognizing these triggers and planning strategies to manage them—such as scheduling downtime, using noise-canceling headphones, and maintaining elements of your regular routine—can help mitigate the impact and make travel more manageable. Certain airports have also installed sensory

isolation booths where you can get a temporary respite from the noise and chaos.

Simple things, like arriving at the airport or bus terminal early, can make a big difference by reducing or eliminating some of the urgency and the anxiety over missing a departure or connection. Traveling with carry-on baggage only can simplify the experience and help avoid the inconvenience and distress of losing your luggage.

If you travel with friends or family, a key aspect of the solution is explaining to your companions what you need and why. Be candid, not demanding, and try to minimize the impact of whatever accommodations you need on the others in your party, at least to the extent you can.

As hard as the first day or two can be, once settled into the new routine, I genuinely enjoy myself and the journey and find myself largely stress-free... but it was not always so! Travel is rewarding on many levels, so if you experience these types of issues, I encourage you to make the needed tweaks and changes to how you approach it, because the alternative – to avoid such travel – would be a shame.

#### When You're Not at Your Best

All this advice is well and good when you're "on" and aware and thinking about it, but what about those days when you're hungry, angry, tired, down, or irritable?

I can be a bear when I'm sick. These days, I'm self-aware enough to make a concerted effort to be kind to those who care for me, but it wasn't always so.

Reflecting on it, I wondered why that was. I find it highly annoying when people don't do or say the right thing, make mistakes that inconvenience me, or create additional work for me. On good days, I overlook it. But on days when my tolerance has worn thin from other stressors, I can be less successful.

At the risk of oversimplifying things, I think the fundamental reason is that as I've matured, I've gained a certain level of patience that eases many of these issues. It might still drive me crazy to hear someone say "supposably," but I'm not compelled to be the "Well, actually..." guy and correct them these days.

When I'm sick, though, it's different. I presume that most people are less patient when they're not feeling well, but for me, it strips that veneer of reflexive civility that I've worked to acquire over the decades. It then takes a concerted effort not to get frustrated and take it out on those around me.

On its face, this seems extremely worrisome. Am I just one step away from being an insufferable bastard at any moment? The scary answer is: sort of.

It's not because I believe it's surprising that I would be short or gruff with people when I'm frustrated. I think if most neurotypical people were experiencing similar frustration, they'd do much the same. The thing, however, is that they don't *experience* that level of frustration in the same situation.

And I think the simple reason is that a life with autism is, at least a great deal of the time, a life of frustration. If you are easily and frequently frustrated and have trouble with emotional regulation, which are both classic autism spectrum characteristics, things can quickly run away from you.

The same experience can happen when I'm hungry, tired, overworked, overstimulated, coping with change, lacking needed accommodations, and misunderstood by others. And, one by one, I'm getting a little better at dealing with each of them as the years go by. But it still takes work.

# **Should You Get Tested for Autism?**

The answer to this question depends on whether any of the content in this book has resonated with you and whether you believe that your life is impacted in any *negative* way by the characteristics we've explored. If so, I strongly encourage you to contact an autism specialist for a thorough assessment.

I must caution you against taking an online questionnaire and self-diagnosing. While scoring highly on such tests might be a good reason to get a real evaluation, a diagnosis of ASD is more about specific unavoidable pathological outcomes than matching a cluster of symptoms. Only a qualified professional can make that assessment.

#### Where to Start

While Google is always a good place to start, you might wish to jump straight to a curated set of resources, such as those at AS360.org. This website, created by the University of Washington, is dedicated to autism answers, support, and community.

#### A Note for Kids and Adolescents

Growing up with autism can be tough. By the time you get to Junior High, you'll likely be well acquainted with the fact that the world can view "different" with a mix of suspicion and derision.

Over the course of the next several years, odds are, you'll find your place in the world. Along the way you'll learn to fit into the world a little better perhaps, and your peers will morph and mature into individuals a lot more tolerant of neurodiversity than what you're accustomed to in the playground and parking lot.

"Sometimes it surprises me that doctors have such a hard time diagnosing autism in youth when it seems that all you need is a group of middle schoolers to locate the nearest autistic kid to pick on!"

I remember in elementary school leaving class after being tormented for the millionth time. I ran to the bathroom for a respite; when I got there, I had a meltdown, though I didn't know what it was at the time. Thankfully, at least I was alone. I remember looking at myself in the mirror and through my tears, proclaiming, "Only three more years!"

I look back at that moment with mixed emotions: pleased that I was at least optimistic and forward-looking yet saddened that I felt I had to resolve myself to tolerate three more years of nonsense. The reality is that those moments are neither continuous nor permanent, but with my monotropic mind, I could only see it as both in the moment.

There were a couple of incidents severe enough that my parents had to get involved. I realize that having a parent run to the principal won't up your street cred, but there really are times when you should get a trusted adult involved! Trust your judgment, and never be afraid to ask for help.

A few years later, in high school, a guest speaker proclaimed that we needed to enjoy ourselves since going to school would be the "best years of our lives." I think the opposite may be true for many kids on the spectrum. On the bright side, it gets better from there—a lot better! So, hang in there!

# Living Your Best Life

My diagnosis of autism served as the trigger for, and a pivotal moment in, my personal growth journey. It signified the starting line where I began comprehending that much of my conduct and many of my abilities are influenced by my autism. It delineated these behaviors into two distinct groups: aspects inherent to my condition that I cannot alter and adaptable areas for improvement. The effort I have put into working on things in that second category has yielded significant beneficial changes in my life.

I'm happier and more productive than ever in my life, and my kids describe me as a "completely new person" in many dimensions.

Ultimately, while acknowledging and understanding my autism came with innumerable practical advantages, I'm still just "Dave." But as with most things from Microsoft, it took a few revisions and versions to get it right!

# Revised Topics: Life on the Spectrum

This section revisits themes from my inaugural work—themes relevant enough here that a second examination seemed not just valuable but necessary. Though rooted in their original composition, these sections have been meticulously revised, updated, and imbued with fresh insights. Although this information was originally intended for people with ASD, I have revised it in this edition to be more applicable to the broader spectrum.

#### **Autism on the Job**

With my diagnosis not coming until after I had already retired from Microsoft, it goes without saying that I spent my entire career largely oblivious to the fact that I was different. In part, this is because the company had so many other people who also exhibited autism symptoms that it really meant I fit in quite well most times! Although many people were not unlike me, it made for a complicated social interaction and management landscape. Microsoft was very much an email culture, and thus, most of what we did every day could be done without face-to-face interaction, but even so, the deficits in social communication became problematic for me.

### The Autistic Employee

In my early days there, I would estimate that a quarter of the workforce at Microsoft was noticeably "on the spectrum." At that time, most of the management was comprised of former developers who had been promoted to leadership positions based largely on their technical achievements, which was also my case. This promotion of technically successful programmers meant many supervisors and leads were possibly on the spectrum as well.

Being an employee with autism can be challenging, particularly if you are not open about it. People with autism can take and deliver expressions too literally, be too blunt, make pointed remarks, and appear aloof or detached. These things complicate any relationship but are especially problematic in a coworker, where the relationship differs from that of family or friends.

Here are just a few of the primary ways in which autism can impact on-the-job performance; not each one is always a negative, but they all can have negative implications:

- Failure to make eye contact, smile, or follow other social conventions.
- Interrupting, talking too slowly or too quickly, or with inappropriate volume.
- Missing sarcasm and taking things too literally.
- Lack of flexibility and constantly needing to have things a certain way.

- Unintentionally offending others with honest and direct statements.
- Discussing a topic long past its freshness date or asking questions after its clear question time is over.
- Speaking to supervisors, managers, and owners without appropriate deference.
- Problems controlling anger or frustration.
- Advice incorrectly perceived or received as criticism.
- They may be gullible and subject to exploitation.
- Ending conversations by simply turning or walking away.
- Needing breaks in long meetings to "decompress" periodically.
- Tendency to assign blame during conflict resolution.
- Unable to successfully navigate office politics.

If employees on the spectrum face so many challenges, why would a company like Microsoft be so highly populated with them? The reasons could include:

- Very strong logical and analytical skills.
- A lack of social filters can be valuable for unvarnished truths.
- Deep specialized knowledge in their field of expertise.
- Creative problem solving.
- Highly technically able.
- Incredible perseverance in solving problems.
- Excellent memory and detail recall, accuracy, and attention to detail.
- Love of structure, order, and even repetition.

- Honesty, loyalty, predictability, reliability.
- Thrive on routine.
- Highly accountable to dates and milestones.
- Self-motivated and driven to do well at whatever they are passionate about.
- Highly conscientious.

Although fraught with risk, the lack of social filters can be, at times, a blessing. It's a powerful ability to see through the social haze of niceties and extract the sometimes inconvenient or painful truth. Consider the parable of the *Emperor's New Clothes*. It is the ability to say what everyone is thinking but afraid to say.

#### Central Coherence in

# **Autistic Employees**

Central coherence refers to the cognitive ability to process information holistically, enabling an individual to understand the context or the "big picture." It involves integrating details to create a meaningful overall perspective. People with strong central coherence are good at seeing patterns and making connections in data or visual and auditory inputs. This concept is particularly highlighted in discussions of autism, where individuals may exhibit "weak central coherence" — a tendency to focus on details rather than the overall concept or context.

