

Choose Your Own Adventure

Pros and Cons of a Formal Autism / ADHD Diagnosis vs Self-Diagnosis

Agenda

- My lived experience
- The rise in diagnosis rates & misinformation
- The conventional health insurance path to diagnosis
 - Pros & Cons
- The private provider path to diagnosis
 - Pros & Cons
- Self-diagnosis
 - Pros & Cons
- Questions & Answers
- Resources

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My Lived Experience



Growing up, I'm sure I knew undiagnosed Autistic people, including other members of my family. But my cousin Joey was distinctive. He was diagnosed. Invariably someone — from neighborhood kids to complete strangers — would rudely ask “what’s wrong with him?” Occasionally, my aunt would push back with “what’s wrong with you?” A fair question.

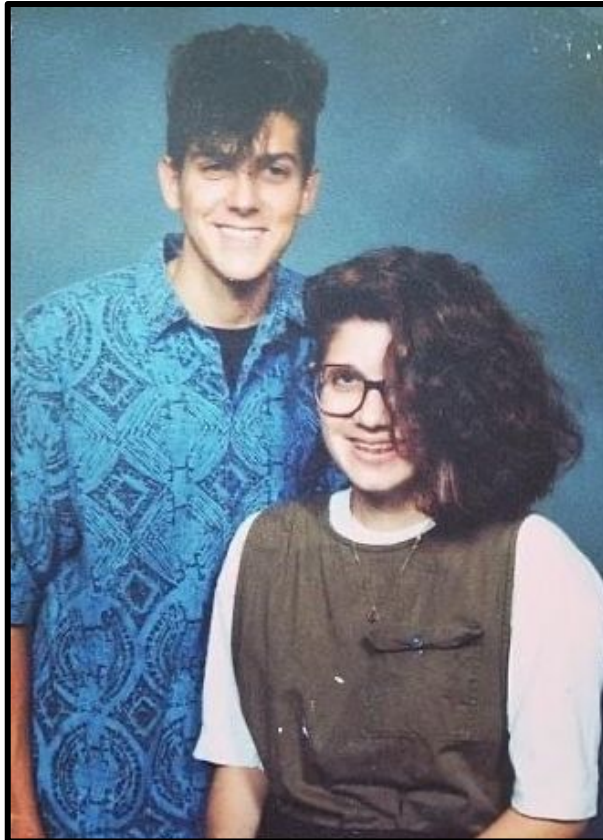
Portrayals in Media

Joey's behavior was outside of "the norm." Like some autistic people, he prefers to talk about his areas of interest. His hyperfocus mainly covers **Superman**. Everything from the Christopher Reeves movies to animated versions and the comic books. Also, the Rocky movies. And running. Which was in a Rocky movie. His main outlet was track and field sports in the Special Olympics when he was younger.

The movie ***Rain Man*** came out in 1988. It was the only mainstream media representation of autism. It raised awareness about autism and some common autistic traits. But it also pushed a stereotype that became a common misconception. That most autistic people are savants of some sort. And we've seen that play out in other media, like *The Good Doctor* television series.



High Potential, Underachiever



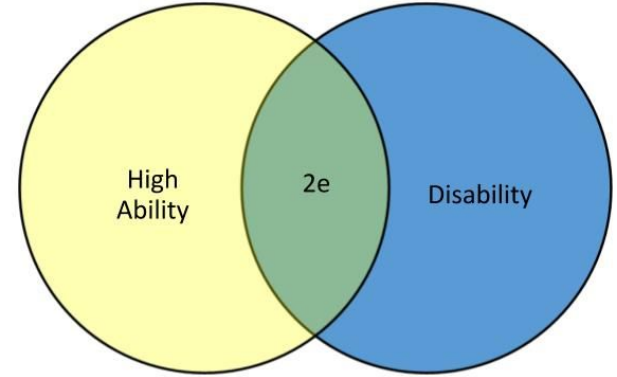
Twice Exceptional (Exceptional Ability and Disability)

I was identified as having unique needs early on. But I was identified as gifted rather than autistic. I didn't receive any supports — other than being taken on cool field trips once in a while.

Some classmates, almost always boys, were frequently reprimanded for having short attention spans and outbursts. I remember one kid from grade school who flipped over his desk more than once. I was alarmed by that behavior. For me, school was the place for structure. Home was where the chaos was.

