



## The Women's End of the Spectrum

### Support Groups for Women with Asperger Syndrome/Autism Spectrum Conditions

by Eva Mendes, MA, LMHC, AANE Spouse and Women's Group Facilitator

*Eva Mendes, MA, LMHC, psychotherapist and couple's counselor, has been facilitating two support groups for women at the AANE since 2010. Here, she answers some questions about these groups.*

**Q: For whom are the women's groups intended?** AANE currently offers two women's groups each month: One is the Young Women's Group (ages 18 to 34), and the other is the Women's Group open to women of all ages (whose participants are currently 24 to 70+). Both groups are for women who have an Autism Spectrum (ASD) or Asperger's Syndrome (AS) diagnosis, or self-identify.

AANE created these groups especially for women with AS/ASD precisely because there were no other appropriate groups out there. Women often told us that they had tried attending other groups (for depression or other mental health issues), but felt and that they just didn't fit in there. Their needs were not addressed, and they didn't find participating in those groups very helpful.

The current diagnostic ratio in the AS field is 4:1 in favor of men, perhaps because AS is harder to detect in women. At AANE, we strongly suspect that there are a lot more women with AS out there who have not gotten a diagnosis. Some women may get a Personality Disorder diagnosis; some may carry multiple diagnoses over the years until they finally find out about AS.

**Why do you think it is harder to detect Asperger's in women vs. men?** There's research that indicates that women learn social skills differently from men. Their AS might be harder to detect because they may mimic their non-AS peers more successfully than men with AS can. Women also tend not to fit the geek-Asperger's stereotype as much. Highly intelligent but somewhat quirky women may have more socially acceptable interests than men with AS, including animals, astrology, poetry, or even fashion. Also, clinicians aren't trained or experienced in diagnosing AS in individuals that don't appear stereotypically or obviously "Aspie." In particular, individuals (men as well as women) who are highly accomplished and/or married and/or employed often don't get the diagnosis.

**Q: Does a woman need to have a formal diagnosis of Asperger's or Autism to attend the groups?** No. Some women come because they've done a lot of reading on AS and have concluded on their own that they have it. They come to the group to meet other women with AS. Once they come to the group and spend time speaking to the other women on the spectrum, they feel that they can relate to what's being discussed. Meeting others like themselves is the final confirmation they feel they need in order to self-identify as having AS. Over the years, more than one woman has said, "I feel that I can be myself in this group, and no one will think I'm weird or awkward. I finally feel like I fit in!" Being in an environment where they finally feel safe, accepted, and at ease is so validating!

**Q: Do you have regular attendees or do you have different women who come to the group each month?** While it's true that we have a few newcomers each month, we do have a regular

group of eight women who attend the Women's Group, and a core of five regulars at the Young Women's Group. Many newcomers return, and our circle of regular attendees is ever expanding, but not everyone comes to the group each month. Women come as their schedules permit, and since this is a drop-in group format, this works out quite well.

**Q: Roughly, how many attendees do you have at each monthly group?** For the Women's Group, we have anywhere from 8 to 18 participants per group. In the Young Women's Group, we have 5 to 8 participants per group. The Young Women's Group is smaller. This is a good thing, as the younger women are sometimes shy and have a harder time opening up. That said, the attendance in this group has been steadily going up, and I wouldn't be surprised if we eventually have as many participants as the Women's Group does.

Many of the women who attend regularly drive from as far as 2 hours away! Even though our group meets in AANE's Watertown office (which is 6 miles outside of Boston, Massachusetts), women have attended the group from as far as New Hampshire, the Berkshires, Connecticut, and Maine! Some of the regular Women's Group participants also have started holding a monthly dinner prior to the group.

The core group participants or "regulars" are an amazing group of wise and compassionate women, who have really worked hard to become more self-aware. They seek to continually learn from one another, and to incorporate healthy behaviors and psychological habits into their lives. They are a great resource and support to the drop-ins and newcomers to the group.

**Q: Could you give us some idea of the participants' marital status, employment, and living situation?** In the Young Women's Group, the women are mostly in their 20s and typically unmarried. Many are in relationships--some even in long-term relationships--while others are single.

Participants in the Women's Group may be single, married, or divorced, with or without children. Some are mothers of children on the spectrum. Some women identify as being lesbian; these women may be single, or in same-sex relationships or marriages.

At present, about 75% of the Women's Group members are employed. The rest are either unemployed, retired, work as volunteers, or live on disability. In the Young Women's Group, too, some women are employed, work as volunteers, or live on disability. However, the majority are students. We also have young students who are taking a break from college or university and are actively planning their future.

Some of the women are leaders in their fields due to their ability to hyper-focus, or their obsession with finding solutions to challenging problems. Others, despite having advanced degrees, are unable to work consistently due to conditions such as

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anxiety, panic attacks, or depression. Many don't advance as far up the career ladder as their neurotypical peers, due to their lack of inability to connect socially with co-workers and superiors. Even many of the most professionally successful women report feeling as if they are masquerading as neurotypicals, only pretending to fit in.

