

## DOCUMENT SUMMARY

This is a formal research report titled "The Price of Knowing," which details the lived experiences of individuals seeking neurodivergent assessments for Autism and ADHD in the United States. Based on first-person accounts from 2020-2025, the report outlines the systemic failures of the assessment process, including prohibitive financial costs, insurmountable logistical barriers, and the invalidating nature of the clinical evaluations themselves. It highlights how these challenges are amplified for marginalized communities and argues for comprehensive reform.

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## FORMATTED CONTENT

# The Price of Knowing: A Lived-Experience Report on the Neurodivergent Assessment Process in the U.S.

## Introduction: The Lifelong Search for an Answer

The formal process of seeking a neurodivergent assessment is rarely the beginning of the story. For countless adults in the United States, the decision to pursue a diagnosis for **Autism** or **ADHD** is the culmination of a lifetime spent grappling with a profound and painful sense of difference. It is a journey that begins not in a clinician's office, but in the quiet, internal world of a person who feels fundamentally out of sync with their environment. First-person accounts from digital communities reveal that before any forms are filled out or appointments are made, there is a long, often agonizing, prelude characterized by feelings of alienation, a history of medical misdirection, and finally, a transformative moment of self-recognition that makes the arduous path forward seem not only possible, but necessary.

## The "Alien" Feeling and the Search for a Name

A pervasive theme woven through the narratives of undiagnosed and late-diagnosed individuals is a persistent, unshakable feeling of being an outsider. From a young age, many report a sense of confusion and isolation, stemming from an inability to intuitively grasp the social codes and rules that others seem to know automatically. This is not a fleeting sense of awkwardness, but a deep-seated conviction of being fundamentally different, often described in stark, existential terms.

One individual recalls a lifetime of feeling "like I was an outsider or alien," a sentiment that drove them to struggle socially and fail to understand the unspoken rules of human interaction.

This feeling can be so profound that it leads to a questioning of one's own humanity. "I had a feeling something about me is not human," another user shares, reflecting on being a constant target for reasons they could not comprehend. This internal state is one of deep loneliness, born from the knowledge that one's mind simply works differently.

As one woman recounts, "I always knew that I thought differently and it made me feel so alone. I felt like there was something so wrong with me".

This "wrongness" is not a moral failing but a neurological reality that, without a name, festers into self-blame and shame. The search for a diagnosis, therefore, is often a search for a vocabulary—a way to name the unnameable and find a framework for an entire life's worth of confusing experiences.

## A Lifetime of Misdiagnosis and Misunderstanding

The path to an accurate **neurodivergent** diagnosis is frequently littered with incorrect ones. Before **Autism** or **ADHD** are ever considered, especially in adults and women, individuals are commonly diagnosed with a host of other conditions, most notably depression, anxiety, bipolar disorder, or personality disorders. They dutifully follow treatment plans for these conditions, often for years or even decades, only to find that the medications and therapies do little to alleviate their core struggles. This experience compounds their sense of being "broken" or "wrong," leading them to believe they are uniquely treatment-resistant.

One user describes being prescribed a litany of antidepressants, recalling, "I never felt any different after taking them, maybe made me more numb".

This experience of being medicated for the wrong condition is a common and deeply frustrating one. For many, these misdiagnoses begin in childhood. "As a teenager I had major mental health issues- I was first diagnosed with depression at age 12," one woman shares. Another individual, after spending thousands of dollars on an assessment, was told his lifetime of sensory and social difficulties were "probably just my C-PTSD," a dismissal that invalidated his core experience. For those with co-occurring **Autism** and **ADHD (AuDHD)**, the cycle of misdiagnosis can be particularly damaging. One person noted that the standard treatments for anxiety and depression "weren't working and even making it worse," a clear signal that the root cause of their distress lay elsewhere. This history of medical misdirection not only delays access to appropriate support but also deepens the individual's internalized belief that they are a failure, unable to get better even with professional help.