Neurotypical people, particularly those with high central coherence, like to organize their tasks and work into neat groups and tie them up with a bow, whereas those with autism

tend to have weaker coherence and can tend to get bogged down in the details.

Difficulties with central coherence may manifest themselves as difficulty with organization, such as:

- They have trouble getting started because they don't know where to begin.
- A perpetually disorganized or messy desk or workspace.
- Difficulty following multi-step directions or plans.
- Needing assistance in setting priorities to organize tasks and deliverables.
- Not being able to estimate how long a project should take accurately.
- Becoming overwhelmed by interruptions and annoyances.
- Becoming too rigorously locked into a particular plan or way of thinking.
- Act impulsively too early on before a complete plan is formulated.
- Asking too many clarifying questions.

Clearly, there is no one template, and any such challenges are complications, not limitations, and can sometimes be overcome.

# Fitting In vs Being

#### Accommodated at Work

In the social arena, people with autism who do not attempt to adjust their behavior to fit in with the accepted norms will find themselves ostracized to a certain extent. Other people will simply choose not to be around you if your behavior is too different, particularly if it is annoying to them in some dimension. In a work environment, however, the other people simply don't have a choice. They must stay at their posts even if they find you incredibly annoying! This can lead to resentment at a minimum.

Fundamentally, the best advice I can offer is to pick your battles carefully. If an aspect of your behavior or personality is causing friction or problems at work, you must carefully consider how attached you are to it. You may refuse to adapt if it is a fundamental cornerstone of who you are. If it's something you can improve without compromising your values, do it!

# The Autistic Manager

Only in the years after retiring did I look back at my career and what it meant to me. Landing the job at Microsoft all the way from Saskatchewan had been a significant psychological vindication that I was the real deal, more than merely a lucky imposter. As is typical in most companies, good performance was met with advancement. In the first decade, I progressed through the ranks from intern to Software Design Engineer to Lead Developer and, ultimately, Development Manager. However, while my performance might have merited the advancement, my management skills did not match my technical ability. I might have been a natural-born coder, but that certainly did not make me a natural-born leader or manager!

I took several classes internally at work to learn about some of the challenges of managing others – thinking that my quirky personality might make it difficult for others to "get" me. Perhaps the most helpful to me were the ones that emphasized different personality styles. The moment I let go of the delusion that everyone would want to be managed precisely as I would, I realized just how different each personality type is and how their needs vary in such an organization. This is a real challenge for someone with any degree of mindblindness.

I had only sought the extra training because I sensed a personal deficit: I had not managed people before, which seemed a weakness, so I wanted to train in that area. It was not because I had autism, which I did not yet know. The key, I believe, for any manager with autism is to try to accommodate all the various personality, learning, and operational styles in your organization. What works for you personally will likely not be an effective strategy for managing others. Your own needs are almost certainly very different from those of a neurotypical employee, so using them to predict what your staff needs would be foolish.

Once I had accepted that people had very different styles in how they operated within the company and what they needed for affirmation and direction, I could adapt my management of each employee to their unique needs and style. Or at least I could try!

If I had it all to do over again, and if my autism were serious enough to be noticeable to my subordinates (as mine is, I believe), and if at the time I enjoyed the luxury of knowing that I had autism, I would certainly tell my employees that I was on the spectrum. Why? I think understanding the context of why my reactions will be different from other managers could be helpful.

One of the biggest challenges for a new manager with autism is the shift in focus away from their area of expertise. In my case, I went from a highly technical role to a management role. Dealing with a group of employees' social and personal issues is *very* different than solving a complex technical challenge off in a corner by yourself. Dealing well with irrationality might be entirely new for you! Office politics can also be challenging, as when you move up the corporate ladder, you wind up operating in a new political sphere as well – whether you realize it or not.

Another option is to resist the drift into management if you can do so without financially scuttling your career. Even in a company as technically focused as Microsoft, there was an almost inexorable push towards management as you went up the career ladder. I say "almost" because given the technical ability to pull it off, an "individual contributor" role might be a better choice, where they remain technically focused. Technically, it is a more demanding path, but it is the most rewarding for certain personality types. After all, when I was a kid riding my bike down to Radio Shack, I was fascinated with computers and programming, not meetings and PowerPoint presentations!

#### Working for an Autistic Manager

If you are working for someone you believe has autism, particularly if you are neurotypical, you are going to face several unique challenges. But how can you even know whether your boss is on the spectrum, especially if they have never been tested? One cannot assume that every introverted technical person has autism – it's simply not the case. And so, the reality is that you may only suspect that your boss is on the spectrum without ever being able to confirm it authoritatively.

Imagine for a moment that your boss has a diagnosis and has been kind enough to inform you of it; then, you can begin to try to make the necessary adjustments. The problem is, without really knowing the person, how can you know which kinds of things are important to them or that they might be sensitive about? Are there things you can do to increase the odds of your success, such as not wearing strong perfume to work, not flipping on the fluorescent lights in their office each time you walk in, or not rearranging things on their desk?

Quite often, if you work for someone with autism in a technical arena, that person will be very well-versed in that field. They likely have deep knowledge of the area in which they are most passionate; their knowledge level and the rate at which they can take in and assimilate new information about it may be far above your own. And equally frequently, these individuals will be straightforward and direct. If they know the answer to your question - and there's a high chance they will - you will get that answer with a minimum of sideshow. More than simply a manager, they might also be a great resource to you.

If your boss has autism and their eye contact is affected, keep in mind that the standard signals one might read from inconsistent eye contact, such as intimidation or disinterest, do not apply; those with autism have their own cadence to their eye contact, depending on how significant their symptoms are and how hard they've worked (or not worked) to address it. Don't take it personally!

A boss with autism might not be as tuned in to the office politics and social structure as a neurotypical individual might be, and you can assist them in that regard by being straightforward yourself. You might even find a role for yourself as a translator of sorts, perhaps subtly letting them know what's going on in your team, one level deeper than they can see into the neurotypical world of personal wants, desires, hurt feelings, and egos.

People with autism often are much more literal about what they say than others. To that end, you, too, should say what you mean and mean what you say – try to be literal yourself. Take dates and facts seriously, as they do. If you regularly pepper your speech with sarcasm and irony, you might have to dial that back for your boss. A dry wit can be misread entirely.

You may also have to resolve yourself to some brutally honest feedback. A manager with autism may not couch their negative feedback as gently as a neurotypical manager would. You must receive that as intended – a factual evaluation, not a personal slight. As a generalization, they tend to avoid being passive-aggressive. Positive feedback from a manager with autism can be the sweetest currency of all because you know it is so literal

and direct. Praise from a manager with autism probably results from a job well done and not some attempt to manipulate you.

It is unlikely that an individual with autism who has trouble controlling their emotions in the workplace would be promoted to a position where it becomes a significant liability, but it *can* happen. In such cases, if a manager with autism becomes unduly upset, I recommend time and distance; give them space. Arguing with them or trying to resolve it factually in the moment might not be the most productive approach, as the manager may simply need time to sort themselves emotionally before they can continue logically. No amount of logic will necessarily short-circuit that process.

A manager with autism might even seem rude at times—not using proper deference towards upper management, interrupting conversations to get a point in, simply walking away at the end of a hallway conversation, and so on. These are deficiencies in their social abilities, to be sure, but you'll do better not to take them personally, as they are not intended as such. They are truly oversights from not knowing better or not understanding why such things are deemed important.

The odds are that as you spend time working for someone with autism, you will find that a few things - like punctuality or order, perhaps - seem disproportionately important to them. What those things are varies from one individual to the next, but those with autism tend to hold a few core concepts in very high regard, such as perhaps the notion that punctuality is a direct placeholder for respect. If you are perpetually tardy, a manager with autism may see that as disrespect or even

insubordination, depending on how passionate they are about it. To you, it might be a simple five-minute delay at the beginning of meetings, but to them, it might be symbolic of the entire relationship between the two of you. Assuming they will get over it and move on is likely a poor bet. They tend not to.

The issues surrounding employment and autism are many and complex, and we have touched only the surface of a topic that could easily support a book on its own! Ultimately, the goal should be to have an individual with autism fully engaged in their passion in such a way that their goals are aligned with those of the company. With those aligned, much of the rest will begin to fall into place if care and attention are paid to the many emotional, social, and interpersonal relationships created along the way, both with other employees and customers.

### **Parenting with Autism**

Imagine being a regimented perfectionist who is quick to anger, doesn't suffer fools gladly, likes peace and quiet, and reads emotions poorly, dwelling on the tiny details and ignoring the big picture. Now add four little kids and stir. Welcome to family life with autism!

This section is not about children that have autism, but rather, it focuses on being the parent with autism. I simply would not be able to write effectively about parenting a child with autism as it is something that I have never done, and my own experience as having been a child with autism is simply not enough context for me to attempt it.

### Being the "Other" Parent

Before we examine the challenges of being a parent with autism, we should acknowledge the unique challenges of being a neurotypical parent in a mixed marriage with kids. There is simply a particular set of things that the partner with autism may not be good at — let's say something as simple as phoning to schedule appointments for the baby with the pediatrician's office. If the partner with autism isn't comfortable on the phone, the neurotypical partner may wind up picking up that role by default.

