

Meeting the Unique Needs of Women on the Autism Spectrum

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The research on adults with Autism Spectrum Disorder (ASD) suggests that outcomes for adult women with ASD are especially poor relative to those of men (Taylor, Henninger, & Mailick, 2015). These findings stand in sharp contrast to research reports that find women and men with primary ASD are largely similar in symptom presentation (e.g.; Van Wingj-garden-Cremers et al., 2014) and that in some affected women, the condition may be milder (Wilson et al., 2016). What then explains these differences in outcomes? Are there particular challenges for women on the autism spectrum that are currently being overlooked? What are the necessary supports for their success?

From the Perspective
of Women With ASD

As part of the development of Felicity House, a social program in New York City for adult women with ASD, focus groups with key stakeholders were conducted to identify the specific needs of this population. Women on the autism spectrum were invited to discuss their perceptions of the sex differences in ASD, their ex-



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periences of being on the spectrum, and their sense of the current gaps in services. The resulting discussion highlighted the current gaps in community-based adult programs. At the start of the focus group, participants immediately commented on how “different” and “nice” it was to be in a room full of women on the spectrum.

Many shared that this was a first for them. This then was the re-occurring theme of the meeting: that women with ASD often feel “alone” and like a minority within a minority group. The women explained that their efforts to socialize often lead to feeling “misunderstood” and “lonely” because they frequently are the only person with ASD or the only female with ASD in a given social scenario. Focus group participants already involved in coed social programs further noted that their communication “style” is consistently at odds with their male peers, limiting their social participation. Additionally, unwanted sexual attention was a common experience for the token female in group activities designed for adults with autism.

“If autism is a form of the extreme male brain, where does that leave women with autism?”

“There’s...a disconnect between what society expects of women with ASD and what we can do.”

“I don’t know how to meet people.”

“For young women with ASD to not feel alone or different and to have space (a place) to belong to, for once!”

“In the support groups for ASD, it’s either get hit on or be seen as an alien!”

Most striking was that the participants quickly zeroed in on their desire for social connections and the lack of social activity as their chief need. Rather than describe the limited availability of clinical services and employment opportunities for adults, the women made a point to describe all of the social opportunities they had as students and contrast this with their experiences as adults. Participants identified social programming designed for women with ASD as most needed, specifically a safe space to pursue leisure interests and build social experiences. Many of the women reflected on their own social and communication challenges, the difficulties involved in interacting with same-age women without ASD, and their interest in building their social experience in the context of a supportive system.

“At [college name], we had a group where we would play games...so just to have that again!”

“I have been looking for programs...with people who are serious about music, drawing, creative writing.”

“We need opportunities to build “real” social connections...”

“...led by someone without ASD, to be able to stop (us) from speaking too much, making sure everyone has a turn”

“Activities with structure, like using Roberts Rules or something...to help us know when to talk”

The Literature on Women’s Experiences

The experiences reported by the women in the focus group are consistent with the research on typical social development and gender-based risks to mental health. First, the level of skill required for social participation is significantly higher for females than for males. Starting in the early adolescent years, girls are expected to be adept in relationship building skills not required of boys (Hannah and Murachver, 1999). Yet school age girls with autism show problems maintaining friendships (Hiller et al., 2014) and find it harder to manage social conflict (Sedgewick, Hill & Pellicano, 2019). Girls with autism also report more experiences of relational aggression (Sedgewick et al., 2016). As adults, women with ASD face unique challenges because of societal expectations of women’s social behavior (Bargiela, Steward, & Mandy, 2016). As a result, the social gaps between adult women with ASD and their non-ASD peers may be greater than they are for their male counterparts.

Beyond gender-based differences in socialization, a not so insignificant challenge for women with ASD is that they are more likely to have been diagnosed later in life than their male peers (Begeer et al., 2013; McCormick et al., 2020). Such differential access to formal diagnoses is concerning because it means less access to services and intervention, which in turn, increases the risk for mental health problems that are already heightened for women in general (Kessler et al., 1994). Indeed, as compared to typically developing girls, those diagnosed with ASD exhibit significantly more internalizing symptoms such as anxiety and depression (Jamison & Schuttler, 2015).

Supporting Adult Women with ASD

As expressed by our focus group participants, adult women with ASD are in need of social opportunities that are inclusive of their needs and interests. As opposed to didactic activities, the women described a need for a community of their own where they can comfortably share experiences and build connections. To provide such opportunities, it is not sufficient to simply gather women with ASD together. Program structures that take into account the effects of social information processing difficulties are required. In this respect, ideal supports are those based on principles of Universal Design, such as incorporating a design for

activities that make them adaptable with respect to pace. A careful use of visual supports is required; the goal is to supplement verbal information when necessary, without overusing visual cues that can confuse or distract the participant. All in all, this approach requires much pre-planning, opportunities for ongoing revisions of programmatic practices, and consultation with professionals who have expertise working with adults with ASD.

Due to the heterogeneity of ASD, another important program element involves anticipating that social communication needs can be varied. At the group level, this can be accomplished via a menu of programs that caters to diverse needs and interests, including experiences that are rich in opportunities for discussion as well as those designed for participants who prefer hands-on activities. Program content should also be informed by the current context and interests of the women. Differences in social motivation are also important factors that affect participation. Thus, identifying special interests, as well as understanding previous negative experiences, is essential for supporting the individual. Additionally, programs will require participation and staffing models that can account for changing support and mental health needs. As best practice, this involves highly individualized participation plans and mechanisms for fostering thoughtful discussions with each participant around their social goals and mental health needs.

How Does Felicity House
Meet These Unique Needs?

Established in 2015, Felicity House is a non-clinical program designed to support the social development of women with a diagnosis of ASD. The program has dedicated space with a design that accommodates large and small group activities, as well as rooms designed to provide restorative, quiet activities. Participation plans are flexible and individualized; they are uniquely informed by a new member process which includes a series of meetings between a woman and staff member, with ongoing follow-up as needed. Programming is varied and includes structured events such as lectures, workshops, and special interest groups, as well as social routines like movie nights and open hours. Each event is supported by at least one staff member and all activities include pre-planned modifications with an eye towards facilitating diverse forms of participation.

Special consideration is given to the fact that Felicity House exclusively serves adults, and programming reflects the maturity and sophistication of adult women. Activities are

chosen based on participant interest and the feedback collected at each event. Staff meet regularly to review and revise the content and format of the program activities; program participants are included in this process through a monthly program-wide leadership meeting where Felicity House participants share ideas, offer feedback and troubleshoot issues that may affect participation.

To make the program accessible, participation is at no cost to the women. There is no requirement of functional limitations for inclusion. On the contrary, the goal at Felicity House is to provide support for women who are able and ready to increase their social participation, including those that may not be able to access state-funded resources due to eligibility thresholds.

What Have We Learned?

The needs of women with ASD are made complex by gender-specific expectations of social participation, minority status within the ASD population, later access to a formal diagnosis, and increased rates of anxiety and depression; all of which ultimately may lead to poorer outcomes than their male peers. Increased availability of social programs designed specifically for women with ASD is needed and they may be an important mechanism to improving outcomes. However, such programs must take into account the complex needs and heterogeneity of the population, and there is still a great deal to be learned about how to best support women to meet their social needs.

For more information about Felicity House, please visit www.felicity-house.org.

References

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46: 3281-3294.

Begeer S., Mandell D., Wijnker-Holmes B., Venderbosch, S., Rem, D., Stekelburg, F., & Koot, H.M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43: 1151-1156.

Hannah, A. & Murachver, T. (1999). Gender and Conversational Style as Predictors of Conversational Behavior. *Journal of Language and Social Psychology*, 18: 153-174.

Hiller, R.M., Young, R.L., & Weber, N. (2014). Sex differences in autism spectrum disorder

based on DSM-5 criteria: evidence from clinician and teacher reporting. *Journal of Abnormal Child Psychology*, 42: 1381-1393.

Jamison, R. & Schuttler, J.O. (2015). Examining social competence, self-perception, quality of life, and internalizing and externalizing symptoms in adolescent females with and without autism spectrum disorder: a quantitative design including between-groups and correlational analyses. *Mol Autism*, 6: 53.

McCormick, C.E.B., Kavanaugh, B.C., Sipsock, D., Righi, G., Oberman, L.M., Moreno De Luca, D., Gamsiz Uzun, E.D., Best, C.R., Jerskey, B.A., Quinn, J.G., Jewel, S.B., Wu, P.C., McLean, R.L., Levine, T.P., Tokadjian, H., Perkins, K.A., Clarke, E.B., Dunn, B., Gerber, A.H., Tenenbaum, E.J., Anders, T.F., Rhode Island Consortium for Autism Research and Treatment (RI-CART), Sheinkopf, S.J., & Morrow, E.M. (2020). Autism heterogeneity in a densely sampled U.S. population: Results from the first 1,000 participants in the RI-CART study. *Autism Research*, 1-15.

Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender differences in social motivation and friendship experiences of autistic and non-autistic adolescents. *Journal of Autism and Developmental Disorders*, 46: 1297-1306.

Sedgewick, F., Hill, V. & Pellicano, E. (2019). ‘It’s different for girls’: Gender differences in the friendship and conflict of autistic and neurotypical adolescents. *Autism*, 5: 1119-1132.

Taylor, J.L., Henninger, N.A., & Mailick, M.R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism* 19: 785-793.

Van Wijngaarden-Cremers, P.J., van Eeten, E., Groen, W.B., Van Deurzen, P.A., Oosterling, I.J., & Van der Gaag, R.J. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44: 627-635.

Wilson, C.E., Murphy, C.M., McAlonan, G., Robertson, D.M., Spain, D., Hayward, H., Woodhouse, E., Deeley, P.Q., Gillan, N., Ohlsen, J.C., Zinkstok, J., Stoenecheva, V., Faulkner, J., Yildiran, H., Bell, V., Hammond, N., Craig, M.C., & Murphy, D.G. (2016). Does sex influence the diagnostic evaluation of autism spectrum disorder in adults? *Autism*, 7: 808-819.