

# DoubleQueer

Being Neurodiverse and Gender Diverse

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**IN** this chapter, we explore neurodiversity among transgender, non-binary, and/or gender-diverse (TNG) people in clinical and community settings. The authors of this chapter are experts in this area as academics and researchers, and are also members of the neurodiverse community. Neurodiversity is broad—we focus here on autism and ADHD (see Chapter 9, "Disability Justice and Access Needs for Disabled TNG People"; and Chapter 18, "Affirming Gender Identity in the Setting of Serious Mental Illness," for additional facets). We begin by outlining the literature and the importance of concepts such as neurodiversity. We then explore diagnosis and clinical practice, research equity, accessibility, criminalization and the law, and the work of neurodiverse clinicians. This chapter will be useful to a broad audience of clinicians, community health workers, scholars, and researchers. We discuss these issues separately for ADHD and autism, but readers will likely find information in both sections useful.

# BACKGROUND

## Autism

A growing body of literature reports on a greater incidence of autism among TNG (vs. non-TNG) people and vice versa. The cause is unclear (Turban and van Schalkwyk 2018), but posited theories often contain anti-TNG bias,

such as attributing the gender dysphoria itself to OCD, social or cognitive challenges, deficits in theory of mind, or cognitive rigidity (Hillier et al. 2019; Jackson-Perry 2020). Those rationales align with professional and societal practices that view disabled people as compulsorily heterosexual and cisgender (Atkinson 2021; Barnett 2014; Kimball et al. 2018). Some clinicians have noted cases in which autistic traits in children disappear after gender affirmation (Fortunato et al. 2022).

The most compelling reason for the autism/TNG overlap may be that autistic people are simply less susceptible to the narrowing effects that prescriptive gender norms have on self-perception of gender and thus more likely to become conscious of the subtle, internal experiences that can lead a person to identify as TNG (Walsh 2021; Walsh et al. 2018). The same argument posits, conversely, that allistic (non-autistic) people are less likely to be aware of or motivated to address incongruity between others' and their own perception of their gender. This is supported by research demonstrating that autistic people are also more likely to be gay, lesbian, and bisexual (George and Stokes 2018). Clinicians should be careful not to characterize an inability to navigate the rigid social mores required to hide one's gender or sexual identity as a psychological disorder.

## ADHD

The literature exploring ADHD in TNG people is less developed than that of autism. Only 17 relevant publications exist at the time of this writing, and all were published in or after 2014 (Goetz and Adams 2022). Gender-affirming care specialists wrote 65% of these articles, and 71% used medical records to report the prevalence of ADHD in a TNG sample. Only four (case reports) discussed potential personal or clinical implications of the TNG-ADHD nexus and focused on holistic diagnosis and treatment. None of the 17 articles proposed an explanation for the reported increased prevalence of TNG + ADHD experience. None of the articles, with the exception of Goetz and Adams (2022), avoided deficit-framing or included explicit authorship by TNG-ADHD individuals.

### Neurodiversity

The term *neurodiversity* has a contested origin. The oldest known term in common use by the neurodiverse community is *neurotypical*, which appears to have originated with Autistic Network International (ANI) in the 1990s (Silberman 2015). *Neurodiversity* itself first appeared in print in *The Atlantic* (Blume 1998) and is credited to Judy Singer, an autistic sociologist who used it in a mailing list (Kapp 2020) and in her thesis (Singer 1998). It was almost exclusively used to describe people with autism; people with "dyslexia, ADHD, dyscalculia, and a myriad of other conditions [were] christened 'cousins." (Silberman 2015, p. 454).