## The "Lightbulb Moment" of Self-Recognition

For many, the turning point is a sudden, powerful moment of clarity. After decades of confusion, they stumble upon an article, a video, or another person's story that accurately describes adult **Autism** or **ADHD** for the first time. In that moment of recognition, a lifetime of disparate, painful experiences clicks into place, forming a coherent narrative. This "lightbulb moment" is often described as intensely emotional, bringing both tears of relief and a radical reframing of one's entire personal history.

One user, upon discovering information about autism, recalls, "I've always felt different and I teared up after realizing how much it fits and how much it explains about me," citing lifelong struggles with friendships and heightened senses.

This feeling of being truly seen, perhaps for the first time, is transformative.

"It's like I'm seeing my whole life and history through new eyes," another person shares after a psychiatrist first suggested she be screened for autism. "So many things make sense now!".

This newfound understanding provides the critical motivation needed to embark on the formal assessment journey. It is a hope for official validation, a confirmation that they are not "broken," "lazy," or "weird," but **neurodivergent**. This hope becomes the fuel that sustains them through the immense financial, logistical, and emotional challenges that lie ahead.

## The Financial Gauntlet: The Prohibitive Cost of Clarity

Once an individual decides to seek a formal diagnosis, they immediately collide with what is consistently cited as the single greatest barrier: the staggering financial cost. The journey to an answer is paywalled, and the price is often far beyond the means of the average person. This is not merely a practical inconvenience; it is a source of profound stress, exclusion, and self-doubt that shapes the entire experience. The financial burden functions as a systemic gatekeeper, effectively making self-knowledge and access to support a luxury item.

### The Shock of the Sticker Price

The initial inquiries into an assessment are frequently met with a sense of disbelief and outrage at the quoted prices. For those paying out-of-pocket, the costs routinely run into the thousands of dollars, a sum that is simply unattainable for many. The numbers shared in online communities paint a stark picture of a system that prices out a significant portion of the population. Users consistently report being quoted figures like "\$2.5 - \$3k", "\$1800", and "\$2500". Some family members have paid as much as "\$5000" for a loved one's assessment. For parents seeking help for a child, the costs can be even more astronomical, with one user reporting a quote of "\$6k".

The reaction to these figures is often one of indignation. "A psychologist really just expects someone to drop 3 thousand dollars at a visit like that? Who the? What the?" one user exclaims, adding, "I don't even make that much in a month".

This sentiment underscores the fundamental disconnect between the cost of the service and the financial reality of the people who need it. Even when going through a college's health services,

which one might expect to be more affordable, a student was shocked to find the out-of-pocket cost was still around "\$1900". This initial sticker shock establishes an immediate and often impassable wall, stopping the diagnostic journey before it can even begin for many.

## **The Insurance Maze and the "Adults Don't Count" Mentality**

For those with health insurance, the process is rarely simpler. Navigating the world of coverage for **neurodivergent** assessments is described as a labyrinthine and frequently futile exercise. A recurring and particularly painful theme is the explicit denial of coverage for adult assessments, a policy that reinforces the outdated and harmful belief that **autism** and **ADHD** are exclusively childhood conditions. Individuals report being bluntly told by their insurance providers that the company "doesn't test adults". This is not an isolated incident. One user on state insurance, **Medi-Cal**, discovered that it "doesn't cover autism diagnoses for adults over 21". This leaves adults who have struggled their entire lives without a diagnosis completely stranded, forced to either abandon the quest or find a way to pay the full, exorbitant fee out-of-pocket. Even those with what they describe as "really good health insurance" are not immune. One person noted that without a special discount offered personally by the specialist, a "\$3000 dollar service" would have still cost them "\$1000 out of pocket". Many are forced to find providers who are "out-of-network," which again shifts the financial burden entirely onto the patient. This systemic failure of insurance to cover adult assessments is a form of medical gatekeeping that invalidates the lifelong struggles of **neurodivergent** adults and denies them access to the care and accommodations a formal diagnosis can unlock.

