

Learning from the Social Experiences of Girls with Asperger's Syndrome: Social Difference or Social Disability?

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Asperger's Syndrome(AS) presentation in girls

- In basic terms the change to merging AS with Autism occurred with the DSM 5. The term AS is still used by people diagnosed under DSM-IV and is considered less stigmatising by them than "mild autism" under the DSM 5.
- Researchers have found using the term AS is also relevant for the current term of "mild autism" (Jarman & Rayner, 2015).
- Social difficulties of girls with AS are not as obvious as those of boys with AS (Head et al., 2014). This results in fewer girls recognised and therefore diagnosed than boys.
- Girls with AS require support, but research is needed to understand how they think and what their social communication needs and expectations are.

Why this research?

- Wanted a lived-experience context for girls' social groups.
- Used a strengths-based lens for viewing social interactions (what are the social needs of girls with AS according to them?).
- Assumed girls with AS can de-code their own experiences (use their own words to explain their actions and feelings).
- This research challenges some conventional beliefs about autism by assuming girls with AS are interested in friendship, in particular girls' groups, in the context of school.

The problem

- The diagnostic criteria of AS include social and communication issues but these are defined by the deficit relationship of autism to neurotypical thinking. Stigmatisation may be the result of a diagnostic label (Calzada et al., 2012).
- There are differences in behaviour that point to differences in values (Attwood, 2007). Could different values create different social expectations in girls with AS? Could the social expectations of girls with AS be considered through their lived experience?
- Difference vs disorder? Professionals "have an obligation to recognise and value different people's perspectives about friendship," (Carrington, Templeton & Papinczak, 2003). The perspectives of girls with AS have been overlooked in the research.
- Understanding how these girls think could change an approach from "fixing" them, to one of support and respectful understanding.

Social problems faced by girls with AS

- We know girls with AS understand social games but don't play them (Yang & Baillargeon, 2013);
- They may be disinclined to participate conventionally in social activities but this is *not* because of poor global processing (Koldewyn, Jiang, Weigelt & Kanwisher, 2013);
- Girls with AS want friends, but may have higher expectations of friendship (Attwood, 2007);
- They are marginalised by not quite belonging (Portway & Johnson, 2005).

Loneliness

- Loneliness has been described as a mismatch between the desire for friendship and the quality of friendship available (Chamberlain, Kasari & Rotheram-Fuller, 2006)
- Loneliness is a recognised issue for those with AS (White & Robertson-Nay, 2009).
- Being alone can be a positive experience and Buccholz (1997) has viewed aloneness as a creative space for self-regulation and self-reflection.
- Being alone is not of itself negative; and being with people does not stop you feeling alone.

Research questions

1. Are girls with AS lonely in their friendships in groups at school?
2. Do girls with AS show social awareness?
3. Is there a difference in social awareness results of girls with a diagnosis and those who self-identify?
4. Do girls with AS use effective social strategies?

Research design

- An on-line survey design, to hear the words and voices of girls with AS, so open response answers were incorporated in the survey.
- This incorporates quantitative (particularly a “scale”) and qualitative (open responses) data.
- To capture their own thoughts on their own lives. Basically “allows” us to have the AS respondent interviewing themselves in a safe environment!;
- Opted for an online survey environment that included responses, short answers and open response opportunities.

Asher Loneliness and Social Dissatisfaction scale (Asher et al., 1984)

The Asher Loneliness and Social Dissatisfaction Questionnaire scale has been used to measure the impact of loneliness on typical children (Asher et al., 1984). 16 loneliness questions were measured using a five point scale (SA, A, N, D, SD). We wanted to see if this scale could also be applied to children with ASD.

PLUS

9 extra statements based on AS characteristics and friendship style were added. E.g.:

- “I enjoy being alone”
- “I can tell when I fit into a group”
- “I prefer having a best friend to being in a group of girls”

Who responded?

- Asperger Services Australia distributed the survey on their website to members via their facebook page.
- There were 68 initiated responses, aged from 10 to 47 (10 year old not included in final data).
- 45 people provided valid, completed responses.
- Those who were older reflected back on their school experiences.