This only works, of course, if the partner with autism picks up other responsibilities and roles in the parenting arena that, in turn, compensate for or take work off the shoulders of the neurotypical parent. It's one thing to be the "other" parent and a completely different thing to be the *only* parent. And if I might be blunt, no matter how much the partner with autism doesn't like the phone (or whatever the task in question may be), parents simply must accept that they will be called upon to do many, *many* things that they aren't good at, that they have no prior experience with, and that they will find distasteful. It's part of the job, so you might as well get used to it on *both* sides.

The best you can do is distribute the work fairly in a way that plays to each of your strengths. The notion that all work not aligned with the skills of the partner with autism must fall to the neurotypical partner is a non-starter, as there is simply too much of it! Remember that much of it isn't likely to come naturally to either party.

With the workload distributed as equitably as possible, the neurotypical partner may still wind up at times feeling like a solo parent as they often must attempt to accommodate and integrate the sometimes-inflexible demands, routines, and expectations on the part of the partner with autism. That parent may also have trouble accepting the new levels of noise, mess, disorder, and interruption that they are not accustomed to. They may have invested a lifetime in building and maintaining a certain semblance of order and structure in their lives, only to have it suddenly demolished by a crying baby or rowdy teen.

I also firmly believe that in the case of your kids, you do what you can, even when it's not enough. For example, in my children's school careers, I calculate there have been likely two parent-teacher conferences per year, per kid, for ten years each, starting in preschool. That's about eighty opportunities to meet with various teachers (granted, many at the same school on the same day), but let's call it forty to make it manageable. My wife would schedule them, and even when I was working full time, I made an effort to be present, even if she was charged with driving the agenda and running the meetings from a social perspective. I could still smile, nod, and flip through to inspect the textbook, ask a few questions, and be invested in my kid's outcome. Let us say that as a highly devoted working parent, I made it to thirty of those. Rest assured that my wife still made it to all of them - as the "other" parent in a mixed autistic partnership, you simply might have to.

I repay what I can of this imbalance in other areas of our lives. It is not enough to be the primary breadwinner – so I am trusted with the alarm systems, audio-visual, telephone, Wi-Fi,

network, pool boiler, and other systems; I'm the only one who knows how the lids come off the septic tanks or how to unclog the pipes; the only human that ventures into the literal crawlspace where the basement furnace lives or where the pool pumps hide; changes the oil in and otherwise maintains the cars; runs the generators; goes up on the roof as needed; does pressure washing in the spring and other similar things that I am personally good at. Hopefully, you can find a delineation between roles in your own relationship that evenly splits the workload *and* leverages the differing abilities of each parent in a helpful fashion.

#### Being a Good Parent with Autism

Being a good parent with autism can be challenging at the best of times. That may sound like some unabashed pessimism, particularly coming from a father of four. Still, it is really rooted in caution: I am incredibly fortunate in that all my kids have turned out healthy, happy, smart, and well-adjusted, but I honestly believe that is, to a certain extent, despite my autism (and thanks to my amazing wife). Had I known then what I know now, I could have made much better adjustments, but it is only now, with a late-life diagnosis, that I can look back at my parenting experience and draw any conclusions. I still have two teenagers at home, so it's not too late to improve!

Here is a partial list of the characteristics that can make parenting even more challenging than it already would be for the neurotypical; naturally, everyone is different, which makes this (like most lists) a gross generalization. This list includes many parallels to the issues we see in the "Autistic Manager" section, but with parenting, you have the added complexity of almost complete authority over your charges.

- Perfectionism.
- Regimentation.
- Quick-tempered.
- Low tolerance for noise and annoyance.
- Tendency to see new friends as home "invaders."
- Open and frank responses to situations without a social filter, regardless of the audience present.
- May often look sad or angry in their facial expressions.
- Poor cognitive shifting from one issue to another, possibly a more important one.
- Compromised ability to read intent and motives.
- Decreased ability to read the child's emotions and to intuit their emotional needs.
- Feedback/correction can be too critical/literal.
- Infrequent positive feedback and praise.
- Difficulty communicating with teachers and others involved in the child's life.

## The Perils of Assuming Motive and Intent

As a parent, you are both the local constabulary and the criminal justice system—you are both law *and* order. Correctly interpreting what a child *intended* to do can be extremely important in deciding whether a child is culpable for any particular action.

From a simple behavioral standpoint, accidentally bumping a flower vase is quite different from maliciously pushing it over to destroy it, and each elicits a very different response. Parenting that seems arbitrary and capricious – where accidental events are wrongly attributed as intentional just a little too often – no doubt becomes increasingly frustrating for the child. I am no child development expert, but I imagine it's challenging to grow up in a learning structure where conclusions about your actions are generally wrong. I'm sure I have made many errors over time; it's a real risk accompanying mindblindness.

In my own case, the compromise is often for me to admit that I do not know what has happened frequently. To frame it hypothetically, I can ask what happened and say what the consequences will be if an action is repeated, but I do make a significant effort not to draw conclusions I cannot prove. Thus, I wind up saying things like, "I don't know who spilled the lemonade, but... (here's why it matters, and here's what'll happen next time)." This runs the risk of the parent coming away looking a little foolish for perhaps not knowing exactly what's going on, but I think that's preferable to risking an environment that feels unjust for the child.

### **Emotional Blind Spots**

I am fortunate that children tend to telegraph, not hide, their emotions. I'm further fortunate that I can read facial expressions reasonably well, so if I can see my child's face, I can learn the context of what is happening. I'll then have a better understanding of what they are feeling.

My wife sometimes needs to explain a nuance to me, such as why something might be important to a child. It's not that I'm often wrong, but I'm occasionally unaware. My own tendency will be to look at the situation, gather all the information, and make an informed decision about how I would feel if I were in that position. As helpful as that dance can be in daily life, it's less helpful when dealing with small children because their priorities, maturity levels, and thought processes are different. My middle-aged brain is a terrible proxy for the wants and needs of a two-year-old. Sometimes, leaning on the neurotypical parent for more perspective, if you can, will open your eyes to the complexity of what might be happening with the child at any particular moment.

#### Remember that Kids are Children

Not to be overly pedantic about this, but kids really *are* immature little children. They will act as such: loud, annoying, and unpredictable in all their rule-breaking, change-making glory. Kids can test the patience of even the most understanding of adults, and if you are the sort of person who has prided themselves on not putting up with a lot of nonsense in the past, get ready for some serious shenanigans!

Some people would find it a lot easier to put up with a troublesome pet than a toddler in their "terrible twos," if you're one of them, you need to consider why a child triggers a negative emotion within you that a dog does not. Perhaps it stems from perceived intent: a child's action might pique your temper because they should know better, whereas a Labrador retriever doesn't have a clue, so it's easier for you to let a

transgression go and move on. If this notion resonates with you, this is where again I stress that children are *not* merely small adults. They make choices in ways that will sometimes flummox you, but you must not fall prey to the trap of assuming intent if you have autism and any degree of mindblindness.

First, their brains are different, not solely because their frontal cortex – which associates future outcomes with present actions – is immature and undeveloped. Sometimes, they intentionally take or select the wrong action merely to explore the consequences. It's hard to anticipate the mind of a toddler.

Second, with mindblindness, even if you were prepared to *accept* the internal motives and intents that drive a toddler, it doesn't mean you can perceive and receive that intent accurately. Imagine for a moment that your baby daughter flips her spaghetti bowl upside down and onto the floor while you aren't looking: the possibilities are endless. She might have just been uncoordinated and dropped it while moving it, or perhaps she was startled and bumped it off the tray. But there's always the slight chance she did it just for laughs and to watch you clean it up at the end of an already long day. If your response to the situation varies markedly with how you interpret the child's intent, you will face serious challenges. Your responses must be a function of the *situation*, not your *mood*.

Raising children while experiencing mindblindness means two things: You will never intuitively know what your child's motives behind any choice or action were, but your attempts to guess, infer, or assign motive are ineffective and doomed to failure – unless you make an intentional effort *not* to assume motive.

## Remembering Your Children's Friends

I'm terrible with names and faces, which means I find it hard to remember the names of even my children's close friends until I've seen them enough times. It does me no good to know "This is Daniel." Even seeing Daniel a half-dozen times and hearing his name might not do it. But if I know that Daniel plays running back for the high school football team and that he's number 32 on the roster, I can usually associate the face and name with "running back," and in a bit of time, they will come naturally as well. If you suffer from some prosopagnosia (trouble remembering faces), let your children know it extends to *all* people, lest they assume you cannot remember their friends because they are somehow less important!

#### Intruder Alert! Intruder Alert!

People with autism often view new visitors to the home that they do not know with a certain "intruder sense." It's not a judgment on the actual individual, as it has nothing to do with them per se. It's really about the sense that something is different and someone else has entered the sanctity of the family home. This is not to say that when my kids have friends over, I become concerned that something will be damaged or stolen: my kids' friends are great people. I merely experience a certain level of angst and irritation from the fact that things are different, and the ordinary course of daily family life is now operating under different rules and has a distinctly different "feel" due to the presence of guests in the home. Since we know

that people with autism often are uncomfortable with change in general, new people in the house represent a very personal form of change. It also likely means switching to a new ruleset and masking as well.

