So your patient disclosed a neurodiversity - now what?

A brief introduction to navigating neurodiversity for patient-facing healthcare professionals

Picture this - you're seated in your usual spot across from a new patient. You run down the list of usual questions, making sure your records are complete and you have a solid understanding of the patient's history and needs.

The patient may be sitting still or fidgeting. Maybe their gaze is focused right on you, or maybe their eyes are darting around the room. They may appear calm, or may be showing minor signs of distress. They may be asking clarification questions that seem unusual to you. There may be a second person in the room with the patient, even though the patient appears able bodied.

The patient may be answering the questions as expected, or there may be some hesitation.

Then they say, maybe a little nervously, "and I'm also neurodivergent*, I don't know if that's worth mentioning".

**or ADHD, or autistic, or any number of other related terms*

For many patient-facing medical professionals, like doctors, nurses, physical therapists, mental health professionals, or those in other similar positions, it may seem like a non-sequitur.

How does your neurotype affect your knee pain, your weight loss, your anxiety - or any number of conditions or complaints that bring people into your office?

It's all about communication

The connection is in communication.

Before digging into how to address patient concerns in a mindful and effective way, it's important to understand what neurodiversity is and how it affects an individual's experience.

Consider neurodiversity the way we consider biodiversity. Minds are made in all different manners. Most minds will fit within two standard deviations of the mean, and some human minds do not, but they are still the natural way the human mind is made.

Neurodivergent is an umbrella term that is sometimes used to refer to individuals with specific diagnoses or unspecified neurological differences, whereas the “neurotypical” individual or “neuro-majority” do not include these differences.

Note: different terminology is preferred by different individuals, and terms may vary in use between medicalized/diagnostic language and human-first language within the neurodiverse community. The following definitions, for simplicity, use diagnostic terms as they are most recognizable to much of the general population.

Conditions under the umbrella of neurodivergence may include autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), epilepsy, anxiety, traumatic brain injury, and more.

These conditions are, both by legal definition and in daily life, disabilities. Neurodivergence can also include non-diagnosed and/or unspecified differences in the neurological functioning of an individual. This is not necessarily classified as a “disorder” so much as a natural difference in physiology.

A popular misconception about neurodivergent individuals is that they don't communicate well. The more honest view is that neurodivergent individuals DO communicate, they just may do so differently than members of the neuro-majority.

Communication can be especially difficult for neurodivergent individuals who have learned compensation, camouflaging, and assimilation skills to "pass" among the neuro-majority.

For neurodivergent people who are able to meet expectations in typical situations, it can be exceptionally challenging to know that your communication style differs from those around you and attempt to accommodate that. This can lead to misunderstandings and frustration on both sides of a conversation, often with neither participant knowing precisely where it derailed.

Take it across the pond

This phenomenon can be likened to jokes about British English versus American English, ie: "how can two populations both speaking English sound so different?"

While a British English speaker may say "carpark," an American English speaker may say "parking lot". The context of a conversation may make it clear that the intention is the same, but for someone who has never heard the term before, it may sound positively unnatural.

In any conversation between any two people, there is always room for misunderstanding. But when neurodivergent minds are in the mix, there are additional layers to consider.

A literal use of the word literal

In modern American vernacular, people often use the word "literal" when it's not what they mean. If a short adult says "this man stood next to me, and he was literally a giant," they actually mean it figuratively but are using the word "literal" to legitimize their (accurate) feeling of being towered over.

To minds that may be more direct and literal in their understanding, this can be extremely confusing. A member of the neuro-majority may grasp the meaning immediately, while the neurodivergent mind may or may not grasp the meaning immediately or at all. The neurodivergent listener is then left wondering why on Earth someone would choose to say something that can be interpreted in so many ways, with the speaker confused or frustrated as to why they were misunderstood.

This isn't a matter of intelligence, it's a matter of communication. Why dance around a point when you can just say what you mean?

Some neurodivergent individuals are extremely adept at compensating for their verbal and mental processing challenges; you'll never know how hard they're working to maintain "normal communication".

While some neurodivergent individuals are skilled at "masking" or "passing," others are not capable of communicating in expected ways. And yet others may need to

shift their communication style when experiencing stressors, meaning that their communication abilities vary based on situation.