## **The Hidden Costs of the Journey**

The sticker price of the evaluation, however steep, is often just the beginning. Users describe a cascade of hidden and ancillary costs that accumulate throughout the process, adding to the already significant financial strain. These are rarely discussed upfront by clinics and can come as a surprise, further complicating an already stressful situation. The assessment is rarely a single event. It often involves multiple, separately billed appointments. One user detailed a process that included a "\$250" initial consultation and a "\$200" follow-up appointment, in addition to the main testing fee of "\$1,500 - 2,700". Furthermore, the assessments themselves can be lengthy, requiring multiple hours or even spanning several days. This necessitates taking significant time off from work, which for many hourly or freelance workers means lost income. The search for a qualified provider can also add travel costs to the bill, as the nearest specialist who assesses adults may be hours away.

As one person noted, "it was so expensive and the nearest person who would work with adults was 2 hours away".

These hidden costs for consultations, follow-ups, lost wages, and travel-can add hundreds or even thousands of dollars to the total price of a diagnosis, making the true financial burden even heavier than it first appears.

## **The Emotional Weight of the Investment: The Fear of "Wasting" Money on a "No"**

The immense financial stake transforms the diagnostic process from a neutral clinical evaluation into a high-stakes emotional gamble. A critical and emotionally resonant theme is the profound anxiety associated with spending thousands of dollars only to be told "no." This fear of

invalidation is not just about the emotional pain of being dismissed; it is intrinsically linked to the terror of having "wasted" a life-altering amount of money.

This agonizing calculus is articulated perfectly by one user contemplating the expense: "Ugh, so expensive. I'll feel embarrassed if I spend all this money and end up not being autistic".

This single statement captures the immense pressure individuals are under. They are forced to weigh a significant financial sacrifice against the deep, personal need for an answer to a lifetime of questions.

The same user continues, "But I don't wanna be left wondering for the rest of my life, so I guess it'll be worth it".

This highlights the desperate position many find themselves in, where the potential for clarity is so valuable they are willing to risk financial hardship and embarrassment to achieve it. This dynamic creates a perverse and unspoken pressure on the individual to "prove" they are "autistic enough" to justify the cost. The financial barrier is not just a practical hurdle; it is a psychological one. It forces individuals to place a monetary value on their own identity and gamble on the outcome. This turns the assessment into a performance, where the person being assessed feels an implicit need to ensure their investment pays off with a "yes," adding a layer of inauthenticity and profound psychological distress to an already vulnerable experience.

## The Logistical Labyrinth: Navigating a Broken System

Beyond the financial barriers, individuals seeking a **neurodivergent** diagnosis are forced to navigate a logistical system that is frequently described as broken, confusing, and profoundly stressful. The process is not a clear, supportive pathway to care but a grueling administrative gauntlet. From interminable wait times that stretch into years to the frustrating hunt for a qualified provider and the black hole of clinic communication, the system itself seems paradoxically engineered to be maximally difficult for the very people it is intended to serve. The immense **executive function** required to successfully navigate this labyrinth adds a layer of cruel irony to the entire endeavor.

### "The Wait is a Character Arc in Itself"

One of the most emotionally taxing aspects of the diagnostic journey is the wait. After finally overcoming the financial and psychological hurdles to seek help, individuals are often placed on waitlists that are shockingly long. This period of waiting is not passive; it is an active state of limbo, filled with anxiety, self-doubt, and the continued pain of living with misunderstood and unsupported struggles. The durations reported by users, particularly parents seeking help for their children, are staggering. Parents in online forums share stories of being told waitlists are "a year + long" or "12+ months long". One parent in Texas was confronted with a "22 months" waitlist, forcing them to turn to a telehealth company to avoid losing therapy services for their child. Another user recounts waiting "almost 2 yrs to see a child psychologist for his diagnosis". In one extreme case, a parent in Ohio reported that it took "6 years for us to finally get his evaluation for ASD / ADHD" after his needs were first identified at age 3. For adults, the wait can be similarly agonizing. While some report processes taking a few months, others face multi-year delays. A user in the UK's National Health Service (NHS) system reported a wait of "3 years 8 months" from their initial referral to their final diagnosis. Even after the evaluation is

complete, the wait for the final report can take weeks, with one user being told to expect a 4-week wait and another receiving their report 6 weeks after their final assessment. This prolonged uncertainty is a form of psychological torture, leaving individuals and families in a state of suspended animation, unable to move forward with their lives.