I internalized my emotions and neurodivergent traits and became highly anxious. Teachers scolded me for daydreaming, but I usually had the correct response when called upon. I could come up with answers intuitively, without showing my work. And would have to reverse engineer to illustrate how one would reach a certain solution, even when the solutions themselves came to me effortlessly.

Later the dreaded phrase “high potential, underachiever” would appear on my report cards. Without taking into account any other support needs I might have, or what was going on at home.



Learning From My Kid

Single parenting while working full-time in tech was challenging. Early on, my son's daycare teacher gave me a book called *The Out of Sync Child* and recommended I have him assessed.

First he attended Early Childhood Special Ed (ECSE). Then a charter school that was a good fit for his needs. His initial diagnosis was Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). That was later removed from the DSM and reclassified as Autism Spectrum Disorder (ASD).

He had an Individualized Education Plan (IEP) to ensure he received the supports he needed at school. The ones I never got. As he got older, I saw more and more of myself in him and in the questions asked in his re-evaluations. Which led me to re-evaluate what I knew about myself and how I interact with the world. Many other parents are being diagnosed this way.



Before the Adventure Begins

The Current Political Climate

‘The national autism registry proposed by RFK Jr. was based on misinformation and lies about autism, which is not caused by "toxins" in the environment and is not a disease. There is not a cure. Autism is largely genetic. It is a difference in brain development that qualifies for disability accommodations under the ADA. The only way to eliminate autism is to unalive autistic people as part of a eugenics program.

Why would Elon Musk (who is autistic) and RFK Jr. (who has a neurological disorder) enable this? People with disabilities are often ableist against themselves. They want to distance themselves from "more" disabled people. This can result in a fixation with hyper-productivity or special skills or status to prove worthiness or superiority. This is a fear and shame response rooted in always feeling on the verge of ostracization.

Meanwhile, parents with disabled children are often desperate to "cure" disability rather than accept and love their children as they are. We don't talk about this enough. Anxious parents are easy marks for conspiracy theories and alternative health scams.’

— Amy Stewart

Higher Support Needs

- We have people in our lives with higher support needs.
- They shouldn't be demonized. They deserve dignity and the right to exist and to be part of their communities.
- My son is still friends with a pal from kindergarten who is non-speaking. He likes to shoot hoops and high five everyone and he brings joy to our gatherings. We look forward to his birthday party every year.



Why has there been an increase in diagnosis of adults?

“People go undiagnosed for all manner of reasons. The stereotype of autism as a male condition (the diagnosis is 4x more common in males than females) is one factor. Teachers might notice the boy who constantly walks the playground perimeter while the rest play football, but overlook the girl who copies everything about a school friend in an effort to fit in. Such masking occurs in all genders and is damaging in itself.” —The Guardian

Before 2013, when the DSM-5 was released, ADHD and autism were officially mutually exclusive. If you had one, you could not be diagnosed with the other. Since then there have been:

- Changes in diagnostic criteria
- A closer look at symptom overlap and misdiagnosis
- Studies showing genetic and neurobiological factors

How "unmasking" leads to freedom for autistic and other neurodivergent people

From [Eric Garcia via NPR's Life Kit, in conversation with social psychologist Devon Price, PhD](#)

Masking is a common coping mechanism employed by autistic people when trying to fit into a neurotypical society. Examples of masking include forcing oneself to smile at the "appropriate" times, looking between someone's eyebrows instead of making uncomfortable eye contact, and suppressing stims like hand flapping, even though they're comforting.



Camouflage and Compensation

While masking is employed by many autistic people, people in marginalized groups, including women, people of color, and LGBTQ+ people might feel even more compelled to camouflage their disability.

"To this day, all of the assessments that we use for diagnosing autism, even in adults are still based on how to identify it in white cisgender boys, usually very young ones," Devon Price, PhD explains. "So what that means is, if you're, let's say, a young autistic black boy, you are far more likely to get diagnosed with something like oppositional, defiant disorder. You're more likely to be seen as a behavior problem."

"If you're a girl, if you're a person of color, if you're gender nonconforming," Price says, "you're more likely to be seen as a problem to be contained."

Unmasking

For every visibly autistic person you meet, there are countless “masked” autistic people who pass as neurotypical. Masking is a common coping mechanism in which autistic people hide their identifiably autistic traits to fit in with societal norms, adopting a superficial personality at the expense of their mental health. This can include suppressing harmless stims, papering over communication challenges by presenting as unassuming and mild-mannered, and forcing themselves into situations that cause severe anxiety, all so they aren’t seen as needy or “odd.”