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Kassiane Asasumasu coined *neurodivergent* circa 2015 (Chapman 2021). Asasumasu hoped that the term would encompass all those with "a brain that diverges [including] Autistic people. ADHD people. People with learning disabilities. Epileptic people. People with mental illnesses. People with MS or Parkinson's or apraxia or cerebral palsy or dyspraxia" (Asasumasu 2015). Neurodiversity has subsequently widened to encompass all people with "variations...in cognitive, affectual, and sensory functioning" (Rosqvist et al. 2020, p. 1) and is defined, most broadly, as "the uniqueness of all brains" (Gillespie-Lynch et al. 2020). The neurodiversity model confronts a disease-based or medical model of health care that "views physical or cognitive differences as disabilities...to be corrected" and is "partly responsible for the creation of systemic barriers and negative stigmas the neurodivergent regularly face" (Jurgens 2020, p. 73).

# **AUTISM: DIAGNOSIS AND CLINICAL PRACTICE**

#### Incidence

According to the CDC (2020), "about 1 in 44 8-year-old children have been identified with ASD (or 23.0 per 1,000 8-year-olds)." Recent research also found a similar rate (2.21%) of adults in the United States with autism (Dietz et al. 2020). These rates are notably higher than earlier prevalence estimates, which may be due to improved reporting practices, increased testing (particularly among lower-income people and people of color) (Winter et al. 2020), and multiple diagnoses being collapsed into "autism spectrum disorder" (American Psychiatric Association 2013; Hansen et al. 2015). A recent meta-synthesis by Warrier et al. (2020) found TNG individuals to have a 3.03–6.36 times greater rate of autism than cisgender individuals, in addition to elevated rates of autistic traits and ADHD.

# Diagnosis

Within the United States, DSM-5-TR (American Psychiatric Association 2022) is used for diagnosis of autism. Although ADHD can occur in tandem with autism, their criteria overlap, so they need to be carefully differentiated during diagnosis. An autism diagnosis is not a neutral act, however; it may interfere with access to TNG health care by causing clinicians to be more cautious than they otherwise would be (Adams and Liang 2020; MacKinnon et al. 2020).

Diagnosis is also not universally accessible. Autism is more commonly diagnosed in children, and until recently, adult diagnosis was rare. Insurance plays a large role in the financial coverage of diagnostic costs, which often reach several thousand U.S. dollars, and may be more available to parents seeking diagnosis for children than to independent adults seeking their own diagnosis. Some people may secure financial coverage through secondary education insurance if referred for a psychoeducational assessment.

The utility of diagnosis varies. Children will often be able to access autism services only with a diagnosis; there are few services available in the United States for autistic adults. An autism diagnosis may give access to psycho-educational resources in university and workplace accommodations. Many autistic individuals also find it reassuring to put a name to their experiences and struggles. The clinician's role is to help the patient explore the pros and cons of diagnosis for them. Clinicians may find it helpful to self-reflect on their internalized notions around autism. Regardless, the autistic community is quite welcoming of people who are self diagnosed or "community diagnosed" (see Bennie 2020; Shekhar 2020).

### **Comorbid Conditions**

Many conditions are more prevalent in autistic people than in non-autistic peers. A recent review reported higher rates of OCD, ADHD, suicidal behavior, and disorders of anxiety, mood, psychosis, sleep, impulse control, eating, and substance use (Hossain et al. 2020). Another found increased risk of sleep problems, epilepsy, self-inflicted oral soft tissue injury, peripheral hearing loss, allergies and autoimmune disease (including diabetes), gastrointestinal issues, and (among those assigned male at birth) hypospadia (Rydzewska et al. 2021, p. 12). The generalizability of these findings may be limited by the setting of individual studies (e.g., clinical vs.community) and whether the sampling strategy was reported.

Autism is a notably heterogeneous condition (see Geurts et al. 2014), and clinicians should guard against the danger of mistaking "treating a comorbidity [for] treating autism itself" (Chown 2020, p. 34). Likewise, we should resist the temptation to cleave autistic people into categories of "low" and "high" functioning, as all people function at different levels throughout their lives; for example, a person may have poor cooking skills but be highly skilled artistically. Moreover, "autistic people can be extremely cognitively able and yet have major difficulties in other domains," and their experience of being disabled can be highly "contingent upon social conditions such as stigma, rather than inherent disadvantage" (Bovell 2020, p. 50). Ultimately, cognitive ability (or perceived ability) is not synonymous with capacity to contribute to society and is not sufficient to deny gender-affirming care.