## Accepting Change and Disorder

As someone with autism, I like things the way I like them. I don't want people messing with the carefully crafted reality I've set up around me, especially after I've managed to get everything in my life arranged "just so." Kids will absolutely create unwanted change and disorder in your life, and you cannot blame them for this unavoidable fact. You'll have to learn to roll with it to a certain extent. I realize that telling you, "It's inevitable – suck it up!" doesn't sound helpful at first, but I'm being intentionally blunt because I genuinely believe this is one of those things in life you just must accept as a fact of life: kids will introduce some chaos into your life, and it's not their fault that they're kids. You need to be able to accept a certain amount of disruption.

That said, as we discuss in the chapter on accommodations, there are many things that the family, the spouse, and the autistic parent can do to help mitigate the impacts of this chaos.

Having a quiet spot that is your own can help a great deal. I have an office with a computer and a workshop to retreat to so that I can decompress when the social demands of having people over and the intruder sense become a bit overwhelming.

When my oldest child reached his teen years, his voice and the voices of his friends changed, sounding more like men. When

they stayed up later than I did, I found it increasingly difficult to sleep with the voices of other adult men in the home – noise-canceling headphones became increasingly helpful.

#### Being Candid with Your Children

By the time I was diagnosed, my oldest son was already twenty years old, so being open about my autism with my eldest kids when they were at a younger age wasn't an option that was open to me at the time. Since my diagnosis, however, I have discussed it with my younger (teen and pre-teen) children extensively. If you have such a diagnosis, I suggest you share it with your children as soon as you believe they are ready.

Here are some of the topics I suggest you address if you do have a discussion with your children:

#### **Autistic Parents and Change**

Change can be tricky. People with autism prefer things to follow certain routines, and they can become anxious or irritated when there is an unexpected change in plans. If you break a rule or do something else that brings unexpected change for an autistic parent, you may wish to wait for them to process or cope with that change before talking to them about the specifics, if possible. If we are in the middle of driving to X and something happens to scuttle that plan, I might react more strongly than the situation merits simply because I dislike changing plans.

## Considerations for Socializing and for Having Friends Over

A parent with autism may not see the need to socialize as much as the kids do, and hence, they may find it strange how much the kids want and need to do so. We know that an autistic parent may be reluctant to disrupt routines by having their kids' friends over, plus any new guest may be seen as an intruder or invader of sorts until they become used to it. But remember, even things that are new and weird to a parent with autism can become routine over time if done in a way so as not to cause undue stress. Making the process of having new friends over into a "normal" thing will benefit everyone involved.

Depending on the family's preference and the situation at hand, you might wish to explain to your friend that your parent has autism and, as a result, is more sensitive than most to noise, disruption, and interruption. The explanations need not go any deeper than you wish.

#### Keep it Down

As described earlier, a parent with autism is likely much more sensitive to certain sensory irritations, like loud or annoying sounds. All parents will inevitably ask you to keep it down, saying, "Turn that music down!" and such, but the tolerance threshold for autistic parents is likely to be a lot lower. For the parent with autism, once the kids are older and you can afford the distraction, I recommend noise-canceling headphones. I'm

wearing a pair\* right now. They do not eliminate the sound entirely but reduce and soften it, making it less distracting and less stressful.

As noted, falling asleep with loud male voices in the home is still nigh impossible for me, as I imagine a crying baby might keep others up, so I need a *certain* amount of quiet past bedtime.

#### Meeting New Friends

Kids are often mortified by their own parents and, at certain ages, can view parents as embarrassing relics that must be introduced to their friends only out of necessity. Don't take it personally, and don't assume it has anything to do with your autism when it does happen – it seems most kids get that way, at least briefly, in their teen years. Your obligation is largely met because you are doing your best to be friendly and welcoming to their friends.

If the symptoms of your autism are readily apparent when someone first meets you because they affect your speech or movement in a way that makes you stand out from neurotypical individuals, remember that kids – especially teens and pre-teens – crave normality. They do not want to stand out and be identified as different for any reason – including for having an autistic parent. Your child might be temporarily embarrassed by you, and it's easy to take offense. Remember,

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<sup>\*</sup> I recommend the Bose "over the ear" style headphones with active noise cancellation! The QC-35 II and QuietComfort Ultra are built well enough that I've never had a pair fail, and I use them a lot!

however, that almost *all* kids are embarrassed by their parents at that age, and your situation is thus hardly unique. It will pass, and it's a stage of normal childhood development, not about you.

#### Timing and Expectations

The timing of friend visits and parties can also be important to me. When my kids became older teens, it took me a long time before I could go to bed before them while they stayed up.

If I'm told earlier that there will be a party/event/gathering from seven until ten o'clock, it can become stressful if it runs substantially longer, off-plan. The unknown and unexpected can act as "stress multipliers" on top of the disruption from regular routines. When things do go off-plan, remember that it impacts the person with autism more profoundly and differently than you might expect it to.

No social event goes entirely according to plan, but at least in my case, the more I know in advance, and the closer things do go to plan, the better. My task becomes to roll with as much change and novelty as possible while the family around me tries to minimize the impact of any significant disruptions.

If a social event we are hosting goes long, which is more than about three to four hours for me (everyone is different), I sometimes need to excuse myself, retreat to my workshop, den, or bedroom, and just "be away from it all" for a while. As we discussed in the section on masking, maintaining any kind of performance for hours on end can be demanding. Sometimes, a break makes a big difference.

When we go out to an event, particularly a family event for kids at the school or similar, it places quite a demand on me. That's not to say that I do not enjoy it or would rather be elsewhere, but it does mean that it's work -- I have a fixed capacity for doing it, even when it's enjoyable.

Sometimes, I should excuse myself, at least temporarily, but I have failed to do so, making it even harder for me. For example, I have three boys who play football, and all have gone through the same local high school program. Each year for three years for three kids — almost ten years now — I've attended their annual youth football awards banquet. It's always planned for two hours but regularly goes well past four, as each kid on the team is thoughtfully spoken of, and every adult in the program receives some well-deserved recognition. Because it's a worthy thing, it's never cut short, and I'm not arguing it should be. For me, however, four hours in a chair at a banquet table listening to speeches about people I don't know is a real test of how much I love my kids! By the third hour, I'd (literally) rather be smashing rocks with a hammer out in the parking lot, but I love them, so I make it work.

My strategy for attending school functions or banquets is to be aware of this three-hour reserve capacity. If an event lasts four hours or more, I must consider accommodations allowing me to take a break or leave early. Because this is not a typical need, it wasn't something we recognized early, but we now know that *everyone* will be happier if we manage to keep Dad at least reasonably comfortable.

Parenting with autism is a complex topic. Your best bet, I contend, would be to keep your primary goal in the forefront of your mind: that you wish to develop your children into healthy, happy, functional, and self-supporting adults. Sometimes, a lack of strong central coherence can cause an autistic parent to lose sight of the big goal and become distracted by temporary annoyances. Focusing on the overall objective will make the surprises and annoyances that inevitably come along much less distracting.

## Love and Relationships with Autism

If I have any qualifications for writing about a successful marriage where autism is involved, they begin with the fact that I have been happily married to my high school sweetheart for over thirty years. It is challenging enough to maintain a great marriage over a long period of time, and even more so when the couple is young when they meet, as we were. People change so much in young adulthood, more often than not, they grow apart and not together over time.

Adding autism to the set of complications that can beset a marriage is one thing, but to have an autistic partner who has not yet been diagnosed – or worse, is autistic but does not believe themselves to be – can make for quite a challenge. My wife and I spent those first twenty-five years without a diagnosis.

People with autism are also at a significantly increased risk of depression, anxiety, obsessive-compulsive disorder, and attention deficit disorder. The odds are that if you've been dealing with undiagnosed autism, perhaps you've also been managing one or more of these other aspects without knowing what is underpinning them – autism itself.

I am no exception, and we have had to contend with each of these at one time or another (except for obsessive-compulsive disorder). That we did so for decades without even knowing they were related is a testament to the strength of our marriage, the character of Nicole, my wife, and the effort we put together.

The simple statistical fact that autism is about four times more common in males than females means that the majority of the "mixed marriages" will involve a woman in the neurotypical role married to a man with autism.

#### The Courtship Stage

One interesting complaint I have seen leveled regarding (usually failed) relationships with a person with autism is that they were "faking it" from the start — that the individual with autism had learned, from movies and books and television, how to mimic the essential human courtship rituals, but once the marriage was consummated and the prize was won, the person with autism no longer had to try anymore, and the relationship fizzled out. That's a cynical description of anyone's relationship, but it argues for a more prolonged premarriage engagement if nothing else!

Many autistic men without a diagnosis will fit the mold of someone kind, highly attentive, intelligent, and maybe a little bit immature – not a bad combination in your late teens or early twenties when playing the relationship game. This can be further enhanced because the individual with autism's apparent intellect and abilities may speak to extensive career opportunities. The person with autism will also, no doubt, pay a high degree of attention to their partner during courtship.

Some have speculated that the limited social abilities, slight immaturity, and "strong silent type" aspect might trigger maternal compensation in some women as well. The neurotypical partner may see an initial blossoming in the autistic partner as they begin to open up and perhaps overestimate how long that blossoming will continue or how far it will go. They may believe the candidate's limited social abilities stem solely from problems in childhood and that love will conquer all given time.

