



# Caring for Transgender and Gender Diverse Youth with Co-occurring Neurodiversity

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## Introduction

Gender is thought to be a developmental process, and for some youth, gender identity may continue to shift and develop throughout childhood and into adolescence or adulthood. Diverse aspects of social, emotional, and identity development may be influenced by the presence of autism spectrum disorder (ASD), and increasingly, the co-occurrence of gender diversity and ASD is a focus of study. While most clinicians are aware of the potential co-occurrence of several psychological symptoms in transgender and gender diverse (TGD) children and adolescents [1, 2], less is known about the seemingly higher prevalence of ASD and/or social developmental impairments in TGD children and adolescents seen in specialized gender services. A growing body of literature has attempted to characterize and quantify the presence of ASD characteristics in TGD youth. This work started in the nineties with descriptions in case reports [e.g., 3]. In 2010, the first systematic study was performed investigating diagnoses of ASD in children and adolescents referred for gender dysphoria (GD) assessment [4]. Since then, the number of publications on the co-occurrence of GD/TGD and ASD has increased every year [5]. So, what do we know now about this potential co-occurrence? For example, can GD be diagnosed in youth with ASD? Likewise, can ASD be diagnosed in TGD youth? Also, what should every clinician working with TGD youth with (characteristics of) ASD know? This chapter describes the

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current state of the literature regarding this co-occurrence and addresses important clinical aspects with regard to assessment and gender affirmative treatment.

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## What Is Autism Spectrum Disorder?

The two main characteristics of ASD are (i) persistent impairments in social communication and interaction (criterion A) and (ii) restricted, repetitive patterns of behavior, interests, or activities (criterion B) [6]. The umbrella term ASD encompasses conditions that were previously referred to in the DSM-IV-TR as autistic disorder, Asperger's syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), and childhood disintegrative disorder [7]. This creates some challenges in comparing literature over time and similarly reflects a changing and growing lexicon as well as growing body of evidence across the ASD frameworks, also visible in TGD data and frameworks.

Characteristics of ASD usually manifest from early infancy onward [6]. ASD is heterogeneous with respect to clinical presentation and severity [8]. The extent to which characteristics manifest depends on the severity of the ASD characteristics as well as on the developmental level and chronologic age [6]. Difficulties in establishing, maintaining, and understanding social relations in youth with ASD vary from a lack of social interaction and play to difficulty adjusting one's social behavior to different social settings (criterion A). Individuals with ASD might also struggle to share thoughts and feelings with others, to use nonverbal communication, such as eye contact or gesturing, and might find it difficult to respond to social situations or find these situations overwhelming. An example of the B criterion of repetitive behaviors typical for ASD could be a tendency to order toys instead of playing with them, or simple motor stereotyped behaviors such as hand flapping, rocking, or spinning [6]. Children and adolescents with ASD might also show a tendency to sameness, as can be apparent from a resistance to change and rigid patterns of thinking (e.g., getting upset by a small change in routines). The limited and fixed interests seen in ASD are often unusual in focus and intensity [6], for example, an intense interest in trains. Sometimes, these interests might be correlated with being over-sensitive or under-sensitive to sensory input or with an unusual interest in the sensory aspect of the environment (e.g., the urge to touch certain fabrics, dislike of specific food textures, or fascinations with shiny objects) [6].

The prevalence of ASD in the general population has recently been estimated around 1%, with a prevalence rate that is two to three times higher in males assigned at birth [8]. The exact cause of ASD is unknown. It has been suggested that ASD has a multifactorial origin, resulting from genetic and nongenetic risk factors (and their interaction) that might interfere with typical neurodevelopment [9]. ASD is often described as a neurodevelopmental condition. A more non-pathologizing approach is to view ASD as a neurodiverse condition resulting from developmental variation or as neurodiversity [10], instead of a disorder per se.

## Co-occurrence

A growing body of literature suggests that neurodiversity and GD/TGD intersect more frequently than might be anticipated by chance. Existing literature has for the most part framed this as a categorical question, attempting to quantify rates of co-occurrence of GD and ASD. Studies have differed in the methods used (both qualitative and quantitative), the samples investigated (TGD individuals and individuals with ASD, respectively), and the use of control groups. The literature with regard to the co-occurrence of GD and ASD in children and adolescents was first described in several case reports [e.g., 3, 11]. The first quantitative study was a Dutch study that examined ASD in children and adolescents consecutively referred to a gender clinic by formally assessing an ASD diagnosis, using the Diagnostic Interview for Social and Communication Disorder [12]. An ASD incidence of 7.8% was found ( $n = 16$  meeting the full criteria of ASD out of a total of  $N = 204$ ) [4]. Other quantitative studies investigated the characteristics of ASD instead of ASD diagnoses in TGD children and adolescents [13–19]. These studies included sample sizes ranging from 25 to 490 TGD children and adolescents. Using different measures, such as the Social Responsiveness Scale [15, 17] or the Asperger Syndrome Diagnostic Scale [18], while using neurotypical [e.g., 13] or ASD reference groups [19], all studies that investigated clinical range ASD percentages found increased percentages of individuals that met the cut-off for a potential ASD diagnosis ranging from 14.5% to 68%. It should be noted, however, that none of these studies used a clinical control group, and therefore, general conclusions about these studies should be made carefully [20].

