ESTABLISHING EFFECTIVE TRANS-AUTISTIC SUPPORT

Waterloo Region Family Network Spectrum Waterloo Region's Rainbow Community Space

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2023-06-02

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Executive Summary

A growing number of researchers have been noting a relationship between autism and gender divergence. Given the degree of marginalization experienced by each respective community, it is reasonable to assume that this discrimination is amplified at the intersection of autism and gender divergence. As a result of prolonged exposure to discrimination and systemic barriers, many individuals experience declines in both their mental and physical health.

Fortunately, community programming and supports have been deemed effective in helping to combat such effects. This programming is only effective, however, if it takes into account the thoughts and opinions of the very community which it is attempting to serve. With this in mind, Waterloo Region Family Network (WRFN) and Spectrum Waterloo Region's Rainbow Community Place (Spectrum) have collaborated to assess the needs for supports amongst the trans-autistic community. Interviews and surveys were conducted to gather insights from the community to help inform the establishment of potential programming.

An analysis of the data revealed a public interest in drop-in programming in the form of a social hub, peer support group, and/or a space to share resources. Additional considerations for programming could be explored, such as skill- building workshops, contracting guest speakers, and designing educational supports for parents. Any programming should undergo ongoing evaluation to ensure it is operating effectively and in the best interest of its participants.

Assessing Trans-Autistic Support

Introduction

This report will begin with a brief background of the relationship between gender divergence and autism. Additionally, it will outline the insights gained through group interviews and surveys conducted amongst the trans-autistic community in order to assess the need for various supports. Following an analysis of the data, immediate recommendations will be provided. Alternative considerations will also be explored in order to emphasize the criticality of ongoing evaluations and improvements to existing programming.

Background

As of late, an increasing number of clinicians and community organizations have noted a relationship between Autism Spectrum Disorder and gender divergence. Autism Spectrum Disorder (ASD) is a broad diagnosis used to describe a diverse, multi-factorial neurodevelopmental condition often characterized by persistent impairments in social interactions and communication, repetitive behaviours, and restricted interests (Joon et al., 2021; Warrier et al., 2020). Gender dysphoria is a clinical condition referring to the persistent psychological distress or discomfort that arises from an incongruence between one's gender identity and gender assigned at birth (George & Stokes, 2018; Stagg & Vincent, 2019). In exploring the impact of gender dysphoria (GD), the terms "gender variance" or "gender divergence" may be used to represent a spectrum of gender-discordant phenomena (Murphy et al., 2020). Further, those with gender dysphoria are commonly categorized as belonging to the transgender community. As an overarching term, "transgender" (trans) may also be used to describe gender identities that do not neatly fit into the binary confines of male or female, such as those identifying as non-binary, gender queer, or gender fluid (Murphy et al., 2020). For the purpose of this report, the term "transgender" will continue to be used in an overarching fashion. It is also important to note that not everyone who is gender divergent will experience gender dysphoria.

Various studies have reported increased rates of gender variance and gender nonconformity amongst those diagnosed with autism. Conversely, many researchers have found a

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high number of traits that are consistent with a diagnosis of autism displayed amongst those who identify as gender-diverse (George & Stokes, 2018; Mahfouda et al., 2019; Murphy et al., 2020; Stagg & Vincent, 2019; Warrier et al., 2020). Although researchers are still exploring the root of this relationship, it is clear that it bears a number of biopsychosocial implications, such as increased risk of physical health deficits, psychopathology, and a reduction in attention and executive functioning (Harris, 2015; Ho et al., 2021; Nijdam et al., 2018; Strang et al., 2021a). Moreover, trans-autistic individuals are at increased risk of experiencing marginalization and a number of systemic barriers, specifically within the realms of healthcare, education, employment, and housing, which can contribute to poorer life outcomes. As such, it is crucial that effective supports are established to support this community.

