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

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Abstract

Objective: Research addressing the co-occurrence of autism (and/or neurodiversity) and gender-diversity (A/ND-GD) has been conducted largely without the perspectives and voices of the A/ND-GD community. Including A/ND-GD community advocates as research partners may be a critical next step for advancing research initiatives on the co-occurrence given the apparent complexity and alterity of the A/ND-GD experience.

Method: Consistent with the community-based participatory research (CBPR) model we propose herein, our authorship team includes a partnership between clinician researchers and diverse A/ND-GD community collaborators. Multiple facets of the A/ND-GD lived experience are examined, including through narratives provided by our A/ND-GD community partners.

Results: Based on our experience conducting A/ND-GD-related research and our lived experience as A/ND-GD self-advocates, we highlight challenges in this line of research, including risks of conducting studies without the involvement of the A/ND-GD community. And given that many A/ND-GD youth present with gender-related urgency during the teen years, we provide a developmental framework for how CBPR-informed methods may enrich our understanding of the

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care needs of these young people and provide context for the apparent heterogeneity in their gender needs and trajectories over time.

Conclusions: Integrating CBPR methodologies in A/ND-GD research initiatives has the potential to optimize the relevance of the research questions asked and the interpretation and contextualization of study findings.

The co-occurrence of autism spectrum disorder (ASD) diagnosis or autism spectrum traits (neurodiversity) among a subset of transgender/gender-diverse individuals is highlighted in a series of international studies (for a review: van der Miesen, Hurley, & de Vries, 2016). The most consistent findings of an over-occurrence of A/ND in gender-diversity have come from studies of gender-diverse youth (e.g., de Vries, Noens, Cohen-Kettenis, van Berkelaer-Onnes, & Doreleijers, 2010; van der Miesen, de Vries, Steensma, & Hartman, 2018a). For example, among 859 transgender youth, 22.5% reported an existing diagnosis of ASD (Strauss et al., 2017). Other studies across various age ranges have reported rates of ASD diagnosis in 6%–25.5% of gender-diverse individuals (Strang et al., 2018a).

Similarly, an over-representation of gender-diversity characteristics has been identified in studies of autistic individuals (Hisle-Gorman et al., 2019; Janssen, Huang, & Duncan, 2016; Strang et al., 2014; van der Miesen, Hurley, Bal, & de Vries, 2018b), with the highest rates thus far reported among autistic adults: Up to 15% of autistic adults report a gender identity other than cisgender (Walsh, Krabbendam, Dewinter, & Begeer, 2018). The association of gender-diversity characteristics and autistic traits has also been identified in a large non-clinical sample of children recruited from the general population (Nabijohn et al., 2018). Expressions of the co-occurrence are observed outside of research, as well. For example, the Autistic Women’s Network recently renamed itself the *Autistic Women and Nonbinary Network* in response to the gender-diversity within its constituency (Allison, 2018), and in 2016, the Autistic Self Advocacy Network, National Center for Transgender Equality, and the National LGBTQ Task Force released a joint statement on the rights of transgender autistic people (“Task Force Joint Statement,” 2016).

The A/ND-GD co-occurrence is complex given the double minority/disparity status and intersection of two diverse identity characteristics. Adding complication are the urgent gender-related treatment decisions facing many A/ND-GD youth as they enter puberty and experience the development of secondary sex characteristics (Strang et al., 2016). There is a pressing need for clinically applicable research on the co-occurrence (Fuchs, Strang & van der Miesen, 2019), but how can allistic (i.e., non-autistic) and/or cisgender (non-gender-diverse) researchers, who are distant from the lived experience of being A/ND-GD, accord their research agendas and interpretations to produce recommendations for a group of people clinicians struggle to understand and relate to? To illustrate the depth, complexity, and alterity of the co-occurrence, we provide a series of vignettes on the A/ND-GD lived experience, with a focus on the emergence of identities over time. We then explore the special challenges faced by youth with the co-occurrence. Finally, we propose a community-based participatory research (CBPR) model to mitigate the potential risks for misinterpretations and misunderstandings in A/ND-GD research, and as a means of attuning research agendas to A/ND-GD community priorities. Our authorship team consists of

clinician researchers experienced in research with this population [JFS, LGA, MK, AIRvdM] and A/ND-GD self-advocate community partners [SEK, RC, ADG, MCH, EKG]. Our A/ND-GD community partners integrate their personal perspectives on the co-occurrence throughout this article, including in their own voices through direct quotations.

The Lived Experience of Being A/ND-GD

“One of the major challenges I have experienced is seeking help when dealing with a double diagnosis. Especially when it comes to regular clinical psychology, the combination is seen to be too complex for the majority of clinicians, which led to long waiting times for specialized psychiatric care. Hence the importance for researchers to include us in their research.”

