Neurodiversity and the Transgender and Nonbinary Community: Advocacy and Support

Meet the Presenters

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Presentation Overview

1. Understanding Neurodiversity and Autism
2. Intersections: the Autistic community and the transgender and non-binary community
   • Specific challenges
   • Current advocacy efforts
3. Review of Research:
   • What can learn from this?
   • Importance of community-led research, focus on meeting needs
   • What assumptions should we avoid?
   • Shared etiology or fetal testosterone theories
4. Best practices for mental health services with this community
What is neurodiversity?

- **Definition**
  - The idea that neurological difference is a normal and healthy part of human diversity.

- **Terminology Considerations**
  - Neurodiverse: refers to a group where some members are neurodivergent.
  - Neurodivergent: Having an atypical neurological configuration, for example a person who has a developmental disorder and/or a mental illness.
  - Often affiliated with the Autism community, but not synonymous with Autistic.
  - Neurotypical: being "neurologically typical" - within the typical (average) range for human neurology.
  - Allistic: Being non-Autistic.

Neurodiversity and Autism

- Neurodiversity often affiliated with the Autistic Community, but not synonymous with Autistic.
- Developmental neurological structures often included (e.g. ADHD, Learning Disabilities, etc.)
- Sometimes includes mental health diagnoses
- Identity-first vs. Person-first language
- Aspect of who neurodivergent or Autistic people are, not a negative quality or problem to be "fixed" or cured

Autism and the Transgender and Nonbinary Community

- Disproportionate number of trans and nonbinary people in the Autistic community
  - Experiences can overlap with, but also be unique from, that of neurotypical trans folks
  - de Vries et al. (2010) frequently cited for statistics
    - Incidence of autism diagnosis in a sample of transgender children and adolescents was 7.8%, around 10 times higher than the 0.6-1% prevalence in the general population
- Consider the role of Intersectionality
  - Connected social categorizations creating overlapping and interdependent systems of experience, but also discrimination or disadvantage
  - Must be trauma-informed
  - Used experiences may be more frequently invalidated due to identity
  - Neuroqueer as both an descriptor and the queering of neurology
- "Nothing about us without us."
The Autistic Community is Queer

• 2019 Autistic Needs Survey
  • Respondents identified 15 unique gender identities.
  • 27% identified themselves as transgender.

![Gender and Sexuality Pie Chart]

Disparities

• 51% of individuals seeking psychiatric services and 71% of individuals seeking physical health services identified their providers’ autism competence as a barrier to services.

![Disability Barriers and Food Security Chart]

Barriers in Access to Trans Care

• Autistic adults report difficulty accessing trans care due to the siloing of care.
• Autistic people are less likely to fit into traditional gender norms.
• Autistic gender identities (e.g. gendervague).
• Perception that autism requires a lack of insight, empathy, or emotional intelligence.
• Discrimination against people with intellectual disabilities.
Access to Developmental Supports

- Access to adult diagnosis is minimal in Pittsburgh.
- Autism supports are increasingly being rolled in the ID/DD system, which does not have the resources or skills to identify Autistic people.
- Autism is not a billable condition in mental health services.
- Waitlists span years.
- No guarantee of provider trans 
  
Filling the Gaps

- Pittsburgh Center for Autistic Advocacy
  - Built by queer Autistic people—staff, board, and community.
  - Peer Support
  - Resource Coordination
  - Community and Provider Training
  - Systems and Individual Advocacy
  - Legislative work

How Can Providers Do Better?

- Learn about autism from Autistic people (and pay us).
- Understand Autistic people can give informed consent.
- SLOW DOWN
- Understand the ADA

Specific Accommodations

- Visual Schedule
- Tactile
- Huddle
- Time-out
- Booklet
- Sound level
- Symbol icons
- Exit
- Lift
- Infusable of time
- Fans and an environment

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Considering Research

- Navigating terminology between medical diagnoses and advocacy movements
  - Differences between DSM IV and DSM V
  - Will use medical terminology/diagnoses in articles as quoted
- Will provide brief review of three recent articles helping to shift medical focus to advocacy lens
- Trends
  - Majority of studies focusing on adolescents
  - Initial focus on transgender and autistic intersection through the gender binary
  - Progress from recognition of coincidence to strategies for care and the mental health impact of societal challenges