### **Treatment and Clinical Care**

Clinical guidelines exist for autistic and TNG children and adolescents (Strang et al. 2018a) but not for adults. Emerging evidence suggests that many clinicians

who serve TNG communities are reluctant to treat autistic people and are overly cautious in doing so (Adams and Liang 2020; Shumer et al. 2016; van der Miesen et al. 2018), perhaps because of differences in the ways that autistic and neurotypical TNG patients present. As has been noted, autistic people may not perceive the need to present in a stereotypically gendered manner (Walsh 2021; Walsh et al. 2018). Jacobs et al. (2014), for instance, observed that TNG autistic people may express discomfort with changing their clothing to "match" the gendered expectations of their felt gender. Although care should be taken to explain possible safety concerns related to not meeting societal gender expectations (e.g., violence and discrimination), clinicians must not make treatment conditional on physical appearance or conformity to a norm. Clinicians are advised to approach the care and treatment of TNG and autistic patients with the same openness with which they approach neurotypical patients.

A related issue is the tendency of anti-trans organizations and activists to use TNG autistic people as a "cautionary tale" against gender-affirming care broadly. This conflation is almost always undertaken without the participation of autistic individuals. A notable exception is the Cain and Velasco (2020) case report of an autistic TNG individual who discusses detransitioning because of anti-trans stigma.

Autism alone is insufficient reason to infer incapacity and deny or delay gender-affirming care. Nevertheless, it is often a factor in decisions to do just that (e.g., Zupanič et al. 2021). Lemaire et al. (2014) go so far as to direct that "if [autism] is diagnosed, rehabilitation centered on social interactions and communication should be proposed before sex reassignment surgery" (p. 397). This recommendation presumes that an autistic person can and should become "not TNG" through rehabilitation, which has never been documented to occur successfully.

Clinicians working with all TNG people should tailor "information and gender-affirming care...to allow for different learning styles [and communication challenges] specific to the individual" (Cheung et al. 2018, p. 236). These concerns do not take precedence over TNG health care, but patients "struggling with social aspects of gender transition [may benefit from]...interventions to develop interpersonal skills, increase self-esteem, and improve social and peer support" (Cheung et al. 2018, p. 236).

#### **Applied Behavioral Analysis**

Applied behavioral analysis (ABA), considered by many to be the gold standard treatment for autistic children, uses discrete operant conditioning to alter autistic behaviors to those more akin to neurotypical children. Several scholars have pointed out striking similarities between ABA and gay/trans conversion therapies (Gibson and Douglas 2018; Pyne 2020), and that the emphasis on compliance from children in ABA fosters increased vulnerability to sexual assault (Sandoval-Norton et al. 2019). Others have noted that ABA inhibits behaviors used by people with autism to self-regulate, and that it causes PTSD (Kupferstein 2018). Autistic children and adults should be supported with information about medical options and risks; however, they should never be compelled to change or hide fundamental aspects of themselves to access health care or for any other reason.

# ADHD: DIAGNOSIS AND CLINICAL PRACTICE

#### Incidence

In a 2016 survey of parents, 6.1 million children in the United States (9.4%) had ever been diagnosed with ADHD (Centers for Disease Control and Prevention 2022). The lifetime prevalence of ADHD was found to be 8.7% among adolescents and 4.4% among adults 18-44 years old (National Institute of Mental Health n.d.). Recent systematic literature reviews (Goetz and Adams 2022; Thrower et al. 2020) found ADHD rates of 4%–20% among TNG children and adolescents (2–13 times greater than cis peers) and 4%– 11% among TNG adults (3–11 times greater than cis peers). These findings are limited by "self-reported diagnoses, a bias [toward] young internet users, and, as birth-assigned sex was not [always] asked,...unlikely to be representative of transgender cohorts" (Thrower et al. 2020, p. 703). Furthermore, hyperactivity and impulsivity in TNG youth are often labeled as "externalizing behaviors" (a broad category encompassing aggression and delinquency), impeding proper diagnosis of gender dysphoria (Coleman et al. 2012; Dawson et al. 2017). There is also little research on the overlap of TNG identity and ADHD, although the literature on TNG identity and autism sometimes comments on a higher incidence of co-occurring ADHD, potentially from stress and inherent vulnerability (Warrier et al. 2020).