Most of our participants in the Women's Group live with family: with parents and/or siblings, or with partners/spouses and/or children. The majority of members of the Young Women's Group live at home with their parents, although some do live independently, sharing their space with roommates. Regardless of age, women with AS love their pets. Animals such as cats, dogs, or fish help reduce the women's loneliness, stress, and anxiety, and are very important members of their families!

**Q: What topics does the group discuss?** Due to the diversity in their ages and life experiences, the women are able to share a wealth of strategies, resources, and problem-solving techniques with one another. They share insights on AS-related issues, and work together to increase their awareness of what it means to be a woman on the spectrum.

I would say that the most common topics are creating and maintaining friendships, negotiating familial relationships, strategies for finding and keeping work, the need for alone time, self-advocating, and being misunderstood by friends, family and peers.

Solutions for succeeding in social interactions in the workplace and in friendships is probably our most frequent topic. The women share their challenges in making small talk, and in initiating and ending conversations, both at work and in their personal lives. They often speak about not being able to enjoy a typical human interaction such as hugging or touching another person, due to overwhelming sensory issues.

Perhaps surprisingly, there isn't much discussion about romantic relationships. Many of the women who do have partners seem to have stable/harmonious relationships—some with men who are also on the spectrum—and they just do not seem to have pressing issues they feel a need to discuss in the group. The single women seem more focused on making and maintaining new friendships, rather than focusing on dating or intimate relationships.

The Young Women's Group is primarily focused on fitting in: in school, at work, in friendships and, to a limited extent, in romantic relationships. Students who are still in high school, or women who have tried but dropped out of college, discuss applying to colleges, and which colleges might be a good fit for a woman on the spectrum. Another major focus is employment: what jobs would be a good fit; finding, applying, and keeping jobs, and navigating challenges at work.

**Q: Is the lack of focus on romantic relationships unique to women with Asperger's?** Yes, I would say that this is very unique to women with AS. I've facilitated groups with neurotypical women (women not on the autism spectrum), who usually *do* want to discuss their romantic relationships in great detail. That said, it's not that women with AS have no interest in dating or relationships; they just don't seem to focus on it as much as their neurotypical counterparts. I can count on one hand the number of

times that romantic relationships have come up for discussion in our AANE women's groups.

The way the women with AS talk about dating and relationships is also different. They usually want concrete strategies on how to date and where to go to find romantic partners, rather than talking about feelings and the state of their relationships. Once we discussed online dating; the discussion focused on internet/social media safety, boundaries, and dating etiquette, e.g.: how many times to email or phone a potential romantic interest, and how long one should wait after the first date to contact the person.

**Q: Do the women find the groups useful?** When asked how and why the Women's Support Group has been valuable to them, participants said that they value feeling accepted and listened to by other women like themselves. Because almost all of them have a diagnosis of AS, they feel understood, and have learned coping strategies from one other. They make friends, bond, and feel they have found a place to belong. The group also helps them to learn more about AS, and to normalize their traits and life experiences as women on the Autism Spectrum. They also pointed out that since women are a minority in the Autism/Asperger's world, their group is unique in that it caters specifically to women in this population.

The Women's Support Group provides the only social outlet for many participants. This sub-group of women report that they rarely get out of the house, due to their social anxiety and/or their inability to develop and maintain friendships. The Women's Support Group provides them with a social outlet, acceptance, support, self-awareness, learning, insight, solutions to life-challenges, friendship, a sense of belonging, and a voice.

When I asked the younger women the same question, and they said that the Young Women's Support Group has been invaluable to them. They finally feel that "Someone gets it!" They bond with each other and learn coping strategies to do better in college or at their jobs. They said that they wanted the world to know that not all adults with AS are "awkward men playing video games in their mother's basements!"

**Q: What would you say is challenging about facilitating these groups for women with AS?** One challenge is to keep the group focused on the topic at hand, as folks with AS do have a tendency to go off on tangents. We could start out talking about how to ask a friend out to dinner, and end up talking about the inventions of [suspected Aspie] Nikola Tesla!

The second challenge is that some group participants have a slower processing time, and can have a difficult time expressing themselves in the moment. It might take them several minutes to think about a certain topic and then weigh in on it. The facilitator also has to make sure that people don't monologue, or interrupt one another—that the atmosphere remains one of support, respect and acceptance, where each person's statements, thoughts and feelings are valued.

Another major challenge can be to have the women think positively about some of their problems. I usually use Cognitive Behavioral Therapy techniques to reframe issues in a positive light. I think it's important to see challenges and difficulties in our lives as opportunities for growth. To quote the great Russian author Leo Tolstoy: "Life is a process of challenging our limita-

tions and expanding our capacities.” I think that these women’s groups are not only a forum for the women to discuss Asperger’s and Autism-related issues, and to gain support from each other, but also to cultivate insight and actively participate in their relationships, families, places of work, and broader communities. Women with AS have incredible reserves of strength, wisdom, compassion, and leadership potential. My hope is that the group supports, inspires, refreshes, and energizes them to contribute to the world.