Initial Clinical Guidelines for Co-Occurring Autism Spectrum Disorder and Gender Dysphoria or Incongruence in Adolescents 1 (2016)

- Autism spectrum disorder (ASD) and GNC/GD co-occur more often than by chance in adolescents: how best to support?
- Two-stage Delphi procedure for clinical consensus with 22 experts
- Data nodes:
  - guidelines for assessment;
  - guidelines for treatment;
  - six primary clinical/psychosocial challenges:
    - social functioning;
    - medical treatments and medical safety;
    - risk of victimization/safety;
    - school;
    - transition to adulthood issues (i.e., employment and romantic relationships).
- Important recommendations:
  - Expertise in both areas for assessment, or collaboration
  - Validity of youth experience, though communication style may require longer time or unique approaches, be open to non-binary identity
  - Social considerations – may connect best with other trans and autistic youth
  - Transition into adulthood

Community-Based Participatory Design for Research That Impacts the Lives of Transgender and/or Gender-Diverse Autistic and/or Neurodiverse People (2019)

- Community-based participatory research (CBPR) model:
  - partnership between clinician researchers and autistic/neurodiverse-genderdiverse (A/ND-GD) community collaborators.
  - Seeks bridge between advocacy and medical communities
- Emphasizes specific risks of doing this work without A/ND-GD collaborators
  - Emphasis on double minority/disparity status
  - Many autistic assessments based on white, cisgender males
  - Need to understand how autistic trans people may think/act in ways that do not align with neurotypical understandings of gender expression, or may describe their gender experiences and needs in ways neurotypical providers may misinterpret
  - Gain knowledge of how language is progressing around autistic and transgender experience
- Continues to emphasise developmental framework from adolescence to adulthood, and unique needs of each individual
- Asking A/ND-GD community about the direction of future research
Autism and transgender identity: Implications for depression and anxiety (2020)

- Reflects shifts in language:
  - "Autism diagnosis and autistic traits are more common in the transgender population than in the wider (cisgender) population"
  - Genderfluid and genderqueer as other identities of note
- Sample of 727 adults that assessed autistic traits, gender identity, depression and anxiety
  - Within the sample not reporting a diagnosis of autism, 566 individuals identified as cis (85.1%) and 99 individuals identified as trans (14.9%).
  - Within the sample reporting a diagnosis of autism (N = 62), 37 identified as cis (59.7%) and 25 identified as trans (40.3%).
  - Autism Spectrum Quotient score higher in transgender men
- Acknowledges need for research to expand into mental health impact of "numerous roadblocks" when seeking transition-related medical care
  - Depression scores were higher in individuals reporting a diagnosis of autism.
  - Individuals identifying as trans had higher rates of depression than those who identified as cis.
- "Depression and anxiety were highest in autistic-trans individuals which were markedly higher than in the non-autistic cisgender population. It is therefore important that future research focus on further exploring the mental health outcomes of autistic-trans individuals."

Summary of Recent Research

- Including Autistic and other neurodivergent transgender and nonbinary people in conversations about what direction research may go, and for better understanding of actual lived experience
- Shifting focus away from why is there a co-occurrence and more towards how does this co-occurrence impact mental health and wellbeing
- Developing additional guidelines for care

Clinic experience: best practices

- Individualized understanding of both Autism and Gender
- Community and Peer Support
- Suggested modalities
Individualized Approach

- If you’ve met one trans autistic person...
- Avoid assumptions!
- Express curiosity about client’s understanding of gender without invalidation:
  - Be open to researching concepts and ideas which are new to you
  - Recognize that gender expression could look very different from neurotypical trans clients

Community and Peer Support

- Connect with local resources
- Learn about ongoing advocacy efforts
- Respect significance of online community
  - TikTok
  - Tumblr (somewhat reduced)
  - Gaming
    - Avatars as representation of ideal identity

Modalities

- April
- Cori
  - Peer Support and Self Advocacy Training
  - Resource Coordination
  - Systems Change and Community Organizing
- Kaitlyn
  - Narrative therapy for identity exploration
  - Solution-focused therapy for addressing immediate needs (employment, food access, housing)
  - Dialectical Behavioral Therapy for trauma-informed care
Questions & Answers

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References


