




Neurodiversity- Affirming Therapy



What Every
Mental
Health
Provider
Needs to
Know



AMY MARSCHALL



clinical terms for many types of neurodivergence are not affirming and are linked to discrimination and mistreatment, and many neurodivergent communities have rejected these terms. For instance, research shows that individuals with a diagnosis of borderline personality disorder experience significant stigma and discrimination, including mistreatment by medical and mental health professionals, as a direct result of the diagnosis appearing in their medical history (Stiles et al., 2023). Similarly, many in the autistic community reject the clinical term autism spectrum disorder, as they conceptualize autism as a neurotype that is not inherently disordered.

As we have discussed, affirming providers honor the language preferences of the communities we serve and take steps to mitigate the harm these individuals face at the hands of the medical system. At the same time, we operate within the system as it exists, and a big part of our job is helping clients access appropriate support. Sometimes, this means using pathologizing clinical terminology, biased diagnostic criteria, or flawed assessment measures. The sections in this chapter explore the issues within the DSM and other components of the mental health system, as well as how we can navigate this system in a neurodiversity-affirming way.

Neurodivergence in the DSM

The DSM includes many forms of neurodivergence. It is not an exhaustive list of ways that an individual can be neurodivergent; Down syndrome, epilepsy, cerebral palsy, and other neurodivergences are not included in the DSM. This section looks at the language and conceptualization of the forms of neurodivergence included in the DSM, but it is important to remember that not

every neurodivergent person meets criteria for a diagnosis listed in the DSM.

The medical model used to develop the DSM makes the text inherently pathologizing and nonaffirming. Of course, having consistent, agreed-upon clinical terms for things can streamline understanding an individual's possible challenges and support needs, and it can make it easier for treatment teams to be on the same page regarding the client's presentation. At the same time, though, the DSM is designed to identify what it refers to as mental disorders. While some might conceptualize their neurodivergence as a disorder, for many in neurodivergent communities, the term disorder is itself stigmatizing and misleading, as it implies that the person with the diagnosis is less than or inferior.

Misdiagnosis

The wording of many diagnoses listed in the DSM leaves room for clinician bias and misinterpretation, as well as misdiagnosis. In an interview with this author, Hannah Owens (2024), a schizoaffective social worker who agreed to be interviewed for this book, shared that she had “a long road” to finding her diagnosis. She was initially diagnosed with major depressive disorder, which was later updated to bipolar I disorder with psychotic features. Ten years after receiving that diagnosis, she learned that she actually has schizoaffective disorder, bipolar type. Receiving a correct diagnosis helped her receive the support she needed, and it took multiple providers over a decade to reach that point.

Unfortunately, misdiagnosis is common for many neurodivergent communities. Ayano et al. (2021) found that approximately 39% of clients with disorders considered severe according to the DSM were misdiagnosed before learning their

true diagnosis. In fact, 75% of those with schizoaffective disorder (like Owens) were misdiagnosed. More than half of those with major depressive disorder were initially misdiagnosed, and almost one-quarter of those with schizophrenia were initially misdiagnosed.

These numbers show glaring problems in the field. Although a client's diagnostic category does not ultimately determine their needs or serve as a be all and end all for treatment planning, it is an important starting point in helping the client understand themselves and their needs. Until these diagnostic issues can be addressed, we are doing our clients a disservice.

Distress or Impairment

Another limitation to the DSM is that many listed neurodivergences require that "the symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning." It is not technically essential that the neurodivergent traits cause impairments in functioning if clinically significant distress is evident; however, this is a vague term. Each person exists within their own brain, and we do not have the power to enter into someone else's mind and experience the world from their perspective. Many default to the assumption that their experience is typical, as it is the only experience they know.

For example, aphantasia is the experience of not being able to visualize things in one's mind. An internet search will bring up hundreds of forum posts of individuals learning that other people can conjure images with their thoughts. These individuals went their entire lives not imagining pictures and assuming that no one could, until learning that their experience was not typical. (Aphantasia is not a diagnosis on its own in the DSM, though

autistic individuals and people with acquired neurodivergence through a traumatic brain injury experience aphantasia at higher rates than the general population.)

If my perspective is that my experience is the norm, I might not recognize and accurately label my distress as clinically significant. In that case, providers might also not recognize my distress because I am unable to communicate to them that I am experiencing something that is not part of typical human experience. After all, everyone is distressed sometimes!