## **The Hunt for an Affirming and Qualified Provider**

Finding a clinician who is not only available but also genuinely qualified and experienced in assessing adults—particularly women and other high-masking individuals is another significant ordeal. The process is often a frustrating and demoralizing scavenger hunt, requiring individuals to sift through endless lists of providers with vague or misleading credentials. Users describe the challenge of trying to parse generic therapist profiles on platforms like Psychology Today, which often provide little real insight into a clinician's specific expertise. One person warns that "some doctors will literally list every mental illness under the sun as their 'specialties'," making it impossible to know who is truly knowledgeable about adult **neurodivergence**. The search is an **executive function** nightmare.

As one user powerfully illustrates, the very nature of **ADHD** makes the process feel insurmountable: "Googling the symptoms of **ADHD** gives me a list of behaviors that feel very familiar, but it's also a list of reasons why finding help is very hard".

They describe spending hours just figuring out their insurance login, only to be presented with a list of over 300 doctors, the first of whom had already moved out of town. The relief upon finding a competent doctor is palpable, with one user describing their experience of finding a helpful, non-dismissive doctor as having "dodged so much chaos". This highlights how the norm is chaos, and finding a clear path is the rare exception.

## **The Black Hole of Communication**

Compounding the long waits and the difficult search is the administrative dysfunction and poor communication that plagues many clinics. Individuals seeking help are often met with unreturned phone calls, confusing instructions, and a general sense of being lost in a bureaucratic void. This requires them to perform an enormous amount of uncompensated administrative labor, constantly following up and advocating for themselves just to stay on the radar. One parent's story vividly illustrates this frustration. After being told to expect a 9-month wait for their child's evaluation, they were still waiting 15 months later with no communication. They finally received a call from the clinic, but it "hung up before the first ring even finished." When they immediately called back, they were met with an automated system demanding an entry code they did not have, effectively shutting them out once again. This experience of being dropped, ignored, and lost in the system is a common complaint. It adds an extra layer of stress and helplessness to an already overwhelming process, making individuals feel like they are shouting into a void.

## **The Trial of the Assessment: Invalidation and the Performance of "Being Neurodivergent"**

For those who successfully navigate the financial and logistical gauntlets, the assessment itself presents a new and intensely personal trial. Far from being a supportive, collaborative process of discovery, the clinical evaluation is frequently described as a cold, intimidating, and

invalidating experience. First-person accounts from within the assessment room reveal a pattern of clinicians relying on outdated stereotypes, dismissing lived experiences, and using assessment tools that feel demeaning and inappropriate. This transforms the evaluation into a high-stakes performance, where individuals feel immense pressure to act "autistic enough" or "**ADHD** enough" to be believed, forcing them to fight against the very **masking** skills they developed for survival.

## "You Can't Be Autistic, You...": The Litany of Invalidation

A core and deeply painful experience reported by many, especially high-masking adults and women, is having their lifetime of struggles dismissed by an assessor based on superficial observations and outdated stereotypes. The reasons for this invalidation are often delivered as simple, declarative statements that betray a profound lack of understanding of how **neurodivergence** can present in adulthood. Users recount being told they cannot be autistic because they "make eye contact," are "married and had friends," or have achieved a certain level of education, such as a "Masters level" degree. One user was told she couldn't have **ADHD** because her standardized test scores were too high, with the doctor claiming that "people with **ADHD** have impaired cognitive abilities". These statements effectively punish individuals for their own resilience and coping mechanisms. Their ability to succeed in certain areas of life is used as evidence that their struggles in other areas are not real or significant. Often, their experiences are re-labeled with other diagnoses. One person was told their issues were "probably just my C-PTSD," while another's symptoms were summarily dismissed as "anxiety and trauma". A particularly galling and common form of invalidation comes from clinicians who use phrases like "well we are all on the spectrum," a statement that minimizes the individual's specific and often debilitating challenges. This litany of invalidation is not just a disagreement over a diagnosis; it is a fundamental rejection of the person's lived reality, often by the first professional who was supposed to understand it.