Objectives

On behalf of WRFN and Spectrum, this project sought out to meet the following objectives:

- Acknowledge the increasingly visible intersection between autism and gender divergence.
- Elevate the voices of autistic and/or trans community members.
- Assess the need for programming at the intersection of autism and gender divergence.
- Establish next steps in potential programming.

Methods

On behalf of WRFN and Spectrum, three group interviews were held between March and April of 2023 – one was conducted in-person and two were conducted virtually over Zoom. All interviews followed the same sequence of questions, see **Appendix A**, with additional questions asked for clarification and elaboration on various insights provided by participants. Following the interviews, a survey was shared via social media and through email newsletters by both organizations. This survey followed a similar question block to the interviews, see **Appendix B**, and allowed individuals to share their insights without the pressure of observers. This survey attracted sixteen participants, none of which were excluded from data analysis. All participants that took place in either the interviews or surveys were made aware that their data would remain anonymous and simply be used to inform the creation of potential supports. Analysis has been done separately for the interview and survey portions of data collection as it possible that interview participants did anonymously complete the survey to provide further insights.

Analysis

Interviews

Two participants were interviewed in-person, both of which identified as trans and/or autistic. Both of these participants possessed formal autism diagnoses and one possessed a concurrent diagnosis of gender dysphoria. Four participants were interviewed virtually – three of which were parents of individuals belonging to the trans-autistic community and one was a member of the community themselves – this participant did not possess any formal diagnoses. All participants expressed an interest in in-person programming running on weeknights. Additionally, when speaking with those belonging to the community, many common themes began to emerge:

- Lack of overall support at the intersection of autism and gender divergence.
- Uncertainty of where to access informed resources.
- Difficulty finding others within the trans-autistic community.
- Lack of racial diversity in community programming.
- Lack of safe, social spaces for the trans-autistic community.
- Preference to engage in programming carried out by individuals with lived experience.
- Preference for reliable, in-person, drop-in programming that requires little commitment.

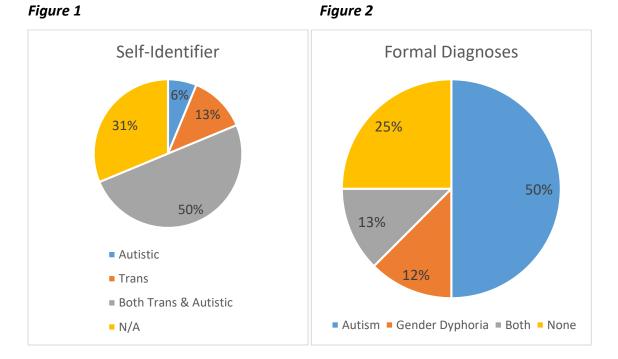
When speaking to the parents of those belonging to the trans-autistic community, the following themes were identified:

- Virtual programming made it difficult for their children to connect and engage.
- A lack of access to resources and information.

• Need for a safe, social space where their trans-autistic children feel represented.

Survey

Although all insights were considered valuable, emphasis was placed on those voices belonging to the community which, in various degrees, accounted for 69% of survey participants, see **Figure 1**. Amongst the 50% of participants who identified as being both trans and autistic, 13% possessed formal diagnoses of autism and gender dysphoria while 25% possessed no formal diagnoses at all, see **Figure 2**. Of those participants who did not identify as trans and/or autistic, four regarded their roles as community workers (i.e., educational support staff and behaviour analyst) and one as a parent.



When asked about the challenges they have encountered, those identifying as autistic and/or trans shared the following:

- Society has a limited understanding of what autism is, thus contributing to the incorrect belief that all those with autism have reduced mental capacity.
- Transness is often invalidated in the presence of autism.
- Systemic discrimination, macroaggressions, and stigma.

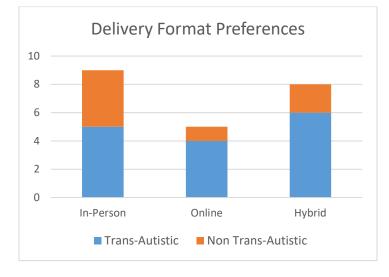
- Navigating as non-binary in a binary world.
- Fear of taking up space (i.e., not being trans or autistic enough to fit in with each individual community).
- Lack of moderated gatherings and safe spaces to meet other individuals belonging to the community.
- Lack of support in communication and accessibility needs.
- Lack of racial and neurodiversity in community programming.