Conversely, one study investigated GD diagnoses in children with ASD [21]. This study found that children with ASD were over four times as likely to be diagnosed with GD, compared to children from the general population. In addition, four studies investigated gender variance (GV), defined as the wish to be of the other gender, in samples of children and adolescents diagnosed with ASD [22–25]. They found elevated levels of GV compared to the general population, with percentages ranging from 4% to 6.5%. One study also found increased levels of GV in individuals with attention-deficit/hyperactivity disorder [24], and therefore, any conclusions about the specificity of these findings should be made with caution. One recent study investigated TGD and ASD in a community-based general population sample of children and found that increased ASD characteristics were associated with increased TGD characteristics [26].

Although the literature strongly points out a more frequent intersection of TGD and neurodiversity, some additional conceptualizations are relevant. Diagnosing ASD properly can be challenging, even more so in clinic-referred youth. In general, more research with validated measures is necessary to investigate the co-occurring prevalence rates. Also, the social cognitive challenges that have been found in TGD youth might represent a distinct phenomenon from ASD; TGD individuals might score higher on social cognitive measures due to a high prevalence of minority stress and poor peer relations, instead of reflecting an ASD diagnosis [20].

## How Could the Possible Co-occurrence of GD/TGD and ASD Be Explained?

In the literature, several ideas have been forwarded to make sense of the possible co-occurrence of GD/TGD and ASD. These can be subdivided into biological, psychological, and social mechanisms or a combination of those, as suggested by van der Miesen et al. [27] and will be discussed below.

### Biological Factors

It may be hypothesized that the intersection between GD/TGD and ASD is related to shared, brain-based factors. In ASD research [28], as well as research related to the potential GD/TGD–ASD co-occurrence, one hypothesis is based on the extreme male brain (EMB) theory [29]. This theory posits that, on average, neurotypical males have a stronger drive to systemize than empathize, while neurotypical females have a stronger drive to empathize than systemize. Empathizing is the drive to understand and respond properly to another person's thoughts and emotions, while systemizing is the drive to analyze, understand, or construct systems [29]. According to the EMB theory, the brain type – with regard to these cognitive profiles – of individuals with ASD has shifted toward an extreme male type, with on average more systemizing than empathizing [29]. Increased prenatal testosterone exposure has been suggested as one of the contributing factors underlying this shift and might influence the development of the brain in the male or female direction [30]. Furthermore, the EMB theory has been suggested to be involved in the GD–ASD co-occurrence [31], as increased intrauterine testosterone exposure could lead to both increase in autistic characteristics or ASD, and also GD, especially in assigned females at birth. While some studies indeed partly support the EMB theory by indirect evidence, most other studies do not support the EMB theory as an explanation [e.g., 19]. In addition, the EMB theory would only explain why assigned females at birth with ASD might have more co-occurring TGD/GD, and therefore, more research is needed to see if and how the EMB theory might be an underlying factor.

### Psychological Factors

For clinicians assessing children or adolescents with ASD who exhibit gender diverse behavior (e.g., cross-dressing), it is important to consider whether this behavior might reflect the sometimes limited, fixed, and intense or focused interests, which are one of the B criteria for ASD [6]. Correspondingly, authors of several case reports have suggested that TGD in persons with ASD might originate from ASD-related preoccupations or fixations [3, 11, 32]. The first author who suggested this hypothesis described two boys with gender diverse behavior that was thought to be the result of a tendency to unusual objects [33]. In line with this hypothesis, one study investigated obsessions and compulsions in children referred for GD and found that both