Additionally, not every neurodivergent individual experiences clinically significant distress. Some simply do not experience distress as a result of their neurodivergence, which is valid, and some would experience distress if they were not in a supportive and accommodating environment. For instance, many neurodivergences like ADHD, autism, learning disorders, and communication disorders have a strong genetic component, and many members of the same family will share traits or diagnoses. Sometimes, a child may not appear impaired in an obvious way because their caregivers and other family members are simply meeting their needs appropriately. This is a wonderful thing, as every person (neurodivergent or neurotypical) deserves to have their needs met, but it can create a barrier to diagnosis when the individual does not appear to be struggling enough to require support. Sometimes, a neurodivergent child whose needs are appropriately met in the home struggles significantly when they enter a school system with very different expectations. Unfortunately, these children are often denied accommodations before they exhibit distress or impairment in the classroom. We could avoid stress and trauma if we could recognize the neurodivergence and provide adequate support before the child struggles, falls behind,

or experiences trauma at the hands of the school system, but current diagnostic criteria technically prohibit this.

If clinically significant distress cannot be documented, many neurodivergent diagnoses in the DSM can still be diagnosed if impairment in functioning is evident. Although an individual might self-report functioning issues (e.g., “I struggle with remembering or getting myself to attend to my hygiene” or “I can’t manage my finances independently”), functional labels have significant limitations and problems. First, they emphasize the individual’s impact on other people rather than their own support needs. Second, it invalidates the experience of someone with low support needs, as someone who is high-masking or can camouflage their neurodivergent traits is considered higher functioning and therefore not needing support. Third, the ranking of neurodivergent people by functioning level creates a hierarchy with the higher functioning individuals deemed better than lower functioning individuals. Someone’s value is not determined by their ability to complete tasks independently. Similarly, higher functioning is a label often attributed to someone who is able to work full time. This emphasis on participation in a capitalist system perpetuates systems that oppress disabled communities and individuals.

Some red flags that an individual might be experiencing more distress than what is obvious at first glance include:

- A client who works a full-time job but reports that they are completely drained after work, do not have hobbies, and spend days off simply recharging from work because they do not have the bandwidth for anything more.
- A client whose skills get them by, but they report taking

Do Not Distribute

more time or effort than their peers to accomplish the same things.

- A client who gets by but has a built-in support system at home that allows them to compensate due to existing supports.
- A client who reports that things that they used to be able to do seem to be getting more challenging.

For neurodivergent individuals, “burnout” refers to when the individual reaches a point of extreme exhaustion, reduced ability to cope, and a loss of skills they had previously mastered. Because neurodivergent individuals experience increased stress from living in a world not designed for them, and many go without adequate support, many constantly stretch themselves past their limit. Over time, this wears them down and can cause burnout. Typically, burnout is long-term and requires rest and space for recovery. It can reoccur as well if preventative measures are not taken.

Note that burnout can seem to emerge suddenly, so if someone is beginning to have difficulty with things that they previously felt were easy, quick intervention is essential to prevent decompensation.

Other Limitations of the DSM

Requirement for distress and impairment are not the only issues with the DSM’s conceptualization of neurodivergence. As noted, although there is a benefit to having a unified, consistent system for crafting a starting point for individual needs, the DSM has significant limitations. While many neurodivergent individuals

express relief at receiving a diagnosis, gaining a sense of community, and getting a better understanding of how their brain works, the current DSM has potential to cause harm.

Although the committees that created the DSM indicate that they strove to create consistent, clear diagnostic criteria, there is significant variability in diagnosis. A client who has been evaluated by multiple professionals often has contradictory diagnoses—for instance, bipolar disorder cannot be diagnosed alongside major depressive disorder because the bipolar diagnosis accounts for the major depressive episodes, and yet many clients have both diagnoses indicated in their charts because different providers disagreed on which mood disorder best described their symptoms (Young, 2016).

Additionally, a number of diagnoses listed in the DSM indicate that they cannot co-occur with other specific diagnoses. For example, the DSM-5-TR (the most recent revision) indicates that one individual cannot be diagnosed with both reactive attachment disorder and autism spectrum disorder. Reactive attachment disorder is a trauma disorder that develops in early childhood and prevents the child from forming emotional bonds to other people or experiencing empathetic feelings. Autistic children are at higher risk for trauma and abuse compared to nonautistic children, and there is no evidence that an autistic child cannot develop an attachment disorder, but the current DSM indicates that it is impossible to meet criteria for both. A particular danger to this kind of rule out is that an autistic child with a reactive attachment disorder diagnosis may face barriers to an accurate diagnosis regarding their autism if their provider believes that it is impossible for an individual to be autistic if they have another diagnosis.

Past editions of the DSM indicated that an individual could

not meet the diagnostic criteria for both ADHD and autism. Although this did not stop some providers from assigning both diagnoses to the same client, or diagnosing a client already diagnosed as ADHD or autistic with the other diagnosis, a provider who closely followed the diagnostic criteria could prevent client from accurately labeling and understanding their neurodivergence.