This book lays the groundwork for unmasking and offers exercises that encourage self-expression, including:

- Celebrating special interests
- Cultivating autistic relationships
- Reframing autistic stereotypes
- And rediscovering your values

Discovering the New Faces
of Neurodiversity

UNMASKING
AUTISM

Devon Price, PhD

author of LAZINESS DOES NOT EXIST

The Zebra Analogy

I've had people question my decision to pursue a diagnosis. Asking "why bother? You've made it this far in life."

The Zebra Analogy

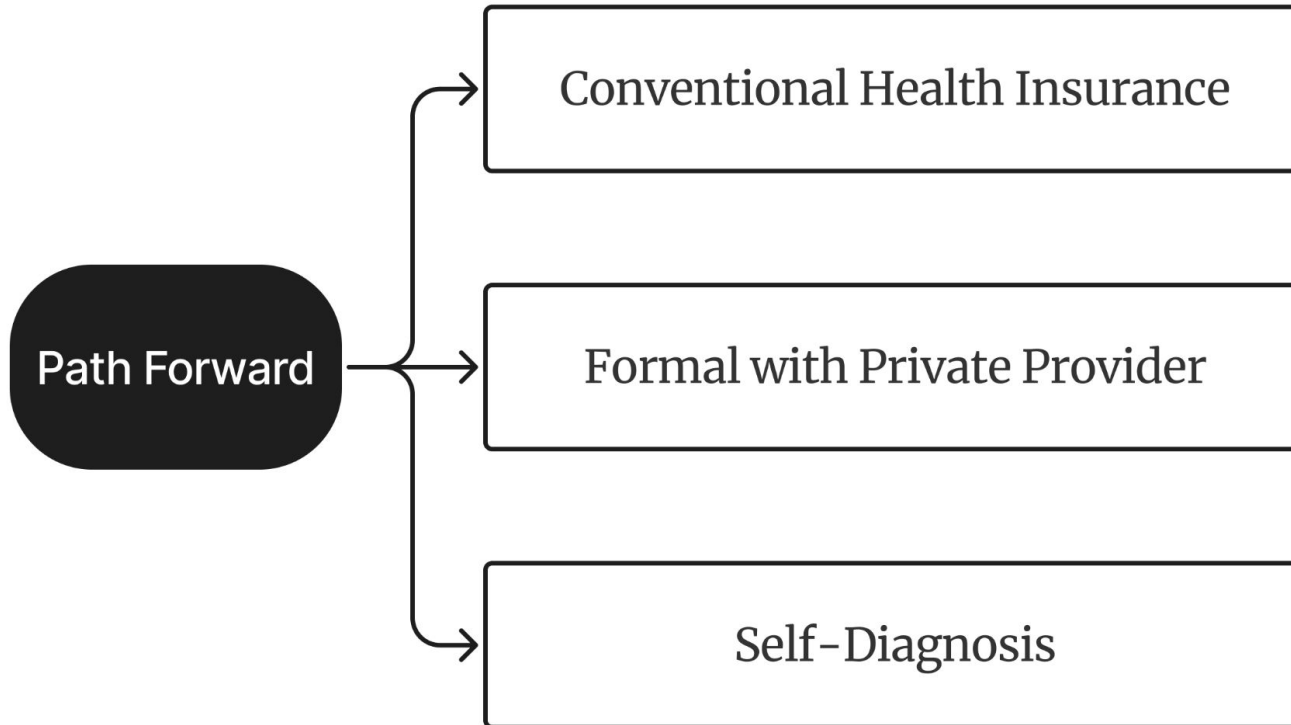
"Why do you need a label?" Because there is comfort in knowing that you are a normal zebra, not a strange horse. Because you can't find a community of other zebras, can't learn what makes a zebra thrive, what brings [you] a zebra joy, if you don't know you are a zebra and you are learning solely from horses. It is near impossible to be happy and mentally healthy if you're spending all your life thinking you're a failed horse, having others tell you you are a failed horse, when all along you could be thriving and understood if everyone, including you, just knew you were a zebra.

Diagnosis is a framework for self-compassion, advocacy, and empowerment. Don't let others delegitimize your concerns.