obsessions and compulsions were elevated compared to nonreferred individuals [16]. In the children assigned male at birth referred for GD, themes in obsessions and compulsions were significantly more gender-related compared to their male siblings. In contrast, no differences were found among those assigned female at birth. Another study investigating different subdomains of the ASD spectrum (e.g., social problems, orientation problems, stereotyped behavior, and resistance to change) in children and adolescents referred for GD found elevations on all subdomains of the ASD spectrum in both assigned boys and girls at birth, respectively [19]. These findings imply that factors contributing to the potential co-occurrence of GD–ASD might not be specific to obsessional interests in individuals with ASD as previously suggested, but rather be related to more than one subdomain of ASD. Thus, it remains unclear whether obsessional interests in cross-gender themes occur in the context of ASD or are in fact related to gender identity development [16, 20]. These interests might be a way of communicating their gender identity, especially when confronted with resistance from, for example, the family, or stem from minority stress or stigma, instead of ASD-related characteristics [15, 16]. TGD youth might, therefore, also score higher on ASD measures in general [20]. Further, other subdomains of ASD, such as hyper- or hyporesponsiveness and developmental rigidity, have been suggested [4] to contribute to TGD in individuals with ASD, but more research is needed to see whether this can be supported by empirical evidence [27].

## Social Factors

Children and adolescents with ASD might be less aware of stereotypical societal gender norms and, therefore, be less hampered to express TGD, allowing them to follow their own creative gender path [24, 34]. Differences in social learning and this lack of awareness may lead to a less concrete, socially determined concept of being a binary “gendered” individual. The experiences of individuals with ASD, with regard to gender, might be very insightful in deconstructing society’s binary view of gender [34]. One study in adults has investigated different ASD characteristics and found support for the hypothesis that individuals with ASD might be more resistant to social gender conditioning [35].

Children with ASD might find it difficult to form relationships with peers and to establish and maintain friendships [6]. Some reasons for these social difficulties include having a lack of shared interests and being less aware of the feelings and needs of others. Being ostracized or bullied might make it extra difficult to fit in with their own peer group. As a result, it has been hypothesized that children might develop a dislike of their own gender and develop feelings of belonging to the other gender [4, 11]. This phenomenon might even be reinforced if children feel that they are more tolerated or accepted by members of the other gender. For example, an assigned boy at birth who is not good at soccer, and therefore is bullied by other assigned boys at birth but is readily accepted by a group of assigned girls at birth, might develop a dislike toward being a boy and a greater sense of belonging to the group of girls. Likewise, an assigned girl at birth who does not understand the

unwritten social rules that apply to a group of assigned girls at birth and shares certain interests or skills with assigned boys at birth (e.g., playing with dinosaurs) might identify more with a group of boys. One study in adults with ASD investigated social identification and found lower social identification with gender groups and less positive feelings (self-esteem) about gender groups compared to neurotypical individuals. In addition, TGD adults with ASD reported lower gender identification and self-esteem than non-TGD individuals with ASD [36]. However, this hypothesis has not been directly investigated with regard to gender identity development and remains, therefore, speculative.

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## Assessment and Treatment

Children and adolescents with ASD or ASD characteristics might present gender-related concerns to health professionals in different settings, for example, to their general practitioner, pediatrician, or mental health specialist. Questions might arise regarding the implications that co-occurring ASD might have on assessment and treatment of TGD children and adolescents. The following section addresses clinical aspects regarding assessment and treatment of TGD youth and co-occurring ASD together with a vignette example. To date, only initial clinical guidelines based on expert consensus for the care of TGD adolescents with ASD were published [37].

### Assessment

While co-occurring ASD might come with challenges in assessment, there is clinical consensus that TGD and ASD can co-occur independently and that an ASD diagnosis should not be an exclusion criterion for a GD diagnosis in children and adolescents nor for gender-affirming treatment in adolescents [37]. It is recommended to screen TGD children and adolescents for ASD and to refer for ASD diagnostics if indicated. Likewise, it is also advisable to screen youth with ASD for gender-related questions [37]. Individuals with (characteristics of) ASD who seek help for feelings of TGD could best be assessed by professionals with both expertise in TGD and ASD or by those with TGD expertise in close collaboration with ASD experts [37].

The role of the mental health provider in general may include assessment for GD/TGD, including affirmative and open exploration of the gender identity, assessment for/treatment of coexisting mental health conditions, to educate and advocate, to provide information on peer support, and to inform about/refer for gender affirmative medical interventions [38].

What ASD-specific characteristics should clinicians take into consideration during the diagnostic process? Youth with ASD who seek help for gender-related concerns might not always present as their experienced gender or find it difficult to socially transition due to social anxiety and impaired executive functioning (e.g., planning, organizing, and abstract thinking). Also, it might be more difficult to present socially in the experienced gender role before any gender affirmative treatment has taken place

[37]. For clinicians and parents, such a presentation could give rise to second thoughts about the credibility of their experience. Nonetheless, many of these youth might have persistent feelings of GD and should not be denied access to the assessment of GD. Instead, these individuals should be referred to professionals who might help them explore their gender identity and goals in a safe and supportive setting that incorporates appropriate integration of any ASD impact on executing an affirmation plan.