## The Pressure to Perform and the Fear of the Mask

The fear of being invalidated creates a profound and paradoxical pressure during the assessment: the pressure to perform one's disability. Individuals who have spent their entire lives developing sophisticated **masking** techniques to hide their **neurodivergent** traits and appear "normal" suddenly find themselves in a situation where they must consciously dismantle that mask to be seen and believed. This creates intense anxiety and a feeling of inauthenticity.

One user, terrified of being dismissed, received advice from a digital community to "Try to let your freak flag fly. By that I mean, avoid eye contact, fidget, stim, repeat yourself... try to let them see it".

This illustrates the conscious effort required to perform the stereotypical behaviors an assessor might be looking for. The core fear is that if one presents as "too put together" or too articulate, their struggles will be written off. This dynamic is particularly acute for women of color, with one user noting the no-win situation: "if I look and feel put together, I don't need medication and I'm just seeking uppers". The assessment becomes a performance, with the individual trying to calibrate their behavior perfectly-not **masking** so much that they are dismissed, but not unmasking so much that they are seen as exaggerating. It is a tightrope walk of authenticity, performed under the intense scrutiny of a judgmental eye.

## The "Childish" and "Stupid" Tests

Adding to the sense of alienation and invalidation is the nature of the assessment tools themselves. Many adults report being subjected to tests and tasks that feel demeaning, confusing, and utterly inappropriate for their age and life experience. These "childish" tests reinforce the feeling that the assessor does not see them as a complex adult but as a collection of childlike deficits.

A 38-year-old woman described her assessment as "exceptionally weird," recounting how she was asked to "tell a story about a paperclip being friends with a matchbox car" and act out scenarios from flashcards. Another user simply referred to the process as doing "stupid puzzles".

This use of juvenile materials can be deeply unsettling. It creates a sense of absurdity and disconnect, making the individual feel misunderstood from the outset.

As one user astutely observed, these tests seem to operate under the assumption that "an autistic adult, decades into their life, having absorbed knowledge and scripts from their environment, still has the mind of a child".

This failure to use adult-appropriate methods invalidates the person's life experience and intelligence, reducing them to a set of symptoms to be observed through a childish lens.

## **The Aftermath: The Paradox of Relief, Grief, and a Useless Report**

The diagnostic journey does not end when the assessment is over. The period following the delivery of a diagnosis is a complex and emotionally charged terrain, often characterized by a paradoxical mix of profound relief, deep grief, and frustrating disappointment. While the diagnosis can provide a long-sought-after answer, the tangible outcome—the diagnostic report—is frequently described as useless, inaccurate, or even harmful. Furthermore, individuals are often left stranded at a "support cliff," given a life-altering label with no guidance on what to do next. This launches them into a new, intensely personal journey of re-evaluating their past and navigating a future that is suddenly, and often painfully, reframed.

### **The Useless PDF: A Dehumanizing Summary of Flaws**

A significant source of anger and frustration in the aftermath of a diagnosis is the quality of the final report. This document, which should be a validating and helpful tool, is often described by users as a "useless PDF," riddled with errors, lacking in useful detail, and written in a pathologizing, negative tone. Users complain of reports that are "very poorly written," taking months to arrive and only after repeated requests. These documents often lack any meaningful data, such as scores, percentiles, or a breakdown of traits, making them functionally useless for seeking accommodations or funding. Factual inaccuracies are rampant, with reports misstating fundamental details like a person's primary language, job history, or ability to manage finances. The tone of these reports is another major pain point. They are written according to a "medical model of disability," which frames every **neurodivergent** trait as a deficit or a flaw.

One user described crying after reading their report because it felt so "dehumanising".