Out of all autistic and/or trans participants, only five had experience with existing programming. Those that commented on their experiences with programming shared that they valued having the ability to learn about themselves and connect with peers in a safe space where they did not feel the need to justify their existence. In addition, these individuals shared the following critiques of their experiences with programming:

- Cisgender folks have made formal attempts against programming in attempt to have it disbanded.
- Organizations often assume what the community needs without getting them involved in the conversation.
- Difficulty in meeting criteria for in-person programming (e.g., formal diagnoses, nonbinary exclusions).

In respect to the delivery format of programming, the majority of people expressed preference in a variety of formatting options, see **Figure 3**.

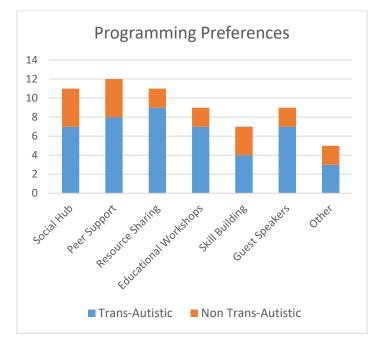
Figure 3



Note: Trans-Autistic refers to individuals who identified as trans and/or autistic.

The survey also sought to explore what participants were hoping to experience during potential programming. Participants expressed interest in a variety of options, see **Figure 4**. Those trans and/or autistic individuals who had noted "Other", suggested fostering conversations about responding to burnout, self-advocating amongst medical practitioners, and building career connections. They also expressed a need for more support and resources geared towards autistic adults. Those individuals who did not belong to the trans-autistic community, indicated a need for greater parental education and parent support groups to aid families in better supporting their loved ones.

Figure 4



Note: Trans-Autistic refers to individuals who identified as trans and/or autistic.

When asked for any final insights, the following remarks emerged from the trans-autistic community:

- Both autistic and allistic minds are equally capable.
- Critical that autistic and/or trans people are involved at all stages of community programming.
- Be mindful of the difference between folks who have known they are autistic/trans for different lengths of time. Although they may experience common challenges, their lived experiences differ, thus requiring different levels of support.
- A language preference towards "autistic community" rather than "autism community".

Immediate Recommendations

Based on the aforementioned data, it is recommended that WRFN and Spectrum collaborate to establish an ongoing, bi-weekly drop-in program for the trans-autistic community. This rate of frequency and open-door policy would provide individuals with consistency whilst alleviating them from any sense of commitment, thereby aligning with those interests expressed by research participants. This programming should be run by Peer Support Workers who identify as members of this community and are able to bring forth their lived experience to the conversation. Based on the data collected from the surveys and interviews, programming should run primarily as a social hub in which community members can come to engage with one another in a low-pressure environment. Peer Support Workers should be equipped with the knowledge and training necessary to provide up-to-date resources to attendees. In addition, it is important to remain mindful of sensory sensitivities and accessibility challenges that may be present amongst the trans-autistic population. Programming run inperson should strive to minimize sensory sensitivities where possible (Mason et al., 2019). This could involve using natural-appearing lighting, minimizing clutter within the space, reducing exposure to loud sounds, enforcing a scent-free environment, and avoiding the use of overly-stimulating decorations.

Next Steps

If WRFN and Spectrum choose to move forward with the recommended programming, several tasks will need completed.