Acknowledging and understanding the weight of a disclosure allows you as the practitioner to see the places where you can improve communication, thus making an encounter safer and more effective for everyone involved.

A history of negativity

Neurodivergent individuals often carry with them a history of negativity. It may be from trauma (based upon lived experiences, real or perceived) at school, home, or work.

Social situations are often difficult for neurodivergent individuals in more dynamic ways, and can be exhausting. Society is quite clear on what it considers normative and acceptable, and people (particularly children) can be quite unforgiving when it comes to social faux pas.

Across the spectrum of human experience, our minds have a tendency to acclimate to what we've experienced. This applies not just to the neurodivergent mind, but to the human mind overall. So when a familiar situation arises in which negative previous experiences have occurred, it is natural for the individual to expect the worst.

This projection of an individual's learned history onto a present encounter can lead to a pessimistic outlook and a belief that bad outcomes are inevitable even when opportunities for positive outcomes exist.

This doesn't typically happen after one or two negative experiences, but after repeated negative experiences or situations in which the individual has no control.

For example:

- If many spontaneous conversations wind up embarrassing, the mind begins to expect socialization to bring shame.
- If most professional presentations feel incomplete or ineffective, the mind begins to believe you simply can't do better.

- If the culmination of every argument is a feeling of being gaslit or ignored, the mind begins to question its own veracity.
- If most doctor appointments end with the patient feeling unheard and their problems not being solved, why will this time be any different?

This is where you come in.

Navigating a disclosure of neurodiversity

Let's go back to your office now, and the initial conversation with your new patient.

What do you hear when they say, "and I'm also neurodivergent, I don't know if that's worth mentioning"?

What you hear and how you respond is crucial to how you build a rapport with this patient and in turn, how you can accommodate and address their needs.

Things this disclosure does not mean:

- I expect special treatment
- I want an excuse for my behavior
- I'm nervous and I feel silly about it

Things this disclosure MAY mean:

- I don't experience pain like most people and may not be able to express when I do feel pain
- My mind processes slowly so I may ask you to repeat yourself and am afraid you'll get irritated with me
- My mind processes huge amounts of information at once and I struggle to focus, but I want you to know that I'm trying
- My memory suffers when I'm under pressure, so I may not remember things you tell me once I've left the office
- I cry when I feel stressed and I'm afraid I'll look foolish
- Completing treatment under bright lights may cause sensory overload which affects my emotional wellbeing and verbal abilities
- I distract easily and want to be here, but know it sometimes seems like I'm not paying attention

- I sometimes interrupt people when they're speaking and don't want to seem disrespectful
- Sometimes when I feel uncomfortable or overwhelmed, I'm unable to communicate verbally
- I have sensory sensitivities that I am embarrassed of
- I have phobias that I can't explain well
- I need to know what to expect during examination or treatment in order to manage my anxiety
- I have poor interoception and can't always notice my body's signals until the last minute and am afraid I will interrupt you at a bad time
- I have poor proprioception and am not confident that I can follow instructions properly, and don't want you to think I'm non-compliant or not cooperative

In many ways, having a minimum working understanding of neurodiversity is much like operating a trauma-informed practice. Recognizing and accommodating the patient as a person with respect for their experiences and needs supports your mutual success in working together.

A prevalence of trauma

It can be argued that trauma is a part of the human condition, and accurately. Unfortunately, trauma is even more a part of the neurodivergent condition.

While this and later sections will speak specifically about the autistic experience as an example, it is important to remember that this is only one neurotype under the umbrella of neurodiversity.

According to the Autism Research Association, autistic youth are three to four times more likely to experience sexual victimization than non-autistic youths. Similarly, when statistics from autistic adults are compared to those of non-autistic adults, the percentage of autistic adults reporting sexual harassment or sexual violence are notably higher. This trend is consistent when reviewing statistics on coercion, domestic violence, and bullying.

It is important to note that much of this research has been conducted on autistic humans who are speaking; it is assumed that the percentages of non-speaking autistic humans who are victimized is even higher.

A sensitive practitioner may rightly assume that any individual may carry trauma, and trauma-related behaviors or reactions. When dealing with a neurodivergent population, the likelihood is even higher.