Instead of a tool for self-understanding, the report becomes another source of trauma—a clinical, often inaccurate, summary of everything that is "wrong" with the person.

## **"You're Autistic. Now What?": The Support Cliff**

A near-universal complaint among newly diagnosed adults is the complete and utter lack of post-diagnostic support. The arduous journey of seeking an assessment often ends abruptly with the delivery of a label. Clinicians provide the "what" but offer no guidance on the "now what," leaving individuals feeling abandoned and holding a diagnosis with no roadmap for the future. This "support cliff" is a stark reality for many.

One late-diagnosed woman vividly recalled her doctor stating he had "nothing to suggest as far as helping me since I'd already been coping this long".

This sentiment—that because an adult has survived this long, they require no further help—is a common and deeply invalidating experience. The recommendations that are provided are often generic and unhelpful. One user reported that the suggestions in their report "seemed to have come from the first page of google," offering no personalized or meaningful strategies. This abandonment leaves individuals with a new, powerful piece of information about themselves but no tools, resources, or guidance on how to use that knowledge to build a better, more supported life. The system identifies the "problem" and then walks away.

## **The Emotional Aftershock: Relief, Grief, and Burnout**

Receiving a diagnosis is rarely a simple moment of joy. It is an emotional earthquake that triggers a complex and often contradictory cascade of feelings. The aftermath is a landscape of relief, validation, grief, anger, and for many, profound **burnout**.

**Relief and Validation:** The most commonly reported positive emotion is an overwhelming sense of relief. Finally, there is an explanation.

"I was actually relieved," one woman shared. "All of a sudden, I could understand my life and my problems in a very different way". Another described it as "a breath of fresh air to finally be able to understand why i felt so out of place".

**Grief and Anger:** This relief is almost always intertwined with grief for the past and anger at a system that failed them for so long.

"Then I got angry," one user wrote. "I was so angry that I had been constantly punished mostly for displaying autistic behaviours".

**Burnout:** The emotional intensity of the assessment process, combined with the psychological weight of reframing one's entire life, often leads to a period of severe **burnout**.

"Post dx, life got harder for a while," one person shared. "My burnout got really bad from the stress leading up to the assessment and from processing the results".

The diagnosis, therefore, is not an endpoint. It is the beginning of a new, often more challenging, phase of the journey. It triggers what one user powerfully termed the "autistifying" of memories, a process where "all of my memories autistified like dominoes, every moment, every memory I have, one by one". This painful re-evaluation of one's entire life through a new

lens is emotionally exhausting. Simultaneously, the diagnosis often gives individuals "permission" to stop **masking**, the lifelong performance of neurotypicality. While ultimately liberating, this process of unmasking is initially destabilizing and depletes already low energy reserves, leading to the profound **burnout** that so many report.

## A System Not Built for All: The Amplified Struggles of Marginalized Individuals

The significant barriers of cost, logistics, and invalidation within the **neurodivergent** assessment system are not experienced equally. For individuals who hold marginalized identities, particularly women and people of color, these challenges are amplified. The system, already difficult to navigate, becomes a near-impenetrable fortress, fortified by outdated, biased models of diagnosis and compounded by societal prejudice.

### "High-Masking is a Trap": The Invalidation of Women

For women, the diagnostic process is often a battle against a medical framework built on a male-centric understanding of **autism** and **ADHD**. The "classic" presentation-often centered on externally visible hyperactivity or overt social deficits in young boys-does not capture the experience of many girls and women, whose traits are more likely to be internalized and hidden behind a carefully constructed mask of social competence.

As one user lamented, "ADHD in women is so often overlooked, misdiagnosed, or dismissed because it doesn't fit the stereotypical image of hyperactive little boys".

### The Intersection of Race and Neurodivergence: A Double Bind

For **neurodivergent** people of color, the systemic barriers are compounded by the pervasive force of racial bias. Research data confirms what personal narratives make painfully clear: Black, Latino/Hispanic, and Indigenous children are diagnosed with **autism** later and less frequently than their white peers. Black children are significantly more likely to be misdiagnosed with behavioral issues like conduct disorder before receiving a correct **autism** diagnosis.