People with autism – diagnosed or not – often seek partners who can compensate for their difficulties in daily life. For example, although it was not by conscious plan, as a somewhat introverted person, I married an extraordinarily gregarious and extroverted neurotypical woman. Where I have rather poor central coherence and executive function, she excels. And so on.

In some cases, the person with autism may have created – whether they are aware of it or not – an internal "shopping list" that comprises the ideal relationship candidate, and they will then go through life vetting potential partners against this list. Often at the top of the list will be those qualities an individual with autism is deficient in – such as superior social skills and executive function. When someone matching the criteria is met,

the full determination of the person with autism can be brought to bear, and such determination can be compelling.

My own case was no exception. Between serious relationships, I dated a half dozen women before meeting my future wife, but after finally getting to know her, I knew in my heart that she was "the one." Once that certainty had been triggered, I undertook my mission as doggedly as anything else I had ever achieved. There have been times in our marriage where, perhaps at an event when Nicole looks exceptionally beautiful, I will look across the room and be struck by what feels like love at first sight all over again. However, the next thought that crosses my mind is always predictable: *I will make her mine – mission accepted*. No question. It's a mental resolution and decision that is made before my conscious brain can even remind itself – typically to my own great relief – that I've been married to her for decades already!

#### The Subtle Social Dance

Even though there are certain issues that I believe affect females with autism differently than males with autism, I have tried to avoid treating the genders differently in this book. When it comes to courtship, however, there can be no denying that eons of biological and cultural evolution have set a complex stage upon which the performers must tread. The roles are very different for women than they are for men, and each faces its own set of unique challenges.



Consider the allimportant moment of good-night the kiss when the evening is ending. Let's imagine that I'm a single adult male on the spectrum and that the girl asks me to come up for coffee. I'm not a complete fool -I know it's late, and

people don't drink caffeine late at night, so it's likely a euphemism for "come on upstairs and let's explore the sexual opportunities."

If, however, the girl asked something more subtle – perhaps today she would suggest that we "watch some Netflix and chill," I would likely demur because I generally have an early schedule, and people really *do* stay up late and binge-watch Netflix. Instead, I would go home to post-process. If I were to Google the phrase "Netflix and chill," I'd then discover that I had just turned down what was likely an explicit overture for sex. The specific lingo and verbiage change and evolve over time, but the fact that people are indirect about sex does not. And indirect does not serve people on the spectrum very well.

Nothing about human courtship is obvious or direct, which places those on the spectrum at a distinct disadvantage. When I initially sensed that I was indeed falling in love with Nicole, it was more than thirty years before my autism diagnosis. Even so, I was self-aware enough to know that I wasn't quite like

everyone else emotionally, either. To that end, I told her something that remains true to this day: I told her, "You will have to go first." I would have to let her lead emotionally in the dance of life. I don't really know where we're going, so I let her take me by the hand and lead me around this emotional life.

Dating, courtship, and romance are vastly more complicated for people on the spectrum because so much of it is subtle, silent, unspoken communication – the area where the most profound social deficits can be found.

## Common Problems Facing Mixed-Autism Couples

The most common cause of issues that I have identified amongst couples with one autistic partner is an overestimation, on the part of the neurotypical partner, of how much the autistic partner will be able to change, adapt, or improve after marriage. Sometimes, the initial effort put forth by the individual with autism, so impressive in the early stages, will fade after the honeymoon period when the motivation to be social is reduced or removed. Since socialization can be hard work for the autistic partner, they may simply (and unfairly) choose to entirely avoid it, forcing the neurotypical partner to adopt some of the lifestyle characteristics of autism into their own lives, often unwillingly.

The problem is that the most common cause is a sense of isolation and loneliness in the neurotypical partner. A person with autism may be perfectly fine if left to their own devices for hours or even days at a time, but this can be downright

emotionally painful for a social person to endure, and it's unreasonable to expect either partner to adopt the lifestyle instincts of the other wholly.

#### Asymmetrical Affection

Another common issue in mixed-autism relationships is an asymmetrical level of affection displayed by the two partners. Most relationships and marriages flourish best when there is an equal, or reciprocal, exchange of regular expressions of love and affection. Many with autism struggle with verbal expressions of their love and affection; even though they may feel it deeply, converting it into words is, for some reason, hard to do. Because it is so difficult, they avoid doing it often enough.

Those with autism also often strive for accuracy and consistency; to them, it might be perfectly sufficient to proclaim their love once; it is now an established fact that has been plainly stated and needs not be revisited repeatedly unless something changes. For the person with autism, frequently restating or reiterating the known and obvious can seem weird and even disingenuous; unfortunately, this will be very unsatisfying for the neurotypical partner.

Perhaps most telling is a recent survey (of women only) who are in a relationship with a partner with high-functioning autism. When asked, "Does your partner love you?" Fifty percent replied, "I do not know." This uncertainty may result from an absence of regular, daily, tangible expressions of love. Too often, the autistic partner will reply with logical

communication of emotions such as "You know that I love you" or "I fixed the dishwasher, didn't I?" and leave it to the neurotypical partner to try to assemble some relationship scaffolding from it, but it's often too little to work with. Acts of service and logic are undoubtedly compelling evidence, but they do not scratch the specific itch of being reaffirmed in the manner that the neurotypical partner needs to be fulfilled and happy.

While individuals with autism who enter marriages generally report being satisfied, happy, and less stressed afterward, the neurotypical partners often feel emotionally exhausted and neglected years later. This disconnect is not acceptable and explains, in many cases, why the partner with autism might be oblivious to the problems in the marriage. It could come as a complete surprise that it needs to be addressed.

People with autism who might start out as not romantic by nature can further complicate their relationships by not understanding the importance of sexual intimacy (particularly as distinct from mere sexual activity). The person with autism may not understand the value of, and need for, the back-and-forth, cat-and-mouse games of sexual tension, of play, of the value of being picked as the one special partner let into the secret garden, of an amorous atmosphere, foreplay, and of cuddling after.

I have elsewhere argued that people with autism spend a lifetime assembling a portfolio of prior experiences that teach them how to act in various circumstances because it does not come naturally. If this is true, then one can imagine that the source material for an individual with autism who has had limited relationship experience is primarily soap operas, movies, and pornography! Unfortunately, none of these are perfect representations of healthy human relationships from which the individual with autism can learn mastery.

Remember, however, that any highly functioning autistic partner has already mastered dozens, if not hundreds, of subtle social and relationship behaviors. Many more can be learned. Like so many other deficits related to this disorder, once the individual is aware of and understands the import, they can often address it.

#### The Bucket Metaphor

One metaphor for explaining the differences between how people with autism process love and affection differently is to compare a bucket and a coffee cup. The neurotypical carry around a bucket that they need to fill with love, and once it is full, they are generally content to carry it around, but it takes a lot to fill it. Those with autism operate with a coffee cup that must be refilled much more frequently with smaller doses. They may operate opposite to this, with the autistic partner being the one to treat affection and affirmation as if it were a logical asked-and-answered proposition of fact that need not be oft-repeated.

It is a safe bet for the individual with autism to assume that the neurotypical partner's bucket is never full and that there will always be room for more. Similarly, it would be hard for the neurotypical individual to "top off" the coffee cup of the autistic partner too often.

#### Sexual Desire

Just as some with autism turn to computers, trains, dinosaurs, or astronomy as a special interest, some turn to sex. Some with autism may turn to pornography as their special interest or as an authoritative relationship guide. Furthermore, in such cases, the desire for sexual activities and sexual intimacy can be excessive or even compulsive. These instances, however, are by far the exception and not the norm with autism. Typically, with autism, it is the neurotypical partner who is most concerned with a lack of sexual desire in the autistic partner, and certainly not an excess.

Some with autism can view sex as purely a practical activity for reproduction. Once children are produced, the need or desire for sexual acts atrophies for them, causing significant problems in the relationship. If the autistic partner views sex as a primarily practical act or as the means to producing a family, once the family is in place, the need for sexuality logically diminishes. Equally logical, however, is the fact that sex remains an essential ongoing factor in a successful relationship – so too for the other partner.

Critically, willingness and availability are not replacements for enthusiasm. For the individual with autism to begrudgingly agree to more sex likely will not help things much, for it is the emotional recharge of being chosen that the neurotypical lacks, and not primarily the physical act; better that they should seek it out with passion half as often rather than simply acquiescing more frequently.

# Mothering and Asymmetrical Responsibility

If the individual with autism lacks sufficient executive function, many roles fall squarely – and solely – onto the shoulders of the neurotypical individual. This partner can manage family finances, budgeting, planning, etc. If all this is not their forte, significant additional stress arises. At the same time, if the individual with autism doesn't pick up a similar level of responsibility in other areas, a neurotypical female partner may begin to develop a "mothering" role in caring for the person with autism rather than forming a true partnership.

#### The Autism Diagnosis

As stressed already, the first and primary responsibility of anyone who believes that they or their partner may have symptoms of autism is to get a proper evaluation and diagnosis. This is not the domain of a web questionnaire or even the informal opinion of your favorite family doctor; for an adult, it should be done by a psychiatrist or neurologist specializing in autism spectrum disorders. Your insurance will likely cover the testing if properly authorized in advance, although comprehensive reporting beyond a diagnosis may be elective and at your own cost.