# Diagnosis

ADHD diagnostic criteria for adults and children differ only by the number of symptoms that must be present (5+ if  $\geq$  17 years old vs. 6+ if <17). Neuropsychological testing or an intensive psychiatric interview may establish diagnosis, although it may be difficult to obtain insurance coverage for the former. As with autism, ADHD is not a neutral diagnosis and may bring with it a host of other socio-logistical problems associated with discrimination. TNG individuals are at particular risk of clinicians invalidating TNG identities, inappropriately assigning mental health diagnoses, and overmedication (Dawson et al. 2017).

Generally speaking, clinicians and researchers appear to express fewer concerns about coincident TNG and ADHD than autism. The specter of autism seems to provoke a fundamental conceptual challenge to the idea of providing gender-affirming care, perhaps because of deficit-based research that stereotypes autistic people as dependent and incapable. In contrast with autism (e.g., Lewis 2016a, 2016b), adult ADHD supports (e.g., medication, psychotherapy) are more widely available, although an official diagnosis is usually required to access them. These supports can make the difference between succeeding in one's education and employment or not (Gupta 2021).

Adult ADHD diagnosis appears to be increasingly common and socially acceptable (Jaynes 2021). However, TNG people may be less likely to obtain a diagnosis in childhood because they fail to match stereotypically gendered assumptions regarding ADHD presentation (Call 2018; Christian-Brandt et al. 2021; Janssen and Leibowitz 2018; Kuvalanka et al. 2018). Diagnosis of ADHD has historically been much less available for Black and Latinx children than white peers (Coker et al. 2016; Joho 2021), and racial and socioeconomic barriers persist (Chung et al. 2019). Among children with diagnoses, white people are most likely to receive treatment, and Asian people least (Shi et al. 2021; see also Chapter 7, "Gender-Affirming Care in Asian American and Pacific Islander Communities"). Clinicians should be well versed in cultural sensitivity regarding different experiences and presentations of ADHD and autism. The Color of Autism Foundation (n.d.) offers excellent resources that may be helpful here. Nevertheless, the cost of an ADHD diagnosis can run into the thousands of dollars, and insurance coverage may be limited. Clinicians should be prepared to advise patients regarding the pros and cons of ADHD diagnosis and to help problem-solve specific issues of access regarding diagnosis, medication, and treatment.

# **Comorbid Conditions**

ADHD is associated with "mood and anxiety disorders, substance use disorders, and personality disorders" (Katzman et al. 2017, p. 1); physical comorbidities include allergies, neurological problems (e.g., seizures, migraines), and immunological problems (Pan and Bölte 2020). Although ADHD is not a true "condition," young people with both autism/ADHD and TNG report notably "high levels of bullying, harassment, and abuse" (Holt et al. 2016, p. 115).

# **Treatment and Clinical Care**

#### Health Care Provision

Clinical guidance for working with TNG/neurodiverse patients is extremely limited, particularly for adults (as opposed to children) initiating care. Accessing any form of gender-affirming medical care can be an extremely slow process that requires a lot of waiting and uncertainty. A person looking to start hormone replacement therapy might need to wait  $\geq 6$ months for a first appointment, a week or even several months between requesting and starting it, then an even longer period before noticing changes. Likewise, going through legal processes to change one's name and gender marker can be long and arduous, consisting of dozens of logistical steps across a variety of systems. Those with ADHD may struggle with the process if they have difficulties with organizational skills, task completion, and other aspects of executive dysfunction. Yet there is no evidence that ADHD cannot be managed optimally during gender affirmation. Many neurodiverse individuals are also sensitive to stimuli and unable to wear transitional garments (e.g., binders). This does not discount their degree of gender dysphoria, but rather highlights the negotiation of multiple important, contradictory needs.

