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Assessing Need and Acceptability of a Youth Mentoring Intervention for Adolescents with Autism by Adults with Autism

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Abstract

Background: *Adult mentors can positively influence development, yet youth with autism spectrum disorders (ASD) have too little access to adult mentors who can provide role modeling, guidance, and support. Furthermore, neurotypical adult mentors (i.e., adult mentors without ASD) may not understand the day-to-day realities that youth with ASD face and the social world they navigate. Therefore, it is possible that adults with ASD may be particularly well-suited as mentors for youth with ASD.*

Method: *Six semi-structured focus groups of four to seven people each explored the need for a mentoring program to bridge the gap between the supports youth with ASD need and what they currently receive. These focus groups included key stakeholders: youth with ASD, adults with ASD, and parents of youth and adults with ASD.*

Results: *Focus groups with key stakeholders demonstrate a significant need for the development of a one-to-one youth mentoring program delivered by adults with ASD.*

Conclusion: *There are significant gaps between the supports (particularly social supports) that adolescents with ASD need and those that are available to them. All of the focus groups concluded that a mentoring program in which adults with ASD are mentors for youth with ASD seems to be an acceptable and much-needed support for adolescents with ASD. Such a program is not currently known to exist.*

Plain Language Summary

Youth and young adults with autism face difficulties. They often feel like they do not have the friendships they want. They also often feel like they are not connected to their communities. Sometimes, adults can support youth informally through mentoring. There are few mentoring programs for youth with autism. Also, all the known programs like that use mentors without autism. This study looks at whether people think it would be useful to develop more mentoring programs for youth with autism. It also looks at using young adults with autism as mentors for youth with autism.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social skills and the presence of repetitive, restricted patterns of behavior (American Psychiatric Association [APA], 2013). Because of the different ways ASD can impact an individual's

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functioning and well-being, many individuals with ASD need and/or benefit from services and supports throughout their lives (Bower Russa et al., 2015). While there are many interventions available for young children with ASD (Howlin & Magiati, 2009), availability of supports wanes by adolescence (McStay et al., 2014). This paucity of services and supports continues during and through the transition to adulthood (Bower Russa et al., 2015).

Despite showing high levels of family coping, families of children with ASD also report high levels of uncertainty and stress during adolescence (Bower Russa et al., 2015; O'Brien, 2016). Indeed, youth with ASD are vulnerable to social, emotional, educational, and vocational difficulties during and around the transition from adolescence to adulthood (Roux et al., 2015). One of the core symptoms of ASD that can have a significant impact on an individual's well-being is difficulty forming and maintaining relationships (APA, 2013). Adolescents with ASD are more likely than other youth to report that they never receive calls from friends or invitations to social activities and never see friends outside of school (Shattuck et al., 2011). Yet, many youth with ASD desire friendships and close relationships and report that friendships are important to their overall well-being (Danker et al., 2019).

Youth who lack quality social support from family and friends are vulnerable to mental health problems (Colarossi & Eccles, 2003; Klineberg et al., 2006) and at-risk of negative life trajectories. Adults with ASD tend to be under-engaged with their communities and often experience low self-efficacy regarding relationships, employment, and independent living (Henninger & Taylor, 2013; Roux et al., 2015). They are also more likely than the general population to experience suicidal ideation (Cassidy et al., 2019). At the same time, young adults with ASD want supportive help to overcome unwanted difficulties so that they can be full, contributing members of their communities (Sosnowy et al., 2017).

It is necessary to identify services that are accessible and satisfactory to young people with ASD because of the difficulties people with ASD face in adolescence and young adulthood. In the general population, relationships with caring, nonparental adults (i.e., mentors) are critical to healthy child and adolescent development (Rhodes & Lowe, 2008). Such relationships can positively influence many outcomes, including interpersonal relationships, academic achievement, self-confidence, mental health, and problem behaviors (Raposa et al., 2019). Despite these important effects, mentoring interventions have rarely been investigated specifically for youth with ASD.

One pilot study examined a program that paired nine adolescents with ASD with neurotypical college- or graduate-student mentors and found evidence of adolescent participants with ASD feeling more socially connected (Curtin et al., 2016). Social connection, in turn, is associated with better mental health for this population (Gotham et al., 2015). Given the reciprocal nature of youth mentoring relationships, there is potential for a program to also benefit young adult mentors. Previous research found that mentoring can positively impact mentors' self-esteem and interpersonal and problem-solving skills (Weiler et al., 2013). It could be advantageous to explore a model in which young adults with ASD provide mentorship for adolescents with ASD. Such a mentoring program could have substantial positive effects for participants on both sides of the mentoring relationship.

