Gender Dysphoria and Autism Spectrum Disorder: Exploring Identity, Healthcare, and Advocacy

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Today’s agenda

• Quick terminology Review

• What is the prevalence of “gender variance” in ASD

• How do we typically assess gender dysphoria AND how should we assess Gender Dysphoria in ASD

• Looking ahead to affirmative therapies

• Information on the Gender Clinic at the Autism Center
The spectrum

Gender

Bigender

Intersex

Passing

Two-spirit

LGBTQIAPP

Trans

Aromatic

FTM

Transition

Dysphoria

Transsexual

Femme

Cisgender

Cissimilation

Non-conforming

Boi

Transmisogyny

Gay

Top-surgery

Monosexual

Queer

Cisgender

Bi-gendered

Orientation

Binary

Bisexuality

MTF

Lesbian

Agender

Stealth

Equity

Fluid
Background: Terms

- Biological sex ≠ Gender (for some people)
- Gender assumed at birth / gender assigned at birth
- Gender identity: Gender one experiences themselves as

Gender Expression ≠ Gender Identity ≠ Gender Dysphoria

Appearance, Interests ≠ Sense of who you are ≠ Mismatch & Dysphoria
Background: Terms

- Cisgender: gender ID = biological sex
- Transgender male: Male ID, assumed female at birth
- Transgender female: female identity, assumed male at birth
- Gender non-binary: Gender is neither male nor female
- Affirmed Gender: Expressing one’s gender ID
- Gender Diversity: Nonconforming gender experiences, IDs, expressions.
Biological Sex

Female  Intersex  Male

Biological sex refers to the objectively measurable organs, hormones, and chromosomes. Female = vagina, ovaries, XX chromosomes; male = penis, testes, XY chromosomes; intersex = a combination of the two.

Gender Identity

Woman  Genderqueer  Man

Gender identity is how you, in your head, think about yourself. It’s the chemistry that composes you (e.g., hormonal levels) and how you interpret what that means.

Gender Expression

Feminine  Androgygynous  Masculine

Gender expression is how you demonstrate your gender (based on traditional gender roles) through the ways you act, dress, behave, and interact.

Sexual Orientation

Heterosexual  Bisexual  Homosexual

Sexual orientation is who you are physically, spiritually, and emotionally attracted to, based on their sex/gender in relation to your own.
Among individuals with gender dysphoria receiving clinical services there is increasing evidence of a higher prevalence rate of ASD compared with the general population.

Glidden et al (Sexual Medicine Reviews, 2016)

De Vries, et al. (J of Autism and Developmental Disorders, 2010)
Combined prevalence was 7.8% in those with GID

Paterski, et al. (Archives of Sexual Behavior, 2014)
Assessed with ASD Quotient
5.5% incidence rate

Strang et al (Archives of Sexual Behavior, 2015)
Compared to controls, children and teens with ASD 7.59 times more likely to express gender variance.
ASD is heterogeneous and so is Gender identity in Autistic Individuals

Gender identity and sexual orientation in autism spectrum disorder

- Surveyed gender-dysphoria
  - 309 participants self-reported ASD.
    - 50 males and 219 females with ASD
  - 261 participants self-reported without ASD
    - 103 males and 158 females without ASD
- Screened with Autism Quotient (AQ)
- Utrecht Gender-Identity/Gender-Dysphoria Questionnaire

*Individuals with ASD reported greater diversity of gender identity and higher gender dysphoric traits than typically developing counterparts.*

Rita George and Mark A Stokes, 2017
Theories to explain correlation between ASD and GID

- GID and ASD are truly co-occurring disorders
  - With possible and complex overlapping biological mechanisms, including sex hormones

- Theory of mind differences. Individuals with ASD are less influenced by societal prejudices and feedback, thus more likely to come out.

- Gender variance may be related to reaction to sexuality.