Many mental health professionals have criticized the DSM and the committee that oversaw its development for prioritizing personal opinions and bias over hard scientific research. In fact, many members who contributed to the DSM have been criticized for being compromised ethically and making changes to the final version of the text, basing these changes on personal agendas rather than what is best for the field of psychology and the clients we serve (Young, 2016).

Every version of the DSM has received criticism for its limitations and bias. As a text developed by and for predominantly white, Western populations, diagnostic criteria are based predominantly on how conditions tend to appear with this specific population, leading to higher rates of misdiagnosis. Much of the diagnostic criteria additionally have gender bias. For example, “inappropriate sexually seductive or provocative behavior” is still listed as part of the diagnostic criteria for histrionic personality disorder. A provider determining whether or not a client’s sexual behavior is “inappropriate” is likely to be biased by that clinician’s personal beliefs and values around sex, which are not universal.

Additionally, many cultures have different experiences of neurodivergence, and Western bias in the DSM leads to pathologizing culturally appropriate behavior. For example, in the United States, individuals with schizophrenia and other psychotic disorders tend to experience anxiety-provoking, scary hallucinations,

while people with schizophrenia in many African countries hear neutral or even enjoyable voices instead (Luhrmann, 2014). The DSM not only approaches neurodivergence from an inherently pathological lens, but it does so in a way that is culturally uninformed and often xenophobic and racist.

Allegations of Financial Conflict of Interest

In 2022, the DSM-5-TR revision was published, the most current version of the DSM at the time this book was written. The DSM is regularly updated, supposedly with the intent of ensuring that the diagnoses listed and criteria for those diagnoses reflect current research about presentation and appropriate treatment recommendations.

Since neurodevelopmental differences, mental health diagnoses, and neurocognitive conditions are not directly observable and quantifiable in the same way that genetic diagnoses and various medical conditions are, there is room for interpretation and debate when developing the categories in the DSM. Unfortunately, the discussions and decisions around inclusion, exclusion, and modification of existing criteria are left up to a task force who are the ultimate decision makers. While public information is not available about each task force member's neurotype and any diagnoses (or lack thereof), it is highly unlikely that this task force has representation of the communities being discussed. Of course, every person has the right to privacy and may choose not to disclose their neurotype publicly, but those in the role of making decisions that can allow or prevent access to support should be part of the communities they are discussing (Hoekstra, Girma, Tekola, & Yenus, 2018).

Lack of representation is not the only problem with the DSM task force, however. An analysis of compensation received by task force members for the DSM-5-TR showed that 60% received payments from industry, meaning that they had financial conflicts of interest that may have impacted or impaired their ability to make objective decisions. Additionally, 33% of task force members publicly reported these payments, meaning that 27% received financial incentive but did not disclose the possible conflict of interest (Davis et al., 2024).

In other words, these financial conflicts of interest may have determined certain decisions made about the DSM and the diagnostic criteria included and excluded. This calls into question the validity of the document as a whole, and yet providers rely on the DSM in informing their client's symptoms, presentation, and access to supportive services. Any provider who bills insurance *has* to assign an approved diagnosis in order to be reimbursed for services rendered, and any client who seeks supportive services *has* to have such a diagnosis in their medical record in order to access those services.

Essentially, with the system as it currently stands, we cannot be effective providers without utilizing the DSM in our practice, but the DSM is rife with problems and limitations. As such, we must be mindful and cautious in our use of this document.

Navigating the DSM as a Neurodiversity-Affirming Provider

Despite its significant limitations and issues, the DSM is the current bible in the fields of psychology and psychiatry. In the United States, many clients can only access mental health care if they can

use their health insurance to offset the cost. In order to bill insurance, the provider must submit a diagnostic code from the DSM or insurance will not pay for therapy.

Neurodivergent individuals with certain support needs—including, but not limited to, financial support because they are unable to work enough to support themselves, live-in or regular in-home care from professionals, or school or workplace accommodations—must have a documented diagnosis in order to qualify. The systems and processes of securing these supports, resources, benefits, and accommodations are not straightforward or simple at all, and many who have the right to these supports are often denied for arbitrary reasons. However, in order to even start the process, they must have a diagnosis and documentation of traits and symptoms according to the DSM diagnostic criteria.

A neurodiversity-affirming provider operating in a flawed system will struggle to navigate and hold conflicting truths: “The DSM is significantly flawed, and the diagnostic criteria I assign to my client are pathologizing and often harmful,” and “Refusing to name a diagnosis can create additional barriers to my client receiving the support they need,” are two statements that are simultaneously and equally valid and true. If every affirming provider refused to comply with a flawed system, this would leave our clients only to providers who are not neurodiversity-affirming, who are more likely to cause harm and trauma to our clients. Thus, many providers choose to operate within the system as it exists.