- Establish a meeting space in which the programming will be held. When selecting a space, accessibility should be a primary consideration (e.g., proximity to public transportation, access to public parking, wheelchair ramps, and adequate signage). It is also crucial that the space be distanced from any place that may be considered hostile to the community (e.g., police station).
- Based on the availability of the selected space, determine the time and day during which the programming will take place. In attempt to foster greater turn out, programming should ideally be held on a weeknight.
- 3. Determine Peer Support Worker compensation, if applicable.
- 4. Develop program management procedures that ensure confidentiality and anonymity of all attendees. Develop grievance procedures for those who feel that their confidentiality

has been breached. Grievance procedures should be clearly posted or available in the shared space.

- Interview and hire peers interested in facilitating the programming. Ideally, these peers would be prepared to share their lived experiences, participate in active listening, maintain a safe and inclusive space, and would be receptive to ongoing feedback.
- 6. Develop the rules that will be enforced at the programming. These rules could be made alongside the Peer Support Workers. Once programming begins, attendees may also suggest additional rules to help curate a space that they feel safe in. Rules can be as simple as respecting one another, keeping the space clean, and no drug/alcohol use inside the shared space.
- 7. Prepare a list of referral services/resources. This could include the names and contact information of general practitioners, psychological services, legal aid groups, health services, alternative programming, and charitable organizations that provide inclusive services to the trans-autistic community.
- 8. Determine start date of programming.
- Create awareness about the new programming. Market through social media and/or community outreach.

Alternative Considerations

Effectively supporting this diverse community involves constantly revising current practices and seeking ways in which they can be improved. The trans-autistic community, comprised of various gender trajectories, requires complex and diverse care. As such, it is crucial to utilize the voices of those individuals belonging to the community, as well as their caregivers, in establishing effective supports. Until recently, trans-autistic representation has been relatively absent from the media and larger social settings. Therefore, it could be beneficial to coordinate the attendance of diverse guests/speakers that reflect the full gender spectrum and abundant neurodiversity experiences, particularly in relation to autism. These guests would represent concrete examples of the gender spectrum and its various associated outcomes; this may be increasingly valuable to autistic individuals whose internalization of new concepts is often dependent upon models (Strang et al., 2021b). Additionally, viewing diverse

speakers who have overcome adversity and take pride in who they are may foster greater optimism for the future amongst the trans-autistic population. This is especially important for those diagnosed with ASD which is often still negatively medicalized in the public sphere (Hamilston, 2019; Strang et al., 2021b).

In designing group interventions, it is critical that inclusive language is consistently utilized to support the potential constancy and fluidity of gender, such that trans-autistic individuals feel accepted regardless of where their gender journeys may lead. By allowing for the flexible exploration of gender both within and outside of the binary, individuals can comfortably discover their identities at their own pace and parents can trust that their children's GD characteristics are being safely addressed (Strang et al., 2021b). Fostering flexibility may be particularly important for those with autism who have had previous experiences with behavioural compliance training that reinforced social and gender conformity (Strang et al., 2021b).

Further, it could be incredibly useful to account for common deficits that accompany an autism diagnosis when designing group programming. Many trans-autistic individuals experience differences and challenges in social awareness, executive functioning, and sensory and motor skills (Strang et al., 2018). As such, it could be beneficial to offer coaching that accounts for these differences (e.g., planning the steps required in obtaining desired clothing or instruction on how to safely wear a binder). Research by Strang and colleagues (2021b) suggests that skill-building interventions may have greater merit when applied to immediate concerns or goals rather than generic targets. These findings stress the importance of facilitators enquiring about attendees' goals and remaining receptive to feedback. Doing so could allow for continued improvements to be made to overall programming as well as tailored changes to be made to address specific concerns within that particular group.

Trans-autistic individuals possess a number of diverse needs and goals, some of which likely differ from others within their own community. A topic that does often arise, however, pertains to safely and successfully navigating relationships. Individuals with autism are incorrectly presumed to have diminished desires for sexual and romantic relationships, thus contributing to the limited educative resources available to this population (Solomon et al., 2019). Similarly, LGBTQ2IA+ youth and adolescents report a lack of inclusive sexual education – contending that their diverse needs are not taken into account (Sondag et al., 2022). As such, the trans-autistic community is vastly underrepresented within dialogues and curriculums surrounding sexual health and relationships. The community would greatly benefit from the expansion of educational programming to include accurate information regarding sex, sexual health, and relationships. Research has found that those who are properly educated within this realm demonstrate increased confidence in effectively communicating with partners and are more likely to engage in sexual practices that reduce the risk of sexually transmitted infections and accidental pregnancy (Solomon et al., 2019). Given the risk of HIV and AIDS amongst the LGBTQ2IA+ community, it is crucial that these individuals have access to the education and resources required to help them make informed decisions.