- Possible similar social presentation in GID youth
Related characteristics in gender diverse and Autistic Individuals

- **High rates of gender variance** in autism, with females particularly varied in their gender identities. **Lower rates** of gender identification and gender self-esteem in participants with ASD than gender diverse controls (Cooper, Smith, & Russell, 2018)

- Consideration of role that social anxiety has on presentation of ASD-like traits (Nobili et al, 2018)

- Elevated prevalence of same-sex attraction amongst those with confirmed ASD, as well as those with ASD traits (Qualls et al, 2018)

- Recurrent themes for gender diverse participants with ASD: recollections of early gender nonconformity, experiences of gender dysphoria, specific challenges with interplay of gender and neurodiversity (Strang et al, 2018)
Ongoing research at Seattle Children’s: Overlap of GD, ASD risk, and co-occurring challenges

- 113 patients, age 8-20, presenting to the Seattle Children’s Gender Clinic completed questionnaires about mental health status
- Autism screening measure included in questionnaires – when patient above AQ-10 screening cutoff, considered high risk for ASD (HR-ASD)
- 20% of patients identified as HR-ASD, while only 8% carried a known diagnosis of ASD
- Common co-occurring disorders in HR-ASD group included anxiety (57%), depression (44%), and ADHD (22%)
- HR-ASD status correlated with elevated rates of self harm

Findings suggest that HR-ASD youth may be under-identified in the community and may have unique risk for psychological distress and reduced coping strategies

Curtis, Earl, Ahrens, & Orlich, 2019
APA conference submission
Ongoing research at Seattle Children’s: Gender Identity perceptions in youth with ASD

- Exploring how youth with Gender Dysphoria and/or Autism Spectrum Disorder (ASD) think about gender and their gender identity.
- Participants ages 14-19, three groups: 1) Cisgender youth with ASD, 2) Gender diverse youth without ASD, 3) Gender diverse youth with ASD

*Initial results identified school acceptance, accommodations, and affirming policies as factors that influence school climate, which play an important role in feeling of safety and support regarding gender identity*
A diagnosis of ASD does not exclude gender affirming medical interventions for individuals with GD

- “Readiness” for intervention and ability to make informed consent are critical to assess
- Supports for individuals with ASD/GD should likely include targeted social skills intervention AND psychoeducation around sexuality and typical development
- GD evaluations should include screening for ASD
Initial evaluation and consultation includes:

- Psychoeducation regarding gender identity and development
- Parenting strategies
- Strategies for talking with schools, relatives, siblings, peers
- Recommendations and referral for additional services/resources

*If a child is approaching puberty, then services may include evaluation/consultation related to readiness/appropriateness for starting puberty blockers*
Assessment goals Adolescents & Young Adults

• Parents and teen seeking consultation/treatment recommendations

• Possible readiness evaluation/referral for cross gender hormones

  ➢ 16-years-of-age (possibly younger in some cases)
  ➢ 6-12 months social transition/ living in role experiences
  ➢ In ongoing treatment with a mental health provider
  ➢ Gender dysphoria diagnosis
  ➢ Stable functioning with age appropriate engagement in school, social activities, work, etc.
  ➢ Evidence of coping skills
  ➢ Following current medical recommendations
  ➢ No suicide attempts/self-harm/ED visits/psych hospitalizations last 6 to 12 months
Unique assessment considerations for ASD/GD patients

- Ability to articulate clear gender identity difference may be limited due to social communication challenges
  - Must consider intellectual and communication impairments and adjust interviews and assessments accordingly

- Evidence that questioning of gender identity may occur later for those with ASD (e.g., at puberty onset)
Unique assessment considerations for ASD/GD patients

• Early childhood evidence of gender differences may be less apparent or not easily recounted by the patient or their parents
  • Differences in peer relationships due to ASD can influence early gender identification/gravitation toward certain gendered peers

• Comorbidities (ADHD, anxiety) are common and may further impact clinical presentation
A Continuum or “Pathway” approach

Multidisciplinary approach to lessen gender dysphoria and build a sense of movement balancing parent and child perspectives and goals