Although youth and adults with ASD may have challenges building relationships, this unique model could bolster resilience for youth and adults. There is evidence that bringing people with ASD together in a group setting can relieve loneliness and ameliorate comorbid mental health difficulties such as anxiety and depression (Spain & Blainey, 2015). A mentoring program in which all participants have ASD could produce similar effects because of the shared experience of living as a person with ASD in a world built around neurotypical individuals. In addition, having mentors who have faced the challenges mentees are currently facing could allow for more targeted and relevant support. Despite this potential, no known program has used adults with ASD as mentors for adolescents with ASD.

Given these preliminary results and associations, mentoring seems like an important and promising support for adolescents with ASD that could benefit from further investigation. The purpose of the current acceptability study was to assess how well the proposed mentoring intervention for adolescents with ASD was received by members of the target population and the extent to which they believed the new intervention might meet the needs of the target population. Following guidelines for assessing the acceptability of a new social and behavioral health intervention with qualitative methods (Ayala & Elder, 2011), our primary research questions were: (1) To what extent do youth with ASD, parents of youth and young adults with ASD, and adults with ASD perceive a need for a mentoring program for adolescents with ASD? (2) To what extent do youth with ASD, parents of youth and young adults with ASD, and adults with ASD perceive the proposed mentoring program as acceptable (i.e., Do the benefits outweigh the costs? Is the model satisfactory?)?

Method

Researchers obtained Institutional Review Board (IRB) approval from the associated university. Participants were informed of the study opportunity in collaboration with a local public high school, an ASD advocacy organization, and a local post-secondary program that supports adults with ASD in developing life skills. Participants included high school students with ASD, parents of high school students or young adults with ASD, and adults with ASD. Adolescents and their parents learned of the opportunity through email from special education teachers and school counselors. Parents also learned of the opportunity through the advocacy organization email announcements. Adults with ASD learned of the opportunity via email announcements from the post-secondary program and/or the advocacy group. Participants who expressed interest were referred to the study team. Inclusion criteria for each group was as follows: high school students with ASD between the ages of 14-21, parents of individuals with ASD, and adults with ASD. Participants also had to be able to commit to up to 2 hours of participation. Adolescent participants did not have an intellectual disability (IQ under 70), as determined by school personnel, and all participants spoke and understood English fluently. Informed assent and consent were obtained from research participants with accommodations made as needed (e.g., reading the consent aloud) in accordance with guidelines from the IRB.

In six semistructured focus groups of four to seven people each (total $N = 33$ participants; see Table 1 for demographics of focus group participants), researchers worked with participants

Table 1

Demographics of Focus Group Participants

Focus group	People with autism			Parents of people with autism		Combination
	Young adults	Adolescents	Adults	Young adults	Adolescents	Community
<i>N</i>	6	4	6	6	7	6
Gender ^a						
Male	4	4	6	5	5	2
Female	2	0	0	1	2	3
Race ^a						
White	6	3	5	6	6	5
Asian	0	1	1	0	1	0
Age (years)	18-32	14-17	19-56	49-69	35-59	28-48 ^a
Education ^a						
High school diploma	4	N/A	2	3	4	0
Some college	1	N/A	1			3
Graduate or professional degree	0	N/A	1	3	2	1

^aNot all participants reported this demographic. Data reported are for participants who provided information.

to explore the need and acceptability of a mentoring program to bridge the gap between the support youth with ASD need and what they currently receive. The six groups consisted of three groups of youth and young adults with ASD and three groups of adults who were parents of youth with ASD or other adults with ASD. Focus groups were held within conference spaces at a local autism advocacy organization. The focus group format was semistructured and included a series of open-ended questions with follow-up probing questions. Sample focus group questions included the following.

- Given our brief description and discussion of this potential mentorship program, what are some of the pros and cons of participating in such a program?
- Do you have concerns or worries about participating in a program like this?
- What type of training would you find helpful before participating?
- Has your child had a relationship with a person who has provided them with ongoing guidance and advice (mentor)? If yes, please describe this relationship.
- Do you believe your child would benefit from having a relationship with a mentor who also has ASD? Why or why not?
- Do you believe you have/would have benefited from having a relationship with a mentor?

- What type of mentoring experiences do you feel would have been helpful to you as a child/teen?

Trained facilitators were encouraged to follow the discussion thread of the group so long as it fit within the scope of the study. Each focus group included two facilitators including one of the principal investigators and a graduate student researcher.