In designing a sexual education plan for the trans-autistic community, it is important to take into account the possible deficits in communication and hindered interpretation of socioemotional situations. Explicit instruction for reading body language and teaching vocabulary that assists these individuals in displaying interest, or in declining sexual encounters, can help forward understanding in social thinking. Information about social boundaries and consent should be consistently reinforced to discourage both intentional and unintentional engagement in unwelcome sexual advances (Solomon et al., 2019). Moreover, it is crucial to teach these individuals the importance of accessing appropriate health screenings based on their particular bodies (e.g., trans men seeking proper gynecological screening) (Solomon et al., 2019; Sondag et al., 2022). To better suit the learning of those with autism, intervention materials can be adjusted to concretize abstract gender concepts through the use of definitive language and imagery (Strang et al., 2018).

As unfortunate as it is, it may also be necessary to discuss current cultural realities. Although organizations should strive to celebrate diversity and foster pride, it is important to discuss the increased risk of harm and rejection associated with expressions of gender that deviate from the social norm (Spivey & Sweatt, 2019; Strang et al., 2021b). Research has found that constant experiences of rejection result in internalized stigma and increased feelings of fear, anxiety, and depression (Spivey & Sweatt, 2019). Additional evidence has found, however, that resilience plays a key role in combating internalized transphobia by reducing feelings of shame (Scandurra et al., 2018). As such, it is proposed that early interventions should aim to develop protective factors and positively mould one's self-perception, thereby increasing resilience to anti-transgender discrimination. Programming could focus on increasing awareness of social cues and situations that predict potential danger by role-playing responses and actions – this may be especially useful for trans-autistic individuals who have difficulty in discerning various social contexts (Kuvalanka et al., 2018). Although the strengthening of resilience is a critical part of development, the general population should be cautious of their historical predisposition of casting the responsibility of affecting change on the shoulders of the very community being targeted.

Community organizations and group interventions are essential in cultivating positive health outcomes and self-esteem in the trans-autistic community (Fish, 2020). Educating transautistic individuals is not enough, however. Research has highlighted the importance of creating spaces that support the psychoeducation and emotional support of families and peers (Kuvalanka et al., 2018; Strang et al., 2021b). Parents have reported difficulty in accepting gender-related divergence, particularly when displayed by their children with autism, due to a lack of understanding and fear for their children's wellbeing in a discriminatory society (Kuvalanka et al., 2018). These sentiments and interest in parent support groups were echoed in the survey and interview participants. By providing these educational workshops to parents and peers, organizations can bring attention to the comorbidity of autism and gender divergence.

These peer workshops can provide insight towards the barriers facing the trans-autistic community, the ways in which internal biases and actions perpetuate these barriers, and strategies for offering support and bringing about change that can be implemented on a micro level. Organizations should ensure that families and peers have the opportunity to address their concerns or hardships in providing support to their loved ones who belong to the trans-autistic community (Kuvalanka et al., 2018). Doing so could help validate the feelings of these families and reduce burnout through the discussion of coping strategies and improving support

networks. Additionally, it would relieve members of the trans-autistic community from their involuntary responsibility of comforting others whilst trying to overcome adversity.