"The diagnosis was just the first step in unraveling the mystery of what made me tick in a way that would allow each of us to grow, change, adapt and accommodate the other.."

In my own case, after all the testing was complete, the doctor prepared the lengthy report detailing the results – some twenty pages of analysis, statistics, and graphs. My wife, Nicole, accompanied me to this meeting to receive the report, not only so that she could ask the doctor questions but also so that we could receive this information together as a couple. I did not want it to be something I brought home from the doctor's office. Autism wasn't something that was newly inflicted upon our marriage simply because I now had a paper diagnosis. Quite the contrary: the diagnosis was just the first step in unraveling the mystery of what made me tick in a way that would allow each of us – not just me – to grow, change, adapt and accommodate the other.

An autism diagnosis should never be looked at as an indictment or an excuse; it is neither. The symptoms of autism can make any complex relationship more challenging, but they should never be used to explain away destructive or problematic behavior. Understanding the deeper origin of the symptoms does not exonerate the individual with autism from the effort needed to manage them or to protect the partner from the impact.

## "I suspect there were a lot of 'Aha!' moments for my wife..."

Similarly, just as the symptoms of autism are not to be used as an excuse, the individual who is affected by them should not be labeled or pigeonholed. A diagnosis is not a set of new limits imposed on the relationship: your path to happiness might have become a lot more twisty, but the destination remains the same. And now you have a roadmap of sorts.

The most critical aspect is likely that both partners accept the diagnosis. This starts the clock on improving two important aspects right away: the individual with autism may no longer feel crazy or broken, as though their idiosyncrasies are the cause of every malady in the relationship, while the neurotypical individual may go through an "Aha!" moment of "I told you something was up!" I'm on the wrong side of the equation to know for sure, but I suspect there were a *lot* of "Aha!" moments for my wife.

Most important, however, is how the diagnosis is used. It should not be used to place nor excuse blame for anything but as a guidebook to help you identify the weakest spots in the relationship so that you can work on them, regardless of where the ultimate responsibility may lie.

Suppose the decision has been made to share the diagnosis with others. In that case, both the neurotypical person and the individual with autism might benefit from the added support and advice of friends and relatives (or this might indeed complicate the situation). Use your best discretion.

## **Autism Topics**

### **Media Portrayals of Autism**

If you want to know what the general population thinks about autism, one approach would be to look at popular media portrayals of autism and find what is common among them. While I enjoy a few examples, much of the drama seems to center on the depressing cliches of the long-ignored sibling, the overwhelmed parent, and other narratives that center on the difficulties of living with an individual with ASD. Most autistic adults are portrayed as childlike and, unless they are savants, rarely contribute a great deal beyond stress.

Rather than focus directly on what screenwriters think of the autism family dynamic, I prefer to look at less overtly stated portrayals of what I believe to be the autism spectrum. When a story is about the characters and their world rather than a disorder, I think we learn much more about what makes those characters tick.

## Stereotypes - Autism in Media

I have a general rule whereby I will not publicly speculate on whether living individuals have ASD. As far as I'm concerned, a person's placement on the spectrum and whether they might have ASD is a personal health matter, and I try to accord it the privacy it deserves.

When it comes to fictional portrayals, however, all bets are off. Whether intentional or accidental, many characters in popular media exhibit autism spectrum characteristics (ASCs), and I believe it can be helpful and instructive to explore how those characters manifest their ASCs and how those characteristics impact their lives and story arcs.

By identifying stereotypical autism traits in literature and film, we can perhaps better learn to recognize our own. Let's focus on just a few of those fictional characters and explore the potential ASCs they exhibit.

#### Ferdinand the Bull

A couple of years ago, I was sitting in the waiting room of my doctor's office, waiting for my neurofeedback appointment to begin. The treatment involved a set of electrodes placed on the head that provided feedback you could use to fine-tune your level of attention.



As I waited that day for my session to begin, I picked up a copy of Ferdinand the Bull, a popular children's book that had somehow eluded me until this point. I was not familiar with it.

In the story, Ferdinand is a young bull who prefers to spend time alone, resting and thinking under a large cork tree. Ferdinand remains independent while the other young bulls leap, play, and fight. Though he is a large and strong bull, he would rather stay under his tree smelling the flowers than rush out and compete physically with the other bulls. It's just not his thing.

Ferdinand's mother grows concerned that he is not socializing enough and worries that he will be lonely. Try as she might to encourage him, when she realizes that he is content and happy as he is, she relents.

Ferdinand continues to spend most of his time alone and ultimately grows to become the largest and strongest of the bulls. Yet he still has no interest in butting heads with the other bulls for sport; he chooses to remain at his tree, smelling the flowers.

This preference for solitude is a common trait in individuals with autism, who often struggle with social interactions and may find solace in being alone. Ferdinand's behavior contrasts with that of the other young bulls, who are more inclined towards rough-and-tumble play and fighting. This further highlights Ferdinand's atypical social behavior, a common autism spectrum characteristic.

One day, five men arrive searching for a bull to compete in the bullfights in Madrid. As the other young bulls compete to show who is the best and most aggressive, Ferdinand remains aloof until he accidentally sits on a bumblebee and is stung. The pain

and surprise cause him to run wildly across the field, snorting and stomping and bucking in distress. Seeing only his spirited reaction, the men mistakenly perceive him to be the most aggressive of all the bulls, and they name him "Ferdinand the Fierce" before taking him away to Madrid.

In the end, however, Ferdinand does not fight. He is more interested in the flowers that the crowd showers into the arena than in fighting, and his lack of willingness to perform for the crowd ultimately has him sent back to the pasture, where he remains, smelling the flowers, to this day.

Ferdinand demonstrates a strong attachment to his special interest: the flowers. Individuals with autism often have restricted interests that they are intensely passionate about, and for Ferdinand, the flowers bring him immense joy. Even when faced with the prospect of a bullfight, Ferdinand remains more focused on the flowers than on the fight itself.

While Ferdinand's behavior might seem odd to some, it is evident that he is content with his life. His happiness stems from his ability to remain true to himself and pursue his passions, regardless of societal expectations. The story of Ferdinand the Bull serves as a reminder that there is no one-size-fits-all approach to happiness and that embracing individual differences can lead to a fulfilling life.

#### Lenny

In John Steinbeck's classic novella "Of Mice and Men," Lenny Small is a character who exhibits traits that would seem to place him on the autism spectrum. However, it's important to note

that the book was published in 1937, long before autism was widely recognized and understood.

Lenny has trouble understanding social cues and often finds himself in uncomfortable situations. For example, he does not comprehend the inappropriateness of touching Curley's wife's hair or holding on to a woman's dress in Weed. These incidents demonstrate Lenny's struggle to grasp social boundaries and conventions, which is a common challenge for individuals with autism.



Lenny is obsessed with petting soft things like mice, puppies, and even a woman's hair. This fixation on a specific sensory input and his repetitive behavior of petting soft objects might be compared to the repetitive behaviors and restricted interests often

observed in many autistic individuals. These could be examples of repetitive behaviors and fixations.

Lenny's fixation on soft textures could also be interpreted as sensory sensitivity, as some individuals with autism are particularly drawn to or repelled by specific sensory experiences. However, this aspect of Lenny's character is not explored in depth, so it is difficult to determine if it parallels sensory sensitivities in autism.

Lenny's speech is simple, and he has difficulty expressing complex thoughts and emotions. He often relies on his friend George to speak for him and explain situations to others. Although this could be an indicator of limited communication skills, which is a common trait among autistic individuals, these limitations on his communication ability could also be attributed to his intellectual disability.

Lenny struggles with abstract concepts and tends to take things literally. For instance, when George tells him to "jump in the river" if he gets in trouble, Lenny initially interprets this as a real instruction. This kind of literal thinking is common among individuals with autism, who might have difficulty understanding figurative language or sarcasm.

Theory of Mind refers to the ability to understand and interpret the thoughts, feelings, and intentions of others. Lenny seems to struggle with this aspect of social cognition, often misunderstanding or failing to anticipate the reactions of those around him. This difficulty with understanding the perspective of others is a common trait among individuals with autism.

Lenny appears to have difficulty with tasks that require planning, organization, and impulse control. For example, he often acts on his desire to pet soft things without considering the consequences of his actions. This lack of impulse control and difficulty with executive functioning is also common.

Throughout the story, Lenny relies on George to provide structure and routine in his life. He finds comfort in their shared dream of owning a farm and frequently asks George to recount the details. "Tell me about the rabbits, George" is a frequent refrain. This need for routine and predictability is also typical of autism.

Lenny also has significant difficulties with emotional regulation. Lenny experiences intense emotions and has difficulty regulating them, sometimes resulting in outbursts or aggressive behaviors. His inability to manage his emotional responses, such as when he accidentally kills Curley's wife or the puppy, can be linked to the emotional regulation challenges faced by some people with ASD, particularly when under intense stress.

Lenny seems to exhibit a significant number of characteristics classically associated with autism, and one cannot help but wonder if Steinbeck drew from an experience with someone who had autism when crafting the character of Lenny.