- Intermediate position—no active effort
- Encouragement of social transition to affirmed gender role and identity
- Foster support and education for family and child
- Address co-occurring issues and challenges
- Develop steps towards gender affirming interventions
Challenges for Gender diverse youth and Families

- Timing of transition varies – socially and physically
- Issues related to school
- Bathrooms
- Reactions of family (extended and immediate), friends, neighbors, religious community
- Impact on parents (experience of loss)
- Impact on siblings
- Romantic relationships
- Social stigma of not clearly “fitting in” to the gender dichotomy (male or female) – bullying, teasing
- Dealing with systems—medical, etc.
Issues at School

- Telling—not telling
- Who to tell and when
- Orchestrating gender diversity training for school
- Transferring to a new school
- Gym class, bathrooms
- Pronoun use by teachers and peers
- Bullying, harassment—peers and adults
Unique barriers for ASD/GD patients

- Limited community mental health providers who are familiar/comfortable with both ASD and gender diversity
  - Can delay or dismiss diagnoses and treatment
  - Gender-informed mental health treatment at the Autism Center to help address this
  - Education for community providers
Unique pathways for ASD/GD patients

• Families are often faced with consulting with multiple specialists (and contending with their waitlists)
  • Established interdisciplinary care at the Autism Center in collaboration with the SCH Gender Clinic to reduce this burden for families
• Perhaps due to cognitive rigidity, some patients with ASD can be hesitant to socially transition prior to starting hormones
Autism Center Gender Clinic

• Started seeing patients Fall 2016
• At least 56 unique assessments completed in that time
• Referrals are primarily from SCH Gender clinic with increasing internal referrals this year
• Clinical research and pathways of care development
• Training clinic
  • Provides training for psychiatry fellows, psychology postdoctoral fellows and psychology graduate students
The Autism Center: Child Psych Components

- **Overall services include:**
  - Psychological evaluation- sometimes limited to gender dysphoria and sometimes comprehensive evaluation
  - Consultation to parents/patients/other providers
  - Recommendations for treatment
  - Evaluation/screening related to mental health readiness for starting puberty blockers
  - Evaluation/screening related to mental health readiness for starting cross gender hormones
  - Treatment to support social transition and readiness for HRT

  - Gender non-conforming patients seen at the Autism Center for other mental health concerns outside of the gender program.
The Autism Center Gender Clinic: Evaluation specifics

- Evaluations are typically scheduled for multiple appointments.
  - Up through 5 years of age - 2 appointments
  - 6 and older - 3 appointments
- Interviews with parent and child together and with each alone. Typically, unless a child is being referred directly to start cross gender hormones (which is rare), a follow-up appointment is recommended (3-6 months for young children and 1-3 for teens depending on goals).
- Collateral contact with ongoing care provider/community therapist
- Collaborative care with gender clinic providers
Clinic flow

Initial referral
- Gender clinic
- Autism Center or Psychiatry

Assessment Day 1
- Gather history
- Child and parent are seen together and separately
- Gender assessments (paper and pencil completed)
- Questionnaires to outside provider(s) and school
- Parent questionnaires completed

Assessment Day 2
- Complete child specific gender interview
- Complete cognitive testing or other neuropsych testing
- Complete additional measures (may include CBCL, YSR etc)
- Complete ADOS where indicated
Next Steps

A referral to the Autism Center Gender Clinic may be appropriate if:

1) Child with ASD is questioning their gender
2) Gender diverse child demonstrates social communication impairments and behaviors that are suggestive of ASD
3) Child has an established ASD and GD diagnosis and you are looking for support on treatment considerations

Gender-informed mental health treatments at the Autism Center:
- Individual therapy
- Upcoming gender diverse social skills group for teens!
Resources

- Community support groups that are ASD-inclusive:

  - Youth Eastside Services
  - Ingersoll Gender Center
  - Gender Odyssey

- Seattle Children’s Gender Clinic at main campus, [https://www.seattlechildrens.org/clinics/gender-clinic/](https://www.seattlechildrens.org/clinics/gender-clinic/)
  Phone: 206-987-2028
THANK YOU!
QUESTIONS?