The Adventure Begins

CHOOSE YOUR OWN ADVENTURE™



Conventional Health Insurance

Pros

- Clarity and self-compassion
- Costs covered by health insurance
- A documented diagnosis can make it easier to access support services and accommodations
- Access to medication that could improve quality of life combined with other supports
- Feeling empowered to self-advocate due to better understanding yourself and your needs
- Connecting with other neurodivergent people informally or in formal support groups



Cons

- Cost. Even with health insurance, the diagnostic process can be expensive.
- Not finding a provider who is a good fit
- Misdiagnosis is a risk
- Process can be slow and cumbersome, with plenty of red tape
- Privacy concerns: not wanting to give health insurance or government entities more information about ourselves than necessary
- The current political climate
- Perceived societal stigma
- Ableism and discrimination at work and in personal life

“Across my work with neurocomplex clients, certain frustrations show up time and again—especially when it comes to accessing effective, affirming care. Many report feeling **misunderstood, minimized, or simply out of sync** with the very professionals who are supposed to help them.”

— Lindsey Mackereth, MA, LPCC, LADC

Formal Diagnosis through Private Practice

Pros

- Faster diagnosis
- More tailored support
- Private assessments may offer more comprehensive reports
- Quicker access to resources
- Assessment results won't be reported to health insurance or government entities unless you request it
- Can feel particularly validating with a provider who is a good fit who is actually listening to you
- Self-acceptance and self-confidence

“We really do tend to moralize these ADHD traits in particular as signs of laziness, as signs of arrogance. Like, you're too arrogant to try - that's a big one. And people internalize that. So in a way, getting told, actually, this is a neurodevelopmental disorder that's a real thing in your brain, is very reassuring. It also can potentially provide people with an infrastructure to learn to better deal with their symptoms, and it provides access or opens up access to care and medication, potentially.”

— Journalist [Kelli Maria Korducki](#)

Cons

- Cost. A private provider assessment can cost \$3000 or more in the U.S.
- Feelings of grief. This can come with a diagnosis through health insurance as well. Some people initially have a negative reaction, even if they were seeking out an assessment.
- Identity issues: A diagnosis can challenge an individual's perception of themselves, potentially leading to a need to adjust and come to terms with the diagnosis.



Self-Diagnosis

Pros

- Avoids barriers (referrals, waiting times, insurance authorization) to formal diagnosis
- Cost effective
- Maintains privacy
- Robust online communities on instagram, tiktok, reddit, etc.



Cons

- Embracing a neurodivergent identity, but it's a misdiagnosis
 - For example, autism symptoms can look a lot like anxiety, depression, trauma, ADHD, bipolar disorder, etc. (but comorbidity is real)
- Interactions with others who are skeptical from family members to friends and coworkers
- Misinformation. See quote.

One study found that over a third of the claims about ADHD on social media weren't related at all to ADHD or even other diagnoses, but were instead just, quote, "**reflecting normal human experience.**" This study suggests perhaps people are over-pathologizing aspects of their own lives.

— Brittany Luse, NPR's [It's Been a Minute](#)

Life After Diagnosis

Progress, Not Perfection

After an adult diagnosis of autism, ADHD, AuDHD, OCD, etc.:

- Allow time to process and adjust
- Embrace self-awareness
- Seek out formal or informal support at your comfort level (my close family members and friends are all neurodivergent)
- Learn to set boundaries and self-advocate
- Request accommodations from your employer if you need them



YOUR



MILEAGE



MAY



VARY

Resources

- [Lindsey Mackereth](#): Minneapolis based psychotherapist, coach, [writer](#), and consultant at Method
- [We're Not Broken: Changing the Autism Conversation](#) by Eric Garcia
- [Unmasking Autism](#) by Devon Price, PhD
- [NPR Life Kit conversation](#) between Eric Garcia and Devon Price
- [What I Mean When I Say I'm Autistic: Unpuzzling a Life on the Autism Spectrum](#) by Annie Kotowicz
- [Sounds Like Misophonia](#) by Dr. Jane Gregory
- [Timer Caps](#) for pill bottles (so I don't inadvertently take medications too much or not enough)
- [no hello](#) (chat etiquette)
- [Organize all aspects of your life](#): Get to-dos out of your mind and get them done in less time.
- [Pomodoro Technique](#) for time management + [Chrome extension](#)
- Ellie Middleton video: [how to give neurodivergent friendly instructions](#)
- [Unmasked: The Ultimate Guide to ADHD, Autism, and Neurodivergence](#) by Ellie Middleton
- National Library of Medicine study: [Autism Identity and the "Lost Generation": Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum](#)
- [What It's Like Having Adult ADHD](#) comics by Megan Berry

Questions?

Thank you!

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- sharynmorrow.com