### Mr. Spock

As a kid, I eagerly anticipated the Saturday morning reruns of the classic TV series Star Trek. While Captain Kirk was the ostensible hero of the show, for many fans such as myself – and I suspect for many people who experience autism – it is the character of Spock who resonates the most strongly and for whom they feel the most kinship. I was as eager as anyone else for Kirk to save the day as soon as Mr. Spock figured out how they would do it.

I've long wondered if the fictional Vulcans of Star Trek were perhaps inspired by someone that the author, Gene Roddenberry, may have known and that this person may have had autism. The parallels, though never explicitly called out, are many.

Spock's appeal lies not in the fact that he's a paragon of virtue or because he is devoid of emotion but because he has learned to master and *control* his emotions. Vulcans are said to have been historically plagued by a lack of emotional control, and so today, they have pledged to suppress and control their emotions lest they erupt negatively.

This focus on logic and reason can be likened to the emotional regulation challenges faced by some individuals with autism, who may struggle to understand or express their emotions in a neurotypical manner.

Vulcans often struggle with social interaction. Vulcans are depicted as having difficulty navigating social situations with species that are more emotionally expressive, like humans. This could be compared to the social interaction challenges that



can exist between the neurotypical and those with autism, who may have difficulty reading social cues or understanding others' emotions.

Vulcans are known for their blunt and direct communication style, which can come across as insensitive to others. Similarly, individuals on the spectrum might struggle with understanding subtleties in communication, such as sarcasm, and can be seen as blunt or overly literal. Numerous episodes contain vignettes wherein Spock is confused by a figure of speech because he has taken it literally rather than as a euphemism.

Vulcans adhere to strict codes of conduct and principles, which can lead to inflexibility in their thinking and actions. This rigidity is like the preference for routines and resistance to change often observed in individuals with autism.

Vulcans, especially Spock, are sometimes depicted as avoiding or minimizing eye contact when interacting with others. This is a common trait in individuals with autism, who may find direct eye contact uncomfortable, overwhelming, or simply unnecessary.

While Vulcans experience emotions, they are trained to suppress them and to remain stoic. This lack of emotional expression can resemble the muted or atypical emotional responses sometimes exhibited by individuals with autism, who may have difficulty understanding or expressing their emotions in conventional ways.

Vulcans also have special interests. They are portrayed as having deep, focused interests in specific areas of knowledge, such as science or philosophy. This could be likened to the intense, narrow interests often seen in individuals with autism.

While Vulcans may be perceived as lacking empathy due to their suppression of emotions, they are, in fact, capable of deep empathy, as evidenced by their telepathic abilities, such as the mind meld.

Spock still experiences emotions and empathy, but often, the context must be explained to him before he does. When Bones is reported to have a terminal illness, for example, it becomes a touching scene where Spock tenderly places a hand on his shoulder for comfort and looks intently at him, making it clear that the news profoundly moves him.

Although not a prominent feature of Vulcan characters, their heightened senses (such as their ability to hear higher frequencies) could potentially be compared to the sensory sensitivities experienced by some individuals with autism.

### Sheldon

While Sheldon Cooper from "The Big Bang Theory" is never explicitly diagnosed with ASD within the show, many fans and viewers have speculated or simply assumed that his character exhibits the traits of autism. It's important to remember that these connections are speculative and not explicitly confirmed by the show's creators. Sheldon's characteristics that could be interpreted as potential indicators of autism could include the following:

Social awkwardness: Sheldon often struggles with understanding social cues, norms, and etiquette. He has difficulty recognizing sarcasm and may take things literally.

This lack of social awareness is a common challenge faced by individuals with ASD.

Rigidity and routines: Sheldon is known for his strict adherence to routines and schedules, such as his designated seat on the couch, his weekly meal plans, laundry night, and his bathroom schedule. Many individuals with autism also rely on routines and may have difficulty coping with changes to their established patterns.

Obsessions and special interests: Sheldon has intense interests in specific topics, like comic books, video games, and physics. He can become wholly absorbed in these subjects and often struggles to understand why others might not share his enthusiasm. This focus on specific interests is reminiscent of the narrow, intense interests frequently seen in individuals with autism.

Difficulty with empathy: Sheldon has a hard time understanding and relating to the emotions of others. While he is brilliant, he often struggles to connect with people on an emotional level. This difficulty with empathy is another common trait among individuals with autism.

Repetitive behaviors: Sheldon exhibits repetitive behaviors and rituals, such as knocking on a door three times and saying the person's name between each knock. Repetitive behaviors are a common trait amongst those on the spectrum.

Sensitivity to sensory stimuli: Sheldon is sensitive to certain sensory stimuli, such as loud noises or specific fabrics. For example, as am I, he is very particular about the type of fabric used for his clothing and bedsheets. Sensory sensitivities are also commonly experienced by individuals with autism.

Literal thinking: Sheldon often takes things very literally and has difficulty understanding figurative language or humor. This kind of literal thinking is common among individuals with autism, who might have trouble grasping abstract concepts or sarcasm.

### Ron Swanson

Ron Swanson, a character from the television show "Parks and Recreation," is known for his unique personality and strong opinions. While he is not explicitly diagnosed with ASD in the show, some viewers have drawn parallels between certain aspects of his character and traits associated with autism. It is again important to emphasize that these connections are speculative and not explicitly confirmed by the show's creators. Some of Ron's characteristics that could be interpreted as reminiscent of autism include the following:

Social interaction: Ron often appears aloof or disinterested in social situations and prefers to keep to himself. He has a small circle of close friends and is not particularly interested in making new connections. When forced to do so, he finds the process stressful and distasteful. This could be reflective of the social interaction challenges faced by some individuals with autism.

Ron has a "flat affect." He is known for his stoicism and reluctance to express his emotions openly. He talks bluntly and straightforwardly.

Ron is entirely set in his ways and strongly prefers routines and specific ways of doing things. For instance, he is particular about his food (mainly meat) and woodworking. While this rigidity is not as pronounced as it might be in someone with autism, there are some parallels.

Ron is deeply interested in specific areas, such as woodworking, hunting, and libertarian principles. He can become wholly absorbed in these topics and is highly passionate about them.

While Ron demonstrates empathy toward his friends and colleagues, he sometimes appears detached or struggles to understand other people's emotions, particularly when they conflict with his beliefs. This might be seen as like the challenges with empathy experienced by some individuals with autism.

### Hermione Granger

Hermione Granger is one of the most beloved and iconic characters in modern literature, and for good reason. As a member of the Golden Trio in the Harry Potter series, she is known for her quick wit, sharp intelligence, and fierce loyalty to her friends. However, some fans and scholars have suggested that there may be more to Hermione's character than meets the eye.

Several traits that Hermione exhibits may be indicative of autism. First and foremost, she is incredibly intelligent and analytical, with a remarkable ability to retain and recall information. She is also very detail-oriented, often noticing



small details that others might overlook. For example, in the first book in the series, she is the first to realize that the devil's snare they are trapped in can be defeated by sunlight.

In addition to her intelligence and attention to detail, Hermione can

be quite socially awkward sometimes. She often struggles to understand social cues and norms and can come across as blunt or insensitive. For example, in the second book, she tells Harry and Ron that they have "the emotional range of a teaspoon" when they don't understand her concern about a dangerous diary.

Hermione's love of routine and structure is trait that may suggest she is on the autism spectrum. She is a stickler for rules and order and can become anxious or upset when things don't go according to plan. For example, she becomes highly distressed in the third book when Harry and Ron don't take her time-turner plan seriously.

Finally, Hermione's intense focus and interest in her studies are other traits that may suggest she has autism. She is passionate about learning and mastering new skills, often spending long hours in the library researching and studying. This single-minded focus on her interests is a hallmark of many people on the spectrum.

It's worth noting that J.K. Rowling has never explicitly stated that Hermione is on the autism spectrum and that these traits may simply be part of her character rather than an intentional portrayal of autism. However, given the similarities between Hermione's behavior and the characteristics of autism, it's not hard to see why some fans and scholars have made this connection.

Hermione's character displays many classic characteristics of autism, from her intelligence and attention to detail to her social awkwardness and love of routine. Whether or not this was intentional by the author, it's clear that Hermione's unique personality and quirks have made her a beloved and relatable character to readers worldwide.

### Wednesday Addams

Wednesday Addams is a fictional character from the Addams Family, a famous American sitcom that has been adapted into numerous TV series, movies, and other forms of media. She is known for her morbid and macabre sense of humor, love of all things dark and spooky, and deadpan delivery. Some fans and scholars have suggested that Wednesday's behavior and personality may be indicative of autism. I will explore some of

the traits exhibited by Wednesday that may support this hypothesis.



Wednesday is highly independent and selfsufficient. She is often shown pursuing her own and interests hobbies. such as practicing archery or playing with her pet spiders, without seeking validation or approval from others. This intense focus and independence

are hallmarks of many people on the spectrum who may struggle with social interaction but excel in solitary pursuits.

Another trait that may suggest Wednesday is on the spectrum is her bluntness and lack of filter. She often speaks her mind and doesn't hold back, even if her opinions are controversial or unconventional. This lack of social awareness and inability to read social cues is common among people who experience autism and who may struggle to understand the unwritten rules of social interaction.