RQ & Thematic analysis



RQ	5 Themes – discussion links
RQ1 - Are girls with AS lonely in their friendships in groups at school?	Loneliness Inclusion and groups
RQ2 - Do girls with AS show social awareness?	Social understanding
RQ3 - Is there a difference in social awareness results between those who self-identify and those who have a formal diagnosis?	Self-identity and values
RQ4 - Do girls with AS use effective social strategies?	Coping strategies

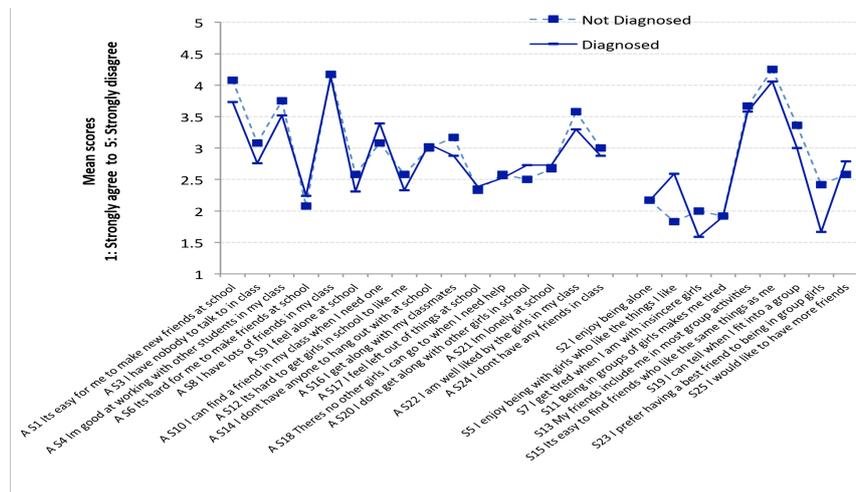


RQ 1

Are girls with AS lonely in their friendships in groups at school?

Closed Questions

Very little difference in answers for diagnosed vs non-diagnosed



Loneliness

In the qualitative questions the girls indicated high levels of loneliness and dissatisfaction with friendships-both in terms of number and in terms of quality. *For example:*

- *“In intermediate I was entirely on my own in all ways.”*
- *“I never had enough close friends to know about problems.”*
- *“I battle to ‘get’ how to do social life and friendship. Always get it wrong...I see I am actually on [the] outskirts and [the] only one not to be invited, stand alone again with no friends, no group to fit in, nothing but feeling wretched and heartsore at [my] inability to have friends or be acceptable by any group. It’s a very lonesome life...”*

Inclusion and groups



Most girls were followers or peripheral group members. Some were loners, but usually not by choice:

- *“Even as part of a team, I was a loner.”*
- *“Always standing in the back, more of a follower and observer. Often taken advantage of due to wanting to please and fit in.”*
- *“I’m mostly left out and ignored because I am too quiet.”*
- *“I don’t have real friends, just people to get through the day. [I’m] just a person in the background 75% of the time.”*

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RQ 1

Are girls with AS lonely in their friendships in groups at school?

Analysis: There were high levels of loneliness recorded in the quantitative questions and these were reinforced in the qualitative answers.

RQ 2 Do girls with AS show social awareness?

Social Understanding: *Can girls with AS recognise when other girls are “fake”?*

- *“Their mouths are moving” “Her face said she lied”*
- *“The way I can tell if some girls are being fake or are lying is through over hearing other people. Since people don't really pay attention to me I hear a lot about others from them.”*
- *“There's a certain vibe or feeling I get when girls aren't being genuine. As though I'm reading a layer that they didn't mean to put out. Kind of like I'm tuned into a different frequency.”*
- *“I just get a feeling that they aren't being honest. Or what they're saying contradicts things they've previously said or done.”*

RQ 2 Do girls with AS show social awareness?

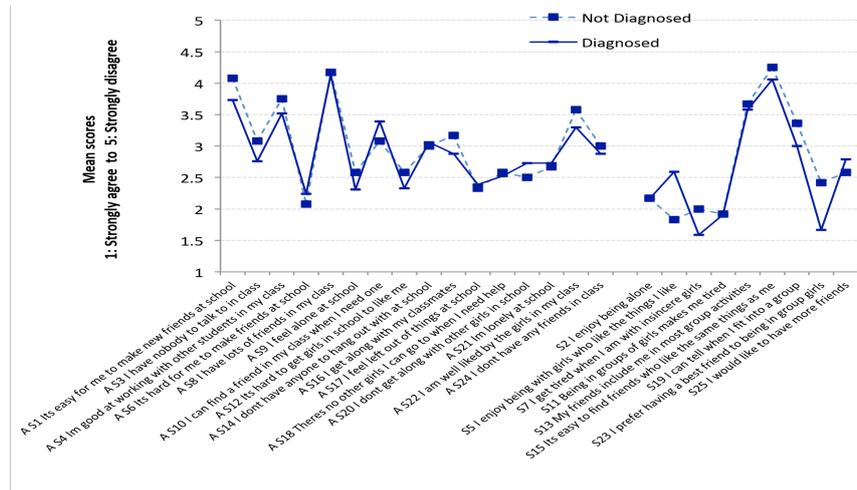
Analysis: overall, there were high levels of self-awareness. In addition, in those who self-identified as having AS, the ability to reflect on their lives and the traits of AS show social awareness (of not fitting, and commonly of social dissatisfaction).