Conclusion

It is clear that not only does a relationship exist between gender divergence and autism, but that its comorbidity may render these individuals increasingly susceptible to discrimination and stigmatization (Mahfouda et al., 2019; Strang et al., 2021a). This community often faces widespread discrimination and systemic barriers beginning early on which can result in various negative developmental outcomes. Perpetual exposure to this discrimination can take an unprecedented toll on one's self-esteem and result in internalized discriminatory views, thus contributing to the prejudicial cycle targeting the community at large (Fish, 2020; Scandurra et al., 2018). As such, the need for more inclusive supports is not only warranted, but necessary. WRFN and Spectrum should collaborate to create this support in the form of regularly scheduled, drop-in programming. This programming should aim to create a safe space in which trans-autistic individuals can interact with members of their community and access reliable resources. It is important that when carrying out this programming, WRFN and Spectrum continue to evaluate its effectiveness and make amendments as necessary.

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Appendix A

- 1. How do you identify?
- 2. Any difficulties in obtaining an Autism or GD diagnosis due to the other being present?
- 3. What do you currently identify as some of your bigger challenges?
- 4. So far, what sort of skills or strategies, if any, have you used to help address or cope with those challenges?
- 5. Does anyone here have any experience with programming intended to support neurodiversity or gender diversity?
 - If so, could you share about your experience?
 - On average, how many attendees were present?
 - Was it delivered through an in-person, remote, or hybrid format?
 - What were the main objectives of that programming?
 - How effective did you find the programming?
 - If you could do one thing to improve it, what would it be?
- 6. If we could formulate the ideal program to help support you, what would that look like to you?
 - Any preferences for a certain delivery format? Hybrid, in-person, remote?
 - What facilitation style are you interested in?
 - What would the focus of the group be?
 - Social Hub
 - Peer support
 - Resource sharing
 - Educational workshops
 - E.g. financial literacy, navigating the healthcare system, planning for social gatherings, explore the link between neurodiversity and gender diversity (can also use a risk-perspective), history of people within the community, discuss medical gender supports
 - Skills building
 - E.g. navigating social relationships, establishing boundaries, navigating bullying, coming out, speech and language therapy (gender-related voice goals), executive functioning skills (flexibility, organization, planning), self-advocacy skills, selfawareness skills
 - Informal (but supported) opportunities to connect socially with one another
 - Structured and unstructured time/activities in each sessions
 - Subgroups to help alleviate social overload
 - Visits from diverse role models
 - How many people in a group?

- Is this contingent on anything? (i.e. larger groups are for those with more developed social and/or coping skills)
- Registration process?
 - Pre-registration and deadline
 - Discrete stops/starts
 - Rolling admissions
 - Helps newly-identified individuals connect with the service asap
 - Duration of program?
 - Note: Redundant if rolling admissions
- Group frequency?
 - Monthly, biweekly, weekly

Appendix B

- 1. Do you identify as autistic and/or part of the transgender community? (check all that apply)
 - Transgender (Used as an "umbrella term". You may disclose how you specifically identify, if you choose)
 - Autistic
 - N/A
- 2. Do you have a form diagnosis of gender dysphoria or autism? (check all that apply)
 - Gender Dysphoria
 - Autism
 - N/A
- 3. If you do not identify as trans and/or autistic, what is your connection to the community? (check all that apply)
 - Parent/Guardian
 - Friend
 - Educational Support
 - Community Worker
 - N/A
 - Other (please specify)
- 4. What sort of challenges have you encountered in respect to being a part of, or supporting, this community?
- 5. Do you have any experience with programming intended to support neurodiversity or gender diversity?
 - Yes
 - No
- 6. If you have had experience with previous programming, what did you enjoy most about it?
- 7. If you have had experience with previous programming, what did you think could be improved upon?
- 8. In respect to programming, what type of delivery format do you prefer?
 - In-Person
 - Online
 - Hybrid
 - N/A
 - Other
- 9. If we were to introduce new programming for the trans-autistic community, what do you think would be most beneficial or of most interest? (check all that apply)
 - Social Hub
 - Peer Support

- Resource Sharing
- Educational Workshops
- Skill Building
- Guest Speakers
- Other (please specify)

10. Do you have any other insights you would like to share?