[SEK]

Clinical providers often struggle to know how best to support individuals with the co-occurrence (Fuchs et al., 2019; Strang et al., 2016), or even how to identify the presence of co-occurring A/ND-GD. Leef and colleagues (2019), in this issue, highlight assessment challenges in their investigation of the psychometrics of brief autism screening measures in gender-referred children. The diagnosis of ASD in gender-diverse individuals may be complexified by the presence of social challenges stemming from gender dysphoria itself as well as limitations inherent in current ASD assessment methods. ASD measures were developed and normed primarily with cisgender males (Rynkiewicz et al., 2016). Less is known about how to diagnose autism in people of other genders, and under-diagnosis may be common (e.g., in autistic females, Bargiela, Steward, & Mandy, 2016), in part due to social masking (i.e., social compensation, Lai et al., 2017).

“Me being either gender-diverse or neurodiverse is, by itself, already quite challenging. It is obvious that a co-occurrence of the two is even more complex. Personally, it took me many years to come to terms with my autism, which has caused me a lot of struggles and sadness when I was younger. Aggression due to overstimulation, anxiety, not being able to participate well in groups, having obsessions which others considered as odd, are some examples of the lived experience as an autistic child. I had to be assessed twice in order to get an autism diagnosis due to my assigned gender at birth (female). In hindsight, the dysphoria which I experienced with gender must have negatively contributed to my well-being, although I only discovered my gender dysphoria at age 25. Fortunately, by that time I was able to self-advocate in such a manner that I was aware of my neurodiversity and its pitfalls, which helped me during medical gender transition.”

[SEK]

SEK’s ability to self-advocate for his gender-related needs as an adult (described in his quotation above) helped him navigate gender-care systems. But unfortunately, the characterization of gender-diversity in autistic people is poorly understood, and some individuals, due to neurodiversity-related differences in communication and self-advocacy skills, may struggle to express their gender-related needs to family members and care providers (Strang et al., 2018b). Even when expressed, these needs may be doubted by

others due to perceptions/assumptions about ASD, or due to less binary or less familiar gender expressions (Strang et al., 2018b). Additionally, it may be more difficult for some A/ND-GD individuals to perceive and understand the social meanings of gender, leading to identity struggles.

“I never felt like a girl, but in the past I didn’t feel like a boy either. I was not at all concerned that there was really a difference between boys and girls. Why can’t you just wear what you want to, without having a gender label attached to it? What is the difference between a boy and a girl? Or is it my autism that makes me doubt about these differences? When I once uttered the phrase: ‘I am Marvel and I am a man,’ I suddenly wondered if I really feel like a man. Never before had I spoken this way: my name ‘Marvel’ associated with the word ‘man.’ I am very sure that I feel satisfied with the mastectomy. Ever since my breasts started to develop, I hated them. I could not imagine living my life with breasts. But if you ask if I feel like a man, I don’t know the answer and the future scares me not knowing how to identify. From my autism I tend to keep thinking about all possible outcomes. My thoughts keep going until I get it throbbing in my head. Thinking about my gender identity is also part of this. I just can’t find a clear answer. Because if I asked different people on the street what is typically masculine or typically feminine, I get unique answers. My autism makes this process more complex. For clinicians and researchers, it is important that they become aware of the autistic thinking style and how this influences the development of a person’s gender identity.”

[MCH]

A/ND-GD Youth

Existing clinical investigations into the A/ND-GD co-occurrence have focused primarily on children and adolescents. One reason for this is the time urgency of gender-related medical decisions in the early pubertal and teen years. Gender-diverse youth with gender dysphoria/incongruence, including A/ND-GD youth, are increasingly presenting to gender programs for medical supports (Arnoldussen et al., 2019) to suppress pubertal progression (puberty blockers) and then later to facilitate maturation in accordance with their gender identity (gender affirming hormones). Some also present for gender-affirming surgical procedures.

Requests for gender-related medical interventions among autistic youth have been met with varied reactions by medical providers (Strang et al., 2018b), and clinicians are seeking guidance on how best to support these young people. Although the initial clinical guidelines for A/ND-GD adolescents clearly indicate that autistic youth should not be denied access to gender-affirming medical treatments due to autism (Strang et al., 2016), the international workgroup that developed these guidelines could not reach consensus regarding criteria for treatment readiness in autistic youth. Self-advocates have noted that withholding needed gender-affirming care from autistic people is unethical and can be both devastating and harmful (Autistic Self-Advocacy Network, 2016; Strang et al., 2018b).