Focus groups were audio recorded and transcribed verbatim. Two graduate student researchers used thematic analysis to analyze the transcriptions (Braun & Clarke, 2006). Student coders were supervised by a principal investigator who has extensive experience with qualitative research and thematic analysis. Each researcher analyzed the transcripts separately and identified content themes within and across the transcripts. Given the clear scope and purpose of the study, identified codes and subsequent themes were very similar between reviewers and consensus coding was used in finalizing the themes. The coding structure was reviewed by the principal investigators, including an expert in ASD (licensed psychologist in a specialty autism clinic, researcher evaluating autism interventions) and an expert in youth mentoring intervention models (researcher evaluating youth mentoring programs). The research team discussed the themes and their relative importance. Namely, researchers discussed which themes from the focus groups were most important and relevant when considering the development of a program in which adults with ASD mentor youth with ASD. Researchers then brought the themes to the community steering committee (composed of adults with ASD and parents of youth with ASD) for a final member check to ensure that the identified themes were comprehensive and complete. The final step was contextualizing the themes and writing an integrated storyline to show relationships among the themes.

Results

Three themes were identified in the focus groups: need for mentoring relationships, acceptability of a mentor with ASD (benefits), and acceptability of a mentor with ASD (concerns). A summary of these themes is provided in Table 2 and described below.

Need for Mentoring Relationships

Overall, there was a perceived need for mentoring of youth with ASD. Parents of youth with ASD reflected on the support their children had received up until adolescence: therapy, social skills groups, personal care assistants (PCAs, people [usually young adults] hired to help someone with a disability with activities of daily living), and nannies or other support professionals. However, parents did not feel that these supports were adequate for meeting the adolescents' current needs for social and emotional support. One parent put it this way, "He has a PCA...but we still feel like we don't meet his needs." Another parent spoke to the decreasing availability of formal supports and recreational activities targeted towards youth with ASD as her son aged, saying, "As he got older and those options started closing in or wrapping up, it has been a little bit more difficult to find or give him the [social and relational] support he needs." A third parent agreed, stating that her adult son "never had a support group or anything like that, and

“I’ve always wished he could have. So, I think there is a need [for a mentor program] out there.” Overall, the parents conveyed confidence that a mentoring program would help fill the gap between current supports and the needs of youth with ASD.

Table 2

Identified Themes

Theme	Description
Need for mentoring relationships	<ul style="list-style-type: none"> • Current supports not adequate for meeting adolescents' needs • Decreasing availability of supports for adolescents • Need for belonging and social affiliation • Mentoring could fill the gap between needs and current access
Acceptability of a mentor with ASD: Benefits	<ul style="list-style-type: none"> • Common ground • Relatability • Allows people with ASD to learn from other people with ASD • Better able to understand youth's challenges • Vision of what is possible for the future • Normalizing youth's experiences • Youth could feel more comfortable and open • Benefit for the mentor - being able to contribute to community
Acceptability of a mentor with ASD: Potential Concerns	<ul style="list-style-type: none"> • Similar struggles • Adult readiness to be a mentor • Lost benefits of neurotypical mentor such as social modeling

Coupled with increased need for social and emotional support during adolescence, participants (particularly adults with ASD and parents of individuals with ASD) worried about youth with ASD finding belonging and social affiliation. One adult simply stated, “There’s a lot of need out there.... Young adults [with ASD] struggle to maintain connection.” One adult with ASD stated that they would have liked having a mentor to gain an “insider’s perspective” on growing up with autism. One participant specifically expressed that high school had been very challenging for him and that there was a lack of support in high school. Of those who noted previous mentoring-like experiences, mentors were typically paid professionals (e.g., social workers, case workers, and mental health practitioners). An adult with ASD spoke about these difficulties, saying of the transition from elementary school to high school, “Heaven help you if you’re different in any way.” In addition, a youth with ASD noted the importance of having a non-parental adult to talk with, saying, “Sometimes it can be difficult to talk a lot with parents. But, yeah, I think it would be easier talking about [social difficulties] with a mentor.”

Across all participants, the need for a mentoring program was clear. Each group of participants highlighted the difficulties of adolescence and the difficulty for youth with ASD. All participant groups indicated that a mentoring program could start to fill the gap between what youth with ASD need and the supports to which they have access.

Acceptability of a Mentor with ASD

Following a brief description of a new intervention model that would include adults with ASD as mentors, participants were asked to discuss the acceptability of the model, including any potential benefits and challenges of such a program. All parents of youth with ASD agreed that they would want their child to participate in a program like the one presented. Participants were quick to share their enthusiasm for the idea of building a program with mentors with ASD despite a few potential challenges (noted below).