As noted, neurodiversity-affirming mental health care involves collaboration and respecting the client’s knowledge as an expert in their own life. This means that we are transparent with our clients about our process, including systemic issues

and problems within our field. When the system requires non-affirming language or assessments in order for a client to receive needed support, have a conversation with your client. Reaffirm to them your commitment to providing neurodiversity-affirming care as well as your commitment to helping them access the support they need. Explain your concerns about the system and what nonaffirming things are required from you in order to help them access what they need. Tell them that you are committed to helping them, which will mean that you operate within the system as you need to and simultaneously remain committed to being neurodiversity-affirming.

This may not be a one-and-done conversation. Clients may sit with the information and have follow-up questions later. We must always be open to questions or concerns by our clients, and we have to remember that informed consent is ongoing. The client has the right to ask more questions, gather more information, or change their mind at any time. In this way, we collaborate with them in determining what is best for their mental health care and for their lives. By providing them with accurate and appropriate information, we can empower them to make the best decisions for their life.

Not only will this honesty help clients understand our clinical decisions, but also this will prevent misunderstanding in the future. Clients have the right to view their records and see what we have written or shared about them to other providers and in their medical chart. If I tell a client that I am neurodiversity-affirming, and then use nonaffirming language in order to operate within the system, but I do not communicate this to the client, they might view the records and believe I was dishonest with them about my commitment to affirming care. They might think that I deceived

them. Explaining my decision making can reassure them of my stance and approach to their care.

Some examples of how we can discuss these things with our clients include:

- “You’ve shared that you need (service) to help you with (goal). I want to help you get the support you need. As you know, the system is incredibly flawed, and those who decide whether or not you can access these services have specific rules. If I do not carefully follow their rules, they can deny you the support that you need. Let’s go over the requirements together. I want to make sure I answer any questions you have about the process.”
- “Because I am committed to providing care that is affirming and has a social justice focus, I have taken time to learn about the limitations and problems with many psychological assessments. There is research showing that this assessment has racial bias. At the same time, it can give us some information about the things you have described to me and give more evidence about the supports you need. If you are comfortable, I will make sure I interpret the results keeping these biases in mind so that we can use the beneficial information to help you. Is that something you are open to?”
- “We have talked about your preferred language around your neurodivergence. I want you to know that I take your preferences seriously, and I recognize that you have the best perception of your own experience. As much as possible, I will use that language when talking to you or when documenting. So you’re aware, the technical clinical terms

Do Not Distribute

are (relevant clinical terms). I know these do not reflect your experience, and I know that you do not agree with the people who determine clinical terminology. When I write your report, I have to use (relevant clinical terms) in order for you to have official documentation of your neurodivergence. Sometimes the language that we know is best is not what has to be documented for people to get the support they need. I want to make sure we have an open conversation about this so that you know what to expect and so that I can answer any questions you have.”

In addition to this transparency, it is important to use affirming language whenever possible. For instance, a provider in private practice who has the freedom to format their progress notes in whatever way they see fit can use affirming language in these notes even if they have to use pathologizing language in a treatment summary or report to be submitted for disability services. Examples of affirming language include:

- While the diagnostic impression has to include the accepted clinical terms, providers can still use community terms elsewhere in documentation. For instance, a provider can write autism spectrum disorder in the diagnosis but refer to the client as autistic elsewhere in their report.
- Providers can choose to describe support needs rather than functioning labels.
- When using assessment measures that contain bias, providers can document these biases and note that they only used the assessment because it was required.

- Providers can include a note stating the client's preferred language, indicate what clinical terms that language refers to, and incorporate preferred language throughout the report.

Advocacy and Striving for Change

While there are moments when we have to operate within problematic systems in order to help our clients receive appropriate supports and services in the short term, the long-term goal of the neurodiversity-affirming movement is to break down these systems and remove the need to operate within nonaffirming parameters. In addition to providing clients support in the moment, we can also advocate for systems changes. Although we are required to follow laws and systems in our practice, we are not required to remain complicit.

For instance, several states in America have autism registries. Exactly as they sound, an autism registry is a government list of autistic residents. The registries have different rules and regulations, and North Dakota law NDCC 23-01-41 requires that any provider who diagnoses autism to submit a multiple page form including extensive identifying and personal information about any autistic client to be included in a database maintained by the health department for “complete epidemiologic surveys, research and analysis, and provide services to individuals with ASD” (North Dakota Health and Human Services, n.d.).

Naturally, any neurodiversity-affirming provider will be opposed to putting their clients on a government list based on their diagnosis. At the same time, noncompliant providers can be