In addition to her bluntness, Wednesday can be very literal in her speech and interpretation of language. For example, in the movie Addams Family Values, she asks her camp counselor if they have "harmony between people and nature," taking the question at face value rather than understanding it as a rhetorical device. This literal interpretation of language is another trait often seen in people with autism.

Wednesday's intense focus and dedication to her interests is another trait that may suggest she is on the autism spectrum. She is often shown pursuing her hobbies and interests with single-minded determination, often to the exclusion of other activities or relationships. This level of focus and intensity is a common characteristic of autism.

Finally, Wednesday's lack of interest in social norms and conventions is another trait that may suggest she has autism. She often wears black clothing and makeup, even at formal events, and is uninterested in conforming to traditional gender roles or expectations. This disregard for societal expectations and norms is often seen in people on the spectrum, who may struggle to understand or care about social conventions.

From her independence and lack of filter to her literal interpretation of language and intense focus on her interests, Wednesday's character displays many common spectrum characteristics.

# Appendix: Autism Definitions

Rather than filling the front of the book with formal definitions, I've moved this content to an appendix, as follows.

# Defining Autism Spectrum Disorder and Related Conditions

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects the lives of millions of people. I spent most of my life not knowing I was counted among them. It impacts our communication, relationships, social interactions, behavior, employment, and even, in some cases, our physical movements. ASD is not a defect or a negative attribute but rather a neurodiverse condition characterized by unique strengths and challenges.

Not everyone who has symptoms or characteristics of autism will have ASD. The extent to which those symptoms impact their lives will ultimately determine whether their condition rises to that of an actual disorder. The very definition of what constitutes ASD seems to be in constant flux. It might be instructive and helpful to arrive at our own definition of an actual disorder.

For this book, I consider the symptoms of autism to be simple neurodiversity until they cause unavoidable pathological impacts on the lives of those who experience them. It is only when those symptoms cannot be accommodated, despite the individual's best efforts, that they likely rise to the level of a disorder. In severe cases, they may be unable to speak or adequately care for themselves. In others, the associated characteristics may be difficult for others to perceive. The range of the autism spectrum is very broad, and it extends in multiple dimensions.

#### The ASD Diagnosis

As someone who was diagnosed with autism spectrum disorder (ASD) in adulthood, I understand the challenges that come with living with undiagnosed ASD. Without awareness of one's condition, the experience of ASD can be exacerbated, as it can be difficult to manage symptoms effectively without a clear understanding of what one is even facing.

In my own experience, I struggled with communication, social interactions, restricted interests, and emotional regulation for many years before receiving a diagnosis. It wasn't until I learned about my condition in much more detail and began to understand my own unique strengths and weaknesses that I was able to make progress in managing my symptoms.

I believe that awareness and understanding of ASD are crucial for individuals who may be living with undiagnosed symptoms. By recognizing the signs and seeking support, individuals with ASD can better navigate the challenges of daily life and access the resources they need to thrive.

No one should simply conclude that they have (or that someone else has) ASD based on symptoms without a formal diagnosis. Assigning a diagnosis of ASD without proper rigorous testing can be problematic for several reasons. The symptoms of ASD are not always clear-cut or consistent across individuals and can often be challenging to differentiate from symptoms of other developmental or behavioral conditions. Furthermore, one must consider the unavoidable impact of those symptoms on the individual's life. This means misdiagnosis or overdiagnosis can occur without proper testing, potentially leading to inappropriate treatments or interventions. Additionally, the label of ASD can carry significant social and emotional implications for individuals and families, and a misdiagnosis or incorrect assignment of this label can have severe consequences on their life trajectory. Therefore, qualified professionals must conduct a thorough and rigorous assessment to ensure accurate diagnosis and appropriate support for those who genuinely need it.

Diagnosing ASD typically involves a comprehensive evaluation by a team of healthcare professionals, which may include a combination of medical doctors, psychologists, psychiatrists, and speech-language pathologists. These professionals are trained to evaluate the various aspects of development that ASD affects, including social communication, behavior, and cognitive abilities.

Thus, in most cases, the official diagnosis of ASD is made by a clinical psychologist or a medical doctor, such as a psychiatrist or a developmental pediatrician, who has specialized training and experience in diagnosing and treating individuals with ASD. The diagnostic process may involve a variety of assessments, such as a battery of standardized tests, interviews with the individual and their family, and observation of the individual in different settings. It is not a diagnosis that should be casually arrived at by a family practitioner without specific training, nor based on anecdotal information or a simple enumeration of issues during an office visit. This is not to say such doctors aren't qualified – they may well be, and the diagnosis may even be obvious. That said, the condition typically warrants evaluation by specialists.

While the diagnosis of a disorder is a complicated matter, many millions of people around the world certainly do experience symptoms of autism, whether or not they constitute a disorder. Those symptoms can, of course, be troubling, and understanding and managing them is the focus of this book.

## Where Did Asperger's Syndrome Go?

The term "Asperger's syndrome" was previously used to describe a subtype of ASD characterized by social and communication difficulties, along with repetitive behaviors or narrow interests. However, this term is now considered deprecated, as it was based on the work of Hans Asperger, a physician who was later found to have collaborated with the Nazi regime in Austria during World War II.

While it is not clear whether Asperger himself signed off on the euthanasia of children with autism, there is evidence to suggest that he may have been aware of, and potentially complicit in, the Nazi program of euthanasia of individuals with disabilities, including those with autism.

Recent research<sup>iii</sup> has found that Asperger referred children to the notorious Am Spiegelgrund clinic in Vienna, where many children with disabilities were subjected to inhumane medical experiments and murdered as part of the Nazi euthanasia program. Asperger also wrote reports on children who were subsequently sent to this clinic and described some of them as "uneducable" or having "unfavorable personalities." Such labels may have sealed their fate.

While the full extent of Asperger's involvement with the Nazi regime is still a matter of debate, his work was used to further the regime's ideology of eugenics and the elimination of people with disabilities. As a result, the use of the term "Asperger's syndrome" is now discouraged, and most healthcare professionals prefer to use the term "autism spectrum disorder" (ASD) to describe individuals who meet the diagnostic criteria.

# DSM-V and "The Big Change"

The most used reference work in diagnosing ASD is known as the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. It is a manual published by the American Psychiatric Association that provides a standardized classification and diagnostic criteria for mental disorders. Mental health professionals use the DSM-V to diagnose and treat a wide range of mental health conditions, and it includes detailed descriptions of each disorder, as well as criteria for diagnosis

and assessment. The DSM-V was first published in 2013 and revised as the DSM-V-TR in 2022.

The DSM is not a textbook but rather a handbook or guidebook used by healthcare professionals to diagnose and classify mental disorders. It attempts to unify terminology and vocabulary amongst professionals, a requisite first step.

The DSM is intended to promote consistent and reliable diagnosis across healthcare professionals and settings. As such, it is structured as a guidebook that outlines each diagnosis's criteria and guidelines rather than as a manual that provides extensive background information and in-depth analysis of the disorders.

As of the release of DSM-V, all the various subtypes of autism were unified under the larger umbrella of ASD. One issue with this new approach is that the previous subtypes of ASD, including "Asperger's Syndrome" and "Pervasive Developmental Disorder Not Otherwise Specified" (PDD-NOS), had come to be recognized and accepted as distinct conditions within the ASD spectrum and many individuals and families had come to identify with these labels. The decision to remove and combine these subtypes into one diagnosis may be seen as a loss of identity or recognition for those who previously identified with a specific subtype. It may also feel necessarily less precise to remove the prior distinctions.

Additionally, some people may feel that the new diagnostic criteria do not accurately capture the full range of symptoms and severity levels that are seen in individuals with ASD. For

example, some individuals who would previously have been diagnosed with Asperger's syndrome may not meet the criteria for ASD under the new guidelines, which could limit their access to appropriate support and services.

There also exists the concern that the new criteria may lead to overdiagnosis or underdiagnosis of individuals with ASD. While the latest diagnostic criteria aim to be more accurate and comprehensive, there is always a risk that the definitions may not capture the full range of symptoms and challenges seen in individuals with ASD or that they may be applied too broadly or too narrowly.

The Columbia University School of Nursing published a metaanalysis of fourteen studies in 2014 that showed there was a thirty percent decrease in ASD diagnoses following the publication of DSM-V.

<sup>&</sup>lt;sup>1</sup> Buie T, Campbell DB, Fuchs GJ 3rd, Furuta GT, Levy J, Vandewater J, Whitaker AH, Atkins D, Bauman ML, Beaudet AL, Carr EG, Gershon MD, Hyman SL, Jirapinyo P, Jyonouchi H, Kooros K, Kushak R, Levitt P, Levy SE, Lewis JD, Murray KF, Natowicz MR, Sabra A, Wershil BK, Weston SC, Zeltzer L, Winter H. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. Pediatrics. 2010 Jan;125 Suppl 1:S1-18. doi: 10.1542/peds.2009-1878C. PMID: 20048083.

ii Mihaly Csikszentmihalyi - TEDTalkhttps://www.youtube.com/watch?v=fXIeFJCqsPs&ab\_channel=TED

 $^{\rm iii}$  Davidson, J. (2018). Why the Truth About Hans Asperger Matters. Spectrum News. https://www.spectrumnews.org/features/deep-dive/truth-hans-asperger-matters/