Assessment could additionally be complicated due to difficulties in communication and expressing/exploring gender-related feelings [37]. Individuals with ASD might be less aware of how they feel about their body, and identity in general, which could make it difficult to discuss feelings with regard to gender identity. Also, because of a tendency to use “black-and-white” thinking rather than “gray,” individuals with ASD might find it difficult during assessment to explore gender from a continuous perspective, instead of a binary concept [37]. Additionally, understanding of the long-term impacts of treatment might be difficult for youth with ASD if they have limited ability to envision the future.

When assessing youth with ASD for GD, it is therefore advisable to have information on their strengths and challenges (e.g., cognitive functioning, communication abilities, executive functioning) and to take ASD-related features into account by, for example, adjusting language to their cognitive level or making use of visual supports. Treatment for specific ASD-related challenges or needs, such as problems with emotion recognition or social communication problems, can be advised, both prior (during the diagnostic phase) and parallel to gender affirmative treatment [37].

#### **Vignette: Sam**

Sam, a 14-year-old assigned male at birth, was diagnosed with ASD at age 8. In early childhood, Sam’s development differed from peers in several areas. While growing up, Sam had several fixations, among others for dinosaurs, later for aliens and elves. Sam had a different way of interacting with peers, misunderstanding the intentions of others, and feeling left out and bullied. Sam also had a friendship with Ellen, a same aged assigned girl at birth living next door. They liked to play together with dolls and dress up as princesses. Sam never talked about gender identity questions till age 12. At that age, Sam mentioned the strong wish to be like Ellen. When presenting at the gender clinic, Sam could at first only describe what Ellen had that Sam also wished for, like having clothes with glitters and having more friendships with girls. Sam also told the clinician that Sam likes her name because it could both be a boy and girl name. During the assessment of GD, it took Sam several months to disentangle their own feelings and thoughts from the picture Sam had made of Ellen. Sam went to a therapist experienced in ASD to enable her to give words to her feelings. During these sessions, the despair became apparent that Sam felt because of the bodily changes caused by puberty. Sam’s parents were supportive, adding examples of gender diverse behavior from early infancy on, and giving room to Sam in discovering her own identity.



It can sometimes be challenging to disentangle GD/TGD from ASD-related characteristics. Clinicians and/or caregivers might be worried that TGD feelings might stem from ASD-related characteristics such as fixations/obsessions, special interests, or a need for certain sensory input. It is to be advised to take an individual approach, with sometimes an extended assessment period [27, 37].

Youth with ASD might report experiences of TGD since elementary school [39]. However, sometimes children with ASD might be devoid of any self-reference to gender when they are younger and might be less aware of social gender norms. They might not think about gender at all when they are little, becoming aware of gender only in late childhood or adolescence, for example, when secondary sex characteristics develop [34, 35]. Involvement of family or caregivers is important because a history from parents or caregivers can provide valuable information of gender identity development in (early) childhood. Moreover, family support can play a very important role in psychological health and well-being [38].

Also, in some studies, an elevation of emotional and behavior problems, especially affective, anxiety, and somatic problems, has been found in individuals with ASD and co-occurring TGD, compared to individuals with ASD alone [25]. Clinicians should, thus, be alert of these and other co-occurring conditions during assessment and incorporate these in the treatment plan or refer individuals to specific services.

## **Nonmedical Interventions: A Stepwise Approach, Psychoeducation, and Gender Exploration**

There is often no clear distinction between assessment and treatment of GD in youth with ASD, and assessment and treatment might partly overlap [37]. ASD-related problems in future thinking might lead to difficulties in envisaging how something in the future will be or feel. Steps in social transition should be evaluated in a stepwise approach, with regard to GD-related distress and general well-being [37]. This careful evaluation of the stepwise approach often continues during gender affirmative treatment, such as hormone treatment.

### **Vignette: Sam (continued)**

The assessment of GD was helped by the parallel treatment with the ASD therapist. Sam was able to express her feelings by, for example, describing difficult situations in a diary, making a painting of herself and formulating steps necessary to become more happy with herself. Sam discovered a more expansive way of understanding her gender diverse thoughts, feelings, and experiences, by separating her gender identity, gender expression, gender assigned at birth, and physical or emotional attraction toward others. One of the more difficult subjects was Sam's wish to be more socially accepted in the group of girls at school. Although she became more at ease with herself, she still experienced challenges in social interactions. It took Sam much effort to understand and accept that not everything would improve after transitioning.