Clinicians caring for those with ADHD may need "a range of different tools and approaches to account for factors such as inattention [and] lack of organization" (Cheung et al. 2018, p. 236). This can include psychoeducation; mindfulness, behavioral, and impulse control techniques; and strategies to deal with depression triggers and stress management. Evidence supports several psychotherapeutic skills-based programs and multimodal approaches (Hesslinger et al. 2002; Philipsen et al. 2007; Solanto et al. 2008; Young and Amarasinghe 2010; Zylowska et al. 2008). An individual's experience with ADHD should not be used to invalidate their gender identity or deny access to gender-affirming health care.

#### Medication

For ADHD symptom management, stimulants such as methylphenidate (e.g., Concerta, Ritalin), dextroamphetamine and amphetamine mixed salts (Adderall), and lisdexamfetamine (e.g., Vyvanse) have been shown to be highly effective and safe with appropriate medical oversight (Groom and Cortese 2022). Nonstimulants such as atomoxetine (Strattera), nortriptyline (Pamelor), and bupropion (Wellbutrin) remain second-line for symptoms management but may be preferred for a specific patient for a variety of reasons (e.g., history of substance use disorder, unable to tolerate side effects of stimulant, cardiac condition) (Groom and Cortese 2022). For information about potential stimulant side effects and interactions with GAHT, see Chapter 4, "Psychopharmacological Considerations for TNG People."

# ACCESSIBILITY

#### **Physical**

Clinicians may need to adapt their practices to be accessible to neurodiverse individuals. Such adaptations may be physical: for example, offering appointments with lowered lights, no scents, and a less busy environment (Lynch 2019). Clinicians should also consider alternative means of holding appointments, such as telehealth or secure messaging service.

Patients with ADHD may have difficulty keeping appointments or arriving on time. Clinicians should not draw conclusions regarding patients' potential desire for or capacity to undergo gender-affirmative care based on such factors alone. Autistic patients, on the other hand, often need appointment times to be precisely observed. Building a time buffer into appointments can help with this. Given that many autistic patients are periodically or completely nonverbal, care should be given to allow for them to respond via text or methods such as sign language (Pezzuoli et al. 2020).

### Communication

Clinicians should be aware of differences between autistic and neurotypical communication styles to adequately provide services and not mistake miscommunication for incapacity. For instance, fidgeting, stimming, and lack of eye contact are normal among those with autism and not a sign of disrespect or disengagement. The disconnect between autistic and neurotypical communication has been termed the "double empathy problem," in which "the misperceptions... of the neurotypical majority influence the perceptions and behavior of autistic people such that they become increasingly separate and indeed isolated from mainstream society" (Milton 2012; Mitchell et al. 2021).

Autistic patients may be better able to respond to closed questions asked in a direct and concrete way, and clinicians should not be surprised by overly literal answers. From the autistic perspective, a question such as "How was your day?" can be too broad to answer—it might not be obvious what part of the day the question refers to, or whether it hides other social expectations. Better to "match conversation styles to those of the client, and to use more concrete starters such as 'How was the traffic?"" (Jacobs et al. 2014, p. 281). Requests and requirements should be explained and have clear rationale. An understanding of the reason for a policy will help an autistic patient to follow it. (Thus clinicians are encouraged to consider the rationale for conditions and requirements.)

This communication approach should be kept in mind when asking questions about gender, which is inherently intertwined with socialization and societal expectations. Questions regarding experience of gender identity and desire for gender-affirming care should be concrete and direct, with clinicians prepared to navigate miscommunications. Strang et al. (2018b) offer the following examples: "When did you first notice that you might be [affirmed gender]? What did you notice? ...What is it like to be transgender and autistic?" (p. 40–42). The Autistic Women and Nonbinary Network has a resource to assist TNG autistic people in preparing for and obtaining TNG health care (daVanport et al. 2020).