References:

- Sexual Victimization in Autism
- Prevalence and Risk Factors Associated with Interpersonal Violence Reported by Autistic Adults: A Systematic Review

Mystery illnesses that get no answers

It is also not uncommon for neurodivergent individuals, and specifically those assigned female at birth, to carry medical trauma.

While not often discussed in the medical world, there are a number of conditions which tend to appear as comorbidities with neurodivergent diagnoses like autism and ADHD but are not regularly recognized as such.

As an example, a school district's treatment team or a medical doctor diagnosing a child with autism may note OCD, ODD, ARFID, dyspraxia, dyscalculia, or numerous other conditions that go hand-in-hand with the diagnosis. These are recognized and accepted comorbidities that often appear alongside a diagnosis of autism.

The student/patient may be exhibiting signs and symptoms of other complaints including hypermobility conditions (including Ehlers-Danlos Syndrome), tinnitus, irritable bowel syndrome, food allergies, eczema, POTS, difficulty breathing in the absence of asthma, anxiety, or depression. These symptoms, if noted at all, are rarely connected as comorbidities even though they very often appear in tandem.

If noted, most often the symptoms are explored and then dropped when no obvious answer appears. Frustratingly, many neurodivergent people are simply told these concerns are "in their head" or "just a normal part of life".

When a lifetime of experience seeking help for any combination of dizziness and headaches, unexplained aches and pains, skin eruptions, twisted ankles, tendonitis, stomachaches and more has been met with no answers, the mind begins to expect,

at best, no answers. At worst, the mind expects the exasperation it has so often been met with, and the shame that comes with being told that the things you are experiencing either aren't happening, aren't important, or are your own fault.

Living in your own body

Some neurodivergent humans are incredibly in touch with their bodies, and note an unusually high level of sensation (which can also lead to sensory overwhelm).

Others have a lack of interoception and feel divorced from their bodies, not noticing hunger, thirst, or bladder pressure until the last moment.

Some have learned to block out their body's sensations because the world is too big, too bright, and too noisy to feel safe in.

Some have poor proprioception, and struggle to understand where their body is in relation to the world around them.

Some may have an incredibly high tolerance to pain, and others an incredibly low tolerance. Or it may change based on the situation; a high tolerance for pain and a preference for absolute comfort can still lead to pain avoidance at a very intense level.

If you're considering these last several paragraphs and thinking, "yes, but who doesn't?"...you're not wrong. But members of the neuro-majority are more likely to be able to express these things in the moment, whereas a neurodiverse individual with a history of trauma is less likely to be able to stop and explain or advocate for themselves.

Where communication suffers

To repeat - a neurodivergent individual with a history of trauma is less likely to be able to stop and explain or advocate for themselves.

When there is stress, pressure, discomfort...the neurodivergent mind and body react differently than the neurotypical mind and body. You may notice a change in body

language, or verbal responses becoming shorter. You may notice an increase in the rate of repetitive motions, or a change in vocal tone.

These are all clear hints that the patient is in distress and struggling to maintain composure. For many individuals, there is still space for communication, but the nervous system is beginning to go into an overload.

It is possible, even when navigated with mindfulness and kindness, that this can escalate into what many will term “a meltdown” or “a shutdown”.

Unlike a temper tantrum, these are not behavioral choices. These are involuntary neurological responses to distress or overwhelm. These may range, to the observer, from a sudden lack of verbal communication to physical responses like flapping, spinning, or crying depending on the individual’s neurology, abilities, and level of internalization.

In any case, a meltdown or shutdown effectively makes communication nearly impossible at the moment.

Again, this is not a choice. It is not a person lashing out or throwing a fit. It is a symptom of a wildly dysregulated nervous system, and often can and will be overcome with time, patience, and support.

Removing judgment from the equation

Neurodivergent people are people as surely as any others are, capable of all of the good and bad that humanity has within it.

They can be polite or rude, kind or mean, talkative or reserved. They can be as sweet or as toxic as any other human. Their neurological differences are not an excuse for any behavior, but may be an explanation.

As an example, imagine spending your workday with a rock in the toe of your shoe. You might be able to ignore it, or it might be endlessly annoying. Your notice of it may come and go based on your position and how busy you are. It might make you crabby; you might even snap at a coworker who asks an innocent question and doesn’t realize how uncomfortable you are.

