

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 Wingjarden-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 differ-



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ences 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 discussions was that anxiety played 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 workbook 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 used 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 parents, siblings, the demands of college

and the workplace. We learn about each woman's experience as they try to navigate through and understand their place in the world. A significant piece of this process is helping young women feel self-confident about who they are so they can advocate for what they want and need.

In this program, we strive for an atmosphere that promotes relationship building through sharing ideas and experiences. A lot of conversation about music, movies and media, school work, parents and friendships happens. Positive energy flows through the room as our participants get to know one another, sharing stories, videos and jokes. Participants often exchange numbers and some get together outside of the group. For many of our teens and young women, our activities are the only social opportunities they have.

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

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

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). 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 caretaking roles and conform to particular expressions of femininity (Milot, 2016). Such patterns of socialization create added challenges for women on the spectrum. As a result, the social gaps between non-affected females and females with ASD are 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). 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 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 share and build experiences. To provide this, 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 and complexity. The latter requires a careful use of visual supports; 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 the variety of social communication needs that can occur with this condition. At the group level, this can be accomplished via a menu of programs that caters to diverse needs, including experiences that are rich in opportunities for discussion as well as those designed for participants who are more interested in doing than talking. Programming content should also be informed by the experiences and interests of the women. Differences in social motivation are also important factors that affect participation. Thus, identifying special interests, as well as previous negative experiences, is essential at the individual level. Additionally, programs will require participation and staffing models that can account for changing 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

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, developing positive relationships 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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mation about Felicity House, please visit www.felicity-house.org.

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and interviews between a woman and staff member, along with ongoing follow-up as needed. Programming is varied and consists of 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 modifications with an eye towards facilitating 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 design of the program activities and 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.

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