# **RESEARCH EQUITY**

#### Autism

Since 1996, >600 articles have been published that touch on people who are both TNG and autistic, with >170 in 2020 alone (N. Adams, personal communication, June 2023). Little of this originates from or accounts for their perspective and instead focuses on the supposed etiology of this overlap, with the implicit goal of reducing or eliminating it. TNG autistic people, on the other hand, frequently cite the need for research that addresses their access to health care and sexuality education (see Adams and Liang 2020).

Another oft-noted concern is the impact of *masking* (not to be confused with physically wearing masks in the pandemic), in which autistic people are encouraged or required to subvert and hide their autistic traits to appear neurotypical (Pearson and Rose 2021). Masking may exert psychiatric stressors similar to those experienced by TNG people, and the effects of hid-ing one's autism and minoritized gender identity can be mutually reinforcing (George and Stokes 2018; Murphy et al. 2020). Research exploring the causes and costs of masking, as well as efforts to promote awareness and understanding and ultimately decrease the degree to which it is required, would be welcome.

## ADHD

The literature on the TNG-ADHD intersection is particularly young and sparse, and it focuses almost entirely on the etiology of and possible problems caused by this overlap (Goetz and Adams 2022). The lack of explicit TNG and ADHD community involvement in existing research is particularly striking. Future work is needed that moves beyond incidence, etiology, and prevention to explore this group's health care needs.

# LAW, POLICE, AND CRIMINALIZATION

Research exploring the risk posed to autistic people by police violence would be useful. Police often respond to calls for mental wellness checks with disproportionate force. Combined with a frequent inability to understand an autistic person's communication and a propensity to misinterpret autistic behavior as evasive or indicative of illicit drug use, police interaction with autistic people is lethal all too frequently. A recent study found that people with autism were more likely to have an interaction with the police, and that these interactions were frequently negative and resulted in escalating the crisis (Tint et al. 2017).

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Police interactions are even more frequently violent when the autistic individual is a person of color and, in particular, Black (Ball and Jeffrey-Wilensky 2020).

Autistic people may be more likely to experience institutionalization and comparatively harsh legal consequences or even indeterminate sentences owing to their presentation (e.g., the autistic and TNG woman discussed in Baker and Shweikh 2016). Again, autistic people of color are more likely than whites to experience racialized health disparities, such as delayed diagnosis, and to receive diagnoses that carry greater stigma and blame, such as conduct disorder or oppositional defiant disorder (Bishop-Fitzpatrick and Kind 2017; Mandell et al. 2007).

Research on people who are TNG and neurodivergent should involve and be led by people who are themselves at this intersection. Some leading journals in this field, such as *Autism*, now require community involvement statements (Community Involvement Reporting FAQ n.d.). It is critical, however, that participation be meaningful and not perfunctory.

# NEURODIVERSE PROFESSIONALS IN TNG HEALTH CARE

Many established professionals are also members of autistic, ADHD, and TNG communities. There are distinct advantages to having a knowledgeable researcher or clinician who is a member of the community being investigated (Cabral and Smith 2011; Zane et al. 2005). For instance, communication between autistic and neurotypical people has been shown to be less effective than between two autistic people (Crompton et al. 2020).

## CONCLUSION

We highlight the need for community-driven research and leadership in neuroqueer scholarship and the paucity of literature on the intersection of ADHD and TNG identities (in contrast to that on autism and TNG identities). This disparity may stem from pathologizing distinct neurodivergent experiences or a perception that they interfere in TNG health care.

Ultimately, gender-affirming care should be available to everyone, regardless of diagnoses. This may require more learning on the part of clinicians, but that is only just. Neurodiverse people are not inherently less capable, and any requirement to be cured or "managed" before care fails to understand the inherent basis of both neurodiversity and TNG identities.

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