Now imagine that's your everyday experience. You can't remove the rock, because it's in your brain. It's simply the way your nervous system is wired and how it interacts with your body.

So maybe you go back and apologize to the coworker you snapped at. You explain that your toe was just so uncomfortable, it got the better of you and you lost patience. It's not an excuse for your behavior, but it's an explanation.

Will your coworker decide that you're a rude person who they'd rather avoid? Or will they smile and give you an easygoing "don't worry, it happens sometimes"?

Removing judgment from the equation decreases the tendency to mentally create a perception of another human that may influence our behavior towards them. It creates a kinder, gentler, more compassionate space where everyone is allowed to be themselves without fear of being punished for who they are.

How do I create a neurodiversity affirming practice?

There are any number of ways that a practitioner can create a neurodiverse friendly space. Being aware of communication differences, sensory sensitivities, and some of the emotional baggage that may come with a voluntary disclosure of neurodivergence allows you as the practitioner to be more compassionate and human centered.

If a patient makes a voluntary disclosure, they are likely willing to talk about it. So take the opportunity to forge a connection. Ask what the disclosure means to them, and how they feel it may relate to the concern that brought them to your office. Check in periodically during treatment to confirm consent and watch for assent withdrawal, which may be as subtle as a sudden change in demeanor. Discuss accommodations that enhance a sense of calm for the patient, and support the ability to be fully present.

The following are suggestions which come from neurodivergent people, on ways practitioners can easily create a more neurodiverse-friendly practice.

Please remember that there are endless variations in human physiology, neurology, experience, and perception, so there is no one-size-fits-all answer, and these suggestions are only a starting point.

- Language - Use language that is inclusive and does not make assumptions. Be prepared with a response if a patient discloses neurodiversity; avoid dismissive statements like “everyone's a little ADHD” and instead invite the patient to say more, or ask how they feel this affects the scope of their treatment.
- Voluntary non-verbal disclosure - You may choose to have a space on your intake form where a patient can disclose any form of neurodiversity, the same way they would disclose family history, surgeries, or other relevant information. You may even include a checkbox indicating if the patient would like to discuss it, or if they simply want you to be aware.
- Sensory sensitivities - Many neurodivergent individuals are sensitive to lights or sounds, and these sensitivities can affect anxiety level or ability to communicate. Particularly for ongoing treatments like physical therapy, the ability to dim or cover lights, or the availability of a white noise machine may help sooth some of these concerns. You can also invite patients to bring and wear a sleep mask or earbuds for the duration of treatment, if both parties are comfortable.
- Communication of intent - Many neurodivergent individuals struggle with the unknown. This distress can often be lessened by a practitioner communicating what to expect, and explaining as they proceed. Periodic verbal check-ins to confirm comfort and ongoing consent can be extremely helpful in supporting compliance and effectiveness of treatment.
- Communication of distress - Some neurodivergent individuals do not experience pain or other sensations in expected ways, and may struggle to communicate their discomfort when they do. For ongoing physical treatments or procedures, establishing a non-verbal cue like raising a hand, tapping on the practitioner’s wrist, or ringing a bell can allow the patient to communicate distress even if they cannot access their speech.
- Augmentative and alternative communication methods - much in the way the pain scale utilizes colors, numbers, and images to convey different levels of pain, other supportive methods of communication can be made available. This may include a printed poster or sign, or note cards that patients can use to get attention, answer questions, or indicate confusion.

- Follow up - Because neurodiversity can affect memory, it may be difficult for patients to follow up as directed. Providing instructions in writing can be an effective way to address this.

By familiarizing yourself with the basics of neurodiversity and equipping yourself to navigate it in a human-first, respectful way, you increase the chances that a population in need has access to the resources and services it requires.

In doing so, you are doing a service to your field as well as society as a whole. Your diligence will be rewarded; you just may find yourself the favorite practitioner of many very interesting individuals, and you're helping build a kinder and more understanding medical field.

This resource has been created in partnership between Naturally Effective Behavior LLC and Ilana Leah LLC as a means to bridge the gap between neurodiverse individuals and neurotypical clinicians. It is written in cooperation with, and with feedback from neurodiverse professionals, clinicians, parents, and patients.

The ideas, opinions, and advice included in this article are editorialized, and are not presented within Naturally Effective Behavior LLC's capacity as a BCBA/LBA.