### The Parent's Journey: Advocating for a Child in the Maze

The quest for a **neurodivergent** diagnosis takes on a unique and intensely emotional dimension when it is undertaken by a parent on behalf of their child. Their experience is often one of being disbelieved, dismissed, and judged, not only by the medical and educational systems but sometimes by their own families.

## Navigating the Maze: First-Person Accounts of Neurodivergent Assessment Challenges (2020-2025)

Based on extensive research across Reddit communities, personal blogs, patient forums, and social media from 2020-2025, this report presents the lived experiences of individuals seeking **autism** and **ADHD** assessments in the United States, with special attention to the Midwest and St. Louis region.

## **Financial Barriers: When Diagnosis Becomes a Luxury**

"I can't afford a diagnosis because it's too expensive. It costs thousands of dollars! I can't finish my Master's degree until I can get appropriate accommodations, which means being assessed for autism, which I can't afford." - Liv Robinson, a Vancouver artist

"I've discovered it's ADHD that has caused my anxiety/depression for my 58 years of life! But the costs are killing me! ... I have been able to work for more than 30 years due to this, how are we supposed to afford it?" - 58-year-old individual, Beyond Blue Forum

In the St. Louis area specifically, private assessment costs range from \$700 at **Enlitens Counseling** to \$2,995 at Healing Spaces, with limited insurance acceptance across providers.

## **The waiting game stretches months to years**

"I scoured the internet, trying to find a provider that specialized in high-masking over achieving 30-something-year-old women. It felt impossible. I found provider after provider using the same testing they would give a 4-year-old boy." - Kristina Risola, a late-diagnosed autistic woman

## **Gender bias creates additional barriers to recognition**

""Of course you don't have ADHD. You're smart,' a friend told me, definitively, before switching to the far more compelling topic: medication." - Yale student with ADHD

## **The emotional toll spans from trauma to transformation**

"When they read my results I started to cry. It was like the earth stopped spinning for a moment and everything slowed down. Autism Spectrum. Wow. Relief. Validation. Hope." - Kristina Risola

"I remember walking out of work two days after my official diagnosis after a long day and stopping in my steps in the middle of the parking lot thinking to myself, 'I feel normal.' It was so frustrating for me not knowing why I was and felt so different. No one seemed to know." - Samantha Ranaghan, diagnosed with autism at 34

## **Masking complicates the assessment process**

"I realized that the anxiety that I could never seem to get under control wasn't anxiety - it was sensory overload. No amount of CBT and challenging my thoughts were going to change the fact that I could hear the electricity from the outlet 50 feet away." - Kristina Risola

## **Post-diagnosis support remains elusive**

"For the two decades prior to my diagnosis, I never would have suspected my symptoms were symptoms. I considered these traits – my messiness, forgetfulness,

trouble concentrating, important-document-losing to be embarrassing personal failings." - Yale student

## **St. Louis and Midwest face regional challenges**

While St. Louis boasts several major medical centers offering **neurodivergent** assessments, families still encounter significant systemic barriers. The region's resources include Washington University Autism Clinical Center, Saint Louis University Division of Developmental Pediatrics, St. Louis Children's Hospital, and SSM Health Cardinal Glennon Children's Hospital. Despite these facilities, regional challenges persist.

## **Systemic themes reveal a broken system**

These first-person accounts illuminate critical failures in our approach to **neurodivergent** assessment. Diagnosis has become a privilege tied to financial resources, geographic location, and the ability to navigate complex healthcare systems. Provider training hasn't kept pace with evolving understanding of how **neurodivergence** presents across genders, ages, and ethnicities. The experiences shared throughout this research demonstrate that current assessment processes often retraumatize those seeking help. These are not merely individual struggles but symptoms of systemic failures requiring policy changes, provider education, insurance reform, and a fundamental shift in how we understand and support **neurodivergent** individuals throughout their lives.