Extended psychoeducation for neurodiverse youth, as well as for parents/caregivers, is an important part of supporting youth and their parents to help develop a broad range of possible gender outcomes and increase flexibility in thinking about gender, self-awareness, and social insight [37, 39]. During consultations with youth, it is often helpful to explore gender as a continuum instead of a binary, to provide alternative gender outcomes (such as gender fluid, a-gender), and to inform them about the options of embodying various aspects of another gender without having a full medical transition.

Youth with ASD should be encouraged to explore their gender identity, various options within the gender spectrum, and gender role/expression in their own pace, before possible irreversible medical treatment interventions. As youth with ASD might be inclined to “all or nothing” thinking, it can be challenging to take a gradual approach in exploring gender-affirming steps [37].

Incorporating aspects of the experienced gender, before medical interventions have started or completed, can be confusing or provoke anxiety. Also, exploration beyond what is familiar or what feels safe can provoke anxiety. When youth with ASD find it complex to initiate or complete a social transition due to, for example, executive functioning problems, rigid thinking, or anxiety, caregivers should be involved to facilitate gender exploration and to support or give guidance regarding any difficulties. Such difficulties can vary from problems with coming out to using makeup or finding an own and satisfactory clothing style. Also, it can be helpful to offer a certain structure in themes to be explored, for example, clothing, hairstyle, and hobbies, and each step should be evaluated carefully.

During this stepwise approach, it is important to monitor the process, and therefore, appointment compliance is important. As youth with ASD find it sometimes difficult to come to sessions, involvement of caregivers and support with planning can be helpful [37].

## Medical Treatment

### Vignette: Sam (continued)

After a period of assessment, the distress caused by the potential virilization of her body became very apparent (e.g., panic attacks because of the feeling of having facial hair, avoiding the confrontation with her body by refusing to take a shower). A treatment with puberty blockers was started as a first step to release this distress and to help Sam take the time to further discover her own unique identity. A big step was coming-out at school. Sam had first planned to transition over the summer holiday, even wanting to change school in order to avoid the confrontation with the in-between phase. Finally, with the help of her teacher, she accepted to change her plans and be open about her feelings in her own class. Much to her surprise, her peers were accepting Sam’s transition. At age 16, Sam started gender-affirming hormones, already feeling a lot more at ease with herself.

TGD adolescents with ASD have undergone gender affirmative medical treatment [4]. It has been suggested that gonadotropin-releasing hormone (GNRH) analogues (puberty blockers) to suppress puberty development and gender-affirming cross-sex hormone (CSH) therapy in adolescents with GD are associated with alleviation of GD and improvement of mental health [40, 41]. Long-term follow-up studies in TGD adolescents with ASD on either the use of GNRH analogues and CSH are lacking, and it is, therefore, until now unsure what the outcomes of gender affirmative treatment are in individuals with ASD. Because of possible difficulties with future thinking, when it comes to medical treatment to relieve GD, prudence should be taken regarding irreversible effects of medical treatment and regarding having realistic expectations for treatment. To be able to consent for treatment, benefits and risks of treatment should be discussed in a way taking the adolescents' thinking style into account [37].

The literature on gender-affirming surgery in adolescents is scarce and mainly comprises gender-affirming bilateral mastectomy [42]. Several studies have shown benefits of mastectomy in adolescents [42], yet no research has been done in adolescents with co-occurring ASD. Long-term follow-up studies are needed to see whether individuals with ASD will equally benefit from gender-affirming surgery as neurotypical individuals.

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## Conclusion

A growing body of literature suggests that neurodiversity and GD/TGD intersect more frequently than might be anticipated by chance. Underlying biological, psychological, and social hypotheses for this potential co-occurrence have been proposed, but empirical evidence for any of these hypotheses is lacking. It has also been suggested that due to minority stress in TGD individuals, they might show characteristics that resemble ASD but are a result of GD/TGD. Further research is needed to investigate if and why GD/TGD and ASD co-occur more frequently.

The experience and expression of gender may be different depending on whether someone is neurodiverse or not. With regard to assessment and treatment, there is clinical consensus that GD and ASD can co-occur independently. Individuals with ASD who seek help for their feelings of GD might come with specific challenges during assessment and treatment. However, ASD should not be an exclusion criterion, and therefore, these individuals should have access to gender affirmative treatment. Future research is needed on the sometimes clinically challenging co-occurrence of GD/TGD and ASD, for example, on the development of specific assessment tools and on long-term follow-up of treatment.

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