RQ3

Is there a difference in social awareness results between those who self-identify and those who have a formal diagnosis?

Closed Questions

Very little difference in answers for diagnosed vs non-diagnosed



Self-identity and values

Most of the girls with AS in this study showed a tendency toward being non-conformist or thinking differently. They showed awareness of how typical girls are supposed to behave, but overall indicated that they couldn't or wouldn't conform to social expectations. For example:

- *"I'm not a girly girl"*
- *"I say what I think and people don't always care for it."*

RQ 3 Analysis



- There was no difference in loneliness levels between diagnosed and self-identified respondents-31% of respondents were undiagnosed. Both groups showed high levels of loneliness and social dissatisfaction.
- Why would there be so many undiagnosed respondents? Older respondents may not have had access to diagnosis; stigma associated with diagnosis is also a concern (Shtayermman, 2009).
- One respondent noted “[I’m] scared of losing my job if I have to disclose this [if I have a formal diagnosis]”. There was felt stigma in work environments about autism.

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RQ4

Do girls with AS use effective social strategies?

Social coping strategies

Keeping their thoughts to themselves was the common social strategy for most respondents. They said:

- *"I never know what to do so I just say nothing, move away or not get involved."*
- *"I am extremely good at making friends if that includes those that let you hang around them as long as you keep your mouth shut."*

There was awareness of compromising values to stay in a group:

- *"I am sometimes forced to be tolerant of cruelty and participate in groups."*
- *"I always feel like I just have to learn to live with things."*

Choosing not to compromise on values and avoid socialising (physically staying home/avoiding friends)

- *"I never do something I don't want to do or I believe is wrong."*
- *"I would prefer to be alone than to be fake or do something against my will."*

Use of facts to solve social problems (scientific logic)-use behavior to identify social games

- *"[Girls] they say one thing, then do another, it is hard to tell which is true."*

Social justice approach

- *"I try to fix the problem. I feel bad when I see a problem and do anything to prevent it from happening or to solve the problem. I get upset when I am the reason for a problem to happen, or if I cannot solve it."*

RQ4

Do girls with AS use effective social strategies?

Analysis: girls use strategies that are frequently passive, but based on their power relationships in the group. This may not be considered different to typical girls, though their answers show they are aware of being marginalised. Girls with AS are frequently voiceless, they also expressed different kinds of values to those of their groups.

Summary

Autism has been defined by outside voices, it is time to ask girls with AS about their social behaviour and the meaning of their social experiences.

Overall, participants showed social awareness of group dynamics and most expressed awareness of their own social powerlessness. They were likely to be silent, ignored, voiceless or quirky and try too hard. They were lonelier than their peers (using the Asher scale).

The respondents relayed examples of poor social behaviour in peers. Many observed social games because other girls ignored them and spoke out against friends in front of them. Respondents were often social observers.

There was no difference in reported loneliness between those with a diagnosis of AS and those without a formal diagnosis. Both groups reported similar levels of loneliness as well as similar social experiences.

Implications for Teachers

- Girls with AS should be consulted about their social concerns and needs.
- Having trouble socially does not make a person with AS socially inept, but it does make them socially vulnerable.
- Girls with AS recognize social games in others, but won't play them because of differences in social values.
- Preference for best friends does not mean students with AS don't need to be part of groups or are not lonely.

Relate to a girl with AS? Take a strength's based approach rather than through the lens of social problems.

ARA social strategy for teachers

- **A**ssume awareness (of social environments)
- **R**ecognise social decision-making (passive choices are still choices)
- **A**ct as an advocate (look at the role of everyone in a social group to improve it)
- *Do not assume social problems in groups are caused by the girl with autism*

The true significance of the study lies in the way it approaches girls with AS to decode the social meaning of their inclusion or exclusion from social groups...

Autism means thinking differently and for yourself. (De Silva, 2016, p. 8)

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