**Q: How do participants find the group?** The group is listed on the Asperger’s Association website under Adult Social Events. Additionally, AANE staff members encourage appropriate women to join.

**Q: Can you say a little bit about the format of the group?** We typically tend to sit around a big oval table in a large conference room. We meet once a month from 7:00-8:30pm. The 7pm start time gives working women ample time to commute to AANE after their work day. The hour and a half session allows all the women to have a chance to speak up and be heard, and enables me as the group leader to encourage the women to explore issues in greater depth. Each session follows this format:

1. **Introductions:** I begin the group with introductions and an ice-breaker exercise or a question.

2. **As the facilitator, I go over some basic Group Rules:**

- We ask that participants arrive on time and that we end the group on time.
- We ask that participants maintain confidentiality and not share names or identifying information of fellow group members outside the group.
- No one is forced to share if she doesn’t want to, e.g. if the topic feels or it’s too personal or sensitive.
- We do ask that participants engage and speak up as they feel comfortable. Typically everyone shares. As the meeting progresses, even the shy/quiet ones tend to open up more.
- We ask that everyone show respect to everyone in the group, so that we can maintain the safe, accepting, and welcoming atmosphere of the group.

3. **Check-ins:** Each participant takes a turn to say something about what is going in her life that she would like to share with the group. Other participants usually respond by asking questions, and perhaps sharing events/happenings in their lives.

4. **Topic Introduction:** After check-ins, I may introduce an Asperger’s-related topics. Often, in these well-established groups, the women already have topics or questions on their minds that they want to discuss.

5. **Discussion:** I facilitate the discussion around 2 or 3 key questions in each group, although the women can jump around and we can cover a lot of ground. Maintaining flexibility while also having structure is key. Often, adults with AS tend to go off on interesting tangents and then the facilitator has to rein everyone back in to the topic at hand.

6. **Conclusion:** In the final 15 minutes of the meeting, I ask everyone to take a minute and think about one thing that they learned from that evening’s discussion. This helps all of us focus on concrete learning outcomes.

**Women’s Support Group topics:** While the women continue to bring fresh and interesting topics to the group to share, here are some topics that we’ve covered in the Women’s Group and the Young Women’s Group at the AANE:

1. Advantages and disadvantages of being on the spectrum; 2. What people should know about AS; 3. Volunteer opportunities; 4. Coping strategies for the holidays; 5. Parenting a child on the spectrum; 6. Financial struggles; 7. Writing, painting, creativity; 8. Socializing; maintaining social connections; 9. Relationships with family and friends; 10. Relationships with co-workers; 11. Bullying at work; 12. Pretending to be normal/mimicking others to appear “normal;” 13. Adjusting to seasonal changes; 14. Exercise; 15. Traveling alone (singles cruises, hiking clubs, guided tours); 16. Men vs. women on the spectrum: similarities and differences; 17. Agoraphobia/social phobias; 18. Question about getting a diagnosis; 19. Acceptance of diagnosis vs. denial; 20. What to say, how to initiate or end conversations; 21. Mock interviews; 22. Disclosure of AS at work or to family and friends; 23. Self-care; 24. Sensory sensitivities, pleasurable sensory input vs. unpleasant sensory experiences; 25. Love of information as an AS trait; 26. The importance of having a support network; 27. How to be more assertive; 28. Why people with Asperger’s/autism generally don’t like to hug; 29. “Why do they [people without AS] think we’re rude/mean?” 30. The challenges of attending a funeral if you’re on the spectrum.

**Young Women’s Support Group topics:** 1. Finding a job: challenges and successes; 2. The LifeMAP coaching Program at AANE; 3. Challenges and coping strategies in high school; 4. Setting boundaries in platonic friendships with the opposite sex; 5. Dual diagnosis of Borderline Personality Disorder; 6. Fitting in on college campuses; 7. Accessing resources on a college campus; 8. How to address potential conflicts with friends; 9. Online dating and internet/social media safety; 10. Developing friends through social media vs. in-person; 11. Volunteering opportunities; 12. Navigating family vacations; 13. Relationships with siblings; 14. Parents who might be on the spectrum; 15. Special interests; 16. Picking up nonverbal cues.

*Women interested in participating in either of the AANE women’s groups, or mental health professions who might want to start their own groups for women with AS, are welcome to contact **Eva Mendes, MA, LMHC** at [Eva.Mendes@aane.org](mailto:Eva.Mendes@aane.org).*

*You can see her article “Marriage with Asperger’s Syndrome: 14 Practical Strategies” at the AANE web site, and learn more about her private practice at [www.evmendes.com](http://www.evmendes.com).*

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