Benefits

Many participants reported that having a mentor with ASD would provide common ground between the mentor and mentee. They believed a mentor with ASD would be able to relate to a mentee with ASD and share their own experiences of growing up. One adult with ASD shared, “Having someone on the spectrum who is doing [the mentoring] is a whole different thing that is really valuable.” Another adult with ASD stated the rationale for this very clearly:

It’s important for kids on the spectrum to be with adults on the spectrum. We come with our own set of challenges and knowing that, knowing what to expect, knowing where to go for help, knowing how to advocate for yourself.... In this, we have an opportunity with this generation of autistic kids to help them be a little more successful than maybe [we] were.

Furthermore, an adult with ASD noted a potential downside of having a neurotypical mentor, stating, “There is so much stress on mainstreaming that the kids with ASD who can learn from each other are being spread out too far.” This participant was speaking to a frequent recommendation for parents to place their child with ASD in settings with neurotypical peers (referred to as “mainstreaming”) as often as possible, so the child learns socially acceptable behavior from peers. This encouragement to mainstream children was also reflected in parents’ comments in focus groups, but this adult with ASD noted a possible loss that occurs when such recommendations are followed—children with ASD do not have the ability to learn from each other.

Participants also noted that a mentor with ASD would better understand what the youth is experiencing, which could be particularly important for youth who may have difficulty articulating their experiences. One parent whose daughter attended a support group led by an adult with ASD shared,

It was really valuable to have someone on the spectrum who was doing the mentoring because she was able to interpret and explain to the parents a lot of things we just didn’t understand and never would have figured out.

Generally, participants believed connecting adults and youth both with ASD would allow the mentees (and their parents) to see what is possible for the youth. The mentors could become types of models of what the youth could attain later in life. One parent said of possible adult mentors with ASD, “They’ve been there. They’ve done it, and it’s possible.” Another parent

shared how this benefit could extend to the rest of the family, “Maybe if we understood better his true capabilities, then we could understand [what his options are].”

Another very common theme throughout the focus groups was that connecting with a mentor with ASD could also normalize the youth’s experiences, which could decrease loneliness. For example, parents stated, “I don’t think my daughter understood ASD until she was around other kids with autism.” Another discussed the ways in which youth with ASD appreciate connecting with other people with ASD, stating, “They get excited because they find other people like themselves.” Participants indicated that mentors with ASD could help youth find and understand their identities generally, and their autistic identities specifically, through the mutual understanding that would emerge in this type of relationship.

Another noted benefit to utilizing mentors with ASD was that youth might feel more comfortable and open. Youth with ASD often struggle with social skills, and this difficulty can cause social anxiety. Participants discussed how having mentors with ASD might lessen this social anxiety. One stated,

I think just letting them...express themselves freely would be important for any kid on the spectrum because social abilities are probably one of the toughest things out there. For them to be able to communicate with someone else and know it’s okay if something comes out that’s not appropriate.... Just to be able to express themselves would be a big plus, with the freedom to be able to [make mistakes].

Participants also spoke about how this type of mentoring relationship could directly benefit the mentor. Adults with ASD, in particular, focused on the fact that people with ASD sincerely want to help others, but they do not always have an opportunity to do so. One such participant shared, “When a person with autism actually genuinely helps somebody in a legitimate way, that’s very meaningful to them.” This potential for such a program to benefit the mentor is an important aspect that would be unique to a model that includes mentors with ASD.

Concerns

Participants’ concerns regarding mentors with ASD were two-fold. First, participants suggested that the mentor and the mentee might have similar struggles (e.g., co-occurring disorders). For example, one adult with ASD shared, “If both individuals have some anxiety issues...worst case scenario would be they both start shutting down.” In this case, participants noted that with the right type of training and support, mentors with ASD could successfully provide this support despite such possible struggles. One participant stated that adult mentors with ASD would need

...guidance continuously throughout the mentorship, just kind of sitting in the background... and then if they get to a place where they’re stumped or something, they step in and just nudge a little bit in the right direction.

Second, some of the parents of the young adults with ASD were skeptical about whether their adult child would be ready to be a mentor for a youth with ASD. Others felt that they could see

their child being a mentor under certain conditions (i.e., with quality training). Some participants thought there would be more benefits to having a neurotypical mentor. For example, a few participants suggested that neurotypical mentors may have an easier time modeling socially acceptable behavior for the youth. One young adult with ASD stated, “It could also be beneficial if they have [neurotypical] mentors to help with things that people with autism could not.”

Discussion

An intervention in which adolescents with ASD are matched with adults with ASD in supportive mentoring relationships could meet a current unmet need in formal support services for young people with ASD. Adolescents with ASD, parents of adolescents and young adults with ASD, and adults with ASD agreed that adolescence is a particularly challenging developmental stage when many youth experience social and emotional difficulties. A mentoring program could intervene to ameliorate some of these negative feelings and experiences. When presented with a program model that included adults with ASD as mentors, participants