Adding complexity, A/ND-GD youth often report challenges communicating their gender diversity-related experiences and needs in a way that parents and providers understand

(Strang et al, 2018b), and providers as well as clinical researchers have identified challenges comprehending the inner gender experiences of these young people (Fuchs et al., 2019; Strang et al., 2018b). Some youth have expressed concerns that their gender identity and gender-related needs have been questioned by providers due to autism (Strang et al., 2018b). And providers are struggling to understand the clinical implications of emerging evidence of a possible heterogeneity of gender trajectories among A/ND-GD youth, with some individuals intensifying in gender-diversity and gender-related needs, and others experiencing an attenuation of gender-diversity/dysphoria over time (de Vries et al., 2010; Griffin, 2016; Shapiro & Izumi, 2018; Strang et al., 2018b).

As an example of this complexity, ADG describes her lifelong journey of discovery around gender, first experiencing herself as transgender and then later finding herself most comfortable within a cisgender identity (for a description of her gender journey and its relationship to autism, see: Griffin, 2016). She reflects here on the relevance of gender-diversity experiences that continue to unfold in her life, and the power of the younger generation of autistics¹ advancing her own personal experience of gender:

“I have never loved being female and I struggled through puberty, as well as being a young adult woman, but menopause is the best time of my life... I think listening to younger autistics and seeing them demand to be called ‘them’ and ‘they’ have been good for me. How we talk about gender is changing.”

[ADG]

The Importance of a Community-Based Participatory Research Approach

How do we move forward clinical research in this field given the many layers of challenge and potential risks for misunderstanding? We propose that community-based participatory research (CBPR) methods may provide a bridge to more attuned research agendas and study designs and interpretations by linking the A/ND-GD community with clinical researchers in true collaborative research partnerships. There are many reasons for employing CBPR in this line of research. A/ND-GD individuals often struggle to have their voices heard and to obtain the care they need (Strang et al., 2018b). A/ND-related communication differences impact self-advocacy with care providers (Strang et al., 2018b), and the apparent heterogeneity of gender trajectories experienced by A/ND-GD youth (de Vries et al., 2010; Strang et al., 2018b) adds further clinical complexity. There are risks related to each of the two A/ND-GD diversity-characteristics separately (i.e., *gender-diversity* [e.g., Hendricks & Testa, 2012] and *neurodiversity* [e.g., Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2019; Fuchs et al., 2019]), and unique additional risks and needs stemming from the interaction of the two identities (Sadikova et al., 2019; Strang et al., 2018b; van der Miesen et al., 2018b). Given these complexities, research that fails to engage collaborators with lived experience of both neuro- and gender-diversity may miss the mark in terms of ecological validity/applicability. Clinical implications generated independent of the lived A/ND-GD experience may prioritize clinical interpretations and recommendations

¹Identity-first language is employed here in accordance with calls from autistic self-advocates for such an approach to language (see, for example: Brown, 2011). It must also be noted that there is not consensus across various communities regarding the use of identity-first versus person-first language for autism.

peripheral to, or even at odds with, A/ND-GD community-based priorities. And CBPR provides a first step in moving toward a research model focused on *Patient-Centered Outcomes* (Bardes, 2012), in line with the U.S. Centers for Medicare & Medicaid Services (CMS) “Meaningful Measures” framework: i.e., healthcare focused “on what is really important to patients, families and caregivers including making informed decisions about their care, aligning care with the patient’s goals and preferences and improving quality of life and patient outcomes.” (CMS, 2017, p. 1).

“It is important to include autistic transgender people in research on autistic transgender people, from development to conclusion. We should be involved to decide what the research will focus on.”

[EKG]

There is emerging recognition within autistic communities and research networks that research about and for autistic people should include contributions from investigators who are themselves autistic (Robertson, 2010). The Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) has developed guidelines for including autistic adults as co-researchers (Nicolaidis et al., 2019).

“There should be different ways of conducting the research questions – different ways of gathering information, in person or online. In autism there are different modes of communication.”

[EKG]

Models for CPBR in gender-diversity research are less developed. There are currently no guidelines for gender-diversity-specific CBPR. And there are only two A/ND-GD-related studies to date to include community-based co-investigators (Strang et al., 2018b; Strang et al., under review). In moving toward a model for CBPR-informed research on the A/ND-GD co-occurrence, we offer the following recommendations based on our initial experiences conducting CBPR-research with this population and our lived experience of being A/ND-GD:

1. Partnering with A/ND-GD self-advocates as collaborators in setting research priorities and developing research designs may help to focus research initiatives on topics of relevance and meaning to A/ND-GD individuals. Whereas most studies thus far have focused on prevalence rates (for a recent overview, see Øien, Cicchetti, & Nordahl-Hansen, 2018), initial A/ND-GD community research partnerships highlight the lived experiences, challenges, and support needs of A/ND-GD individuals (Strang et al., 2018b). By listening to the community, new research questions and agendas can be developed (e.g., Dewinter, Graham Holmes, & van der Miesen, 2019). We cannot presume to know what broad and inclusive partnerships with A/ND-GD communities would reveal in terms of community research priorities. However, our A/ND-GD co-authors offered several recommendations, including a move away from questions of “why” more autistic people are transgender to research that more directly addresses barriers experienced by A/ND-GD individuals. Our A/ND-GD co-authors also noted the importance of research to develop appropriate training for

providers to help them be aware of the co-occurrence, reduce experienced barriers, and provide attuned and appropriate care.

2. Partnering with A/ND-GD self-advocates as collaborators in the interpretation of research may provide more accurate understanding and contextualization of findings.
3. The pubertal and adolescent years are a pivotal time for gender-related medical treatment decision-making for transgender and gender-diverse youth given the physical maturation that occurs during this period, including the development of some irreversible secondary sex characteristics. Few studies have included the voices and direct perspectives of A/ND youth. Given the difficulty clinicians have reported understanding the needs and perspectives of youth with the co-occurrence (Fuchs et al., 2016; Strang et al., 2016), research methodologies that seek to include *both* A/ND-GD youth and adult perspectives and interpretations are critical to begin to parse and understand the varied gender development trajectories in autistic people. A/ND-GD youth can speak to their immediate experiences needs, and A/ND-GD adults can, based on their life experiences over time (e.g., having lived through pubertal maturation, adolescence, and transition to adulthood), contextualize longer-term trajectories of gender and broader development. Both youth and adult perspectives are necessary here, and the interaction of A/ND-GD youth community partners with A/ND-GD adult community partners may offer particularly rich conversations and contextualization for research.
4. Given the evidence of *diverse* gender trajectories among A/ND-GD youth, with some experiencing a continuity or intensification of gender-diversity and others a reduction of gender-diversity over time (de Vries et al., 2010; Strang et al., 2018b), research collaborations with A/ND-GD advocates should engage community partners who reflect a broad range of genders, including A/ND individuals who ultimately identify as gender-diverse as well as those whose gender trajectories are more fluid or who experience an attenuation of gender-diversity and/or gender dysphoria/incongruence.
5. The language of both gender and neurodiversity experiences and identities is evolving. Language in clinical research publications can communicate understanding and respect, or it can perpetrate bias and pathologize identities (Bouman, 2018; Brown, 2011). Including A/ND-GD individuals in the writing and editing of research work products can mitigate this risk, and can support research that is more accessible to the communities for which it is intended.
6. Given the over-representation of gender-diversity among autistic individuals, autism studies should include the perspectives of gender-diverse autistic collaborators. And given the over-representation of autism/neurodiversity among gender-diverse individuals, studies of gender-diversity should include the perspectives of autistic/neurodiverse collaborators. Inclusion of representatives from key subpopulations within the A/ND and GD communities will increase

participation and the relevance and disseminability of the research to the *whole* community.

Conclusions

Clearly, there is a need for expanded research on the A/ND-GD co-occurrence (Strang et al., 2016; van der Miesen et al, 2016). But which topics will we choose to study and how will the research be conducted, interpreted, and disseminated? We can turn to the A/ND-GD community to help address these questions. The benefits of including A/ND-GD stakeholders in research partnerships are significant. Not only does CBPR increase the quality and applicability of research, it also helps to build trust between academic researchers and the community for whom the research is conducted (Bouman, 2018). Given the complexity and depth of the lived experiences of A/ND-GD individuals as described by our self-advocate collaborators, and A/ND-GD community calls for research partnerships (e.g., Strang et al., 2018b), can we move forward a research agenda informed by the neurodiversity-rights movement’s exhortation, “nothing about us, without us”?²

“As a member of the autistic and transgender communities, I have firsthand experience being excluded from the important conversations that affect my life. Community research partnerships are a first step to addressing this disparity and ensuring that autistic gender-diverse people have control over the research agenda. As a community research partner, I’ve encountered situations where my input made a concrete difference in how research on autistic and gender-diverse people was interpreted. Autistic people are often characterized as having social difficulties relating to neurotypical people, but at the same time, neurotypical people have difficulty understanding us.”

[RC]

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²The phrase, “nothing about us, without us” has been employed by the broad disability rights movements, and more recently by the autism and neurodiversity rights movement, particularly in the United States and Canada (Autistic Self Advocacy Network, n.d.). The phrase engenders an evocative call for social justice and inclusion in these countries, but we acknowledge that its meaning and usage in other parts of the world, including in The Netherlands, may be less specific to autism and neurodiversity.

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Implications for Impact Statement:

The perspectives and priorities of the autistic and/or neurodiverse transgender and/or gender diverse community need to be considered when conducting research that impacts autistic/neurodiverse transgender/gender-diverse individuals. Employing community-based participatory designs for studies of this co-occurrence will help to align research agendas with community needs and appropriately contextualize research findings.

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