The Social Needs of Women on the Autism Spectrum

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Current research on adults with Autism Spectrum Disorder (ASD) without intellectual disability 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 recent findings that women and men with primary ASD are largely similar in symptom presentation (Van Wijngarden-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 new program 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 experiences 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.

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. A number of the focus group participants further noted that their social interaction “style” has been consistently at odds with those of their male peers, making their minority status particularly problematic. Additionally, as a result of being the token female in group activities designed for adults with ASD, the women often receive unwanted sexual attention.

“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.”

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

“I don’t know how to meet people.”

“I’ve had bad (social) experiences.”

Most striking was that the participants quickly zeroed in on 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 specific to 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”

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Felicity House is a community space just for adult women with autism. Come enjoy a non-clinical program designed for women who are ready and interested in attending social events and activities.

At Felicity House you’ll find:

- The company and support of other women with autism
- Dynamic activities, workshops and guest speakers on a wide range of topics from culinary arts to comic books
- Small group meetings and special interest clubs
- A safe and welcoming place where you can be yourself
- Spaces like a lounge and art studio
- The expertise of a friendly staff person
- A community

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factor that emerged through the classroom discussion and the anxiety it fed a large role in impeding these women from pursuing the work they would like. Thus, our revised curriculum addresses this issue. The Lean Out Curriculum, participant workbooks and slides are available for download at no charge is available on our website (http://childstudycenter.yale.edu/autism/clinical_services/initiative/young_adults/). We are hopeful this program will be revised and modified to fit the needs of young women anywhere who need help with this important life task.

A weekly support group for young women began this past winter. Our group tackles any subject that comes up, as participants talk over what it means to cope with and modified to fit the needs of young women anywhere who need help with this important life task.

We hope to expand the program in scope, so that new activities address unique challenges for these girls such as developing a healthy mind and body, dealing with disclosure, relationship abilities and an optimistic outlook for the future. Our Advisory Board, which includes parents of girls on the spectrum, professionals, and individuals on the spectrum, as well as additional (anonymous) donors have helped in this regard. Parents, young women and teens have been very enthusiastic about the program, with requests for more activities. Our plan is to increase the opportunities for participation for girls of all ages and all levels of functioning and we hope to incorporate clinical training and research into the program over time. The Initiative for Girls and Women with ASD provides an extraordinarily rich social experience for all who participate.

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“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 this study 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 far less than for males. Starting in the early adolescent years, girls are expected to adept in relationship building skills not required of boys (Hannah and Murachver, 1999). Society also places greater social demands on women that go beyond specific skills. As noted by a recent article in the Spring 2016 issue of Autism Spectrum News by Dr. Milot, the current social culture exerts unique pressures on adult women to take on career-taking roles and conform to particular expectations (2016). Socially patterned of socialization create added challenges for women on the spectrum. As a result, the social gaps between non-aframed females and females with ASD are greater than they are for their male counterparts. Boys are typically gender-based differences in socialization, a not so insignificant challenge for women with ASD that are more likely to have been diagnosed later in life than their male peers (Beege et al., 2013). 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 the female gender (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 lacking support and community. They reported a need for a large role in impeding these women from pursuing the work they would like. Thus, our revised curriculum addresses this issue. The Lean Out Curriculum, participant workbooks and slides are available for download at no charge is available on our website (http://childstudycenter.yale.edu/autism/clinical_services/initiative/young_adults/). We are hopeful this program will be revised and modified to fit the needs of young women anywhere who need help with this important life task.

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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 activities. Participation plans are flexible and individualized; they are uniquely informed by a new member process which includes a series of meetings and interviews between a woman and staff member, along with ongoing follow-up needs. Programming is varied and consists of structured events such as lectures, workshops, and social interaction 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 modifications with an eye towards facilitating 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. Here, such programs matter not only to account the complex needs and heterogeneity of the population, and there is still a great deal of research to be done on how best to support women to meet their social needs. In addition to her role as Senior Advisor at Felicity House, Marisela Huerta, PhD, is an Assistant Professor of Psychiatry at Weill Cornell Medical College and an Attending Psychologist at NewYork-Presbyterian/Columbia for Women and the Developing Brain. For more information about Felicity House, please visit www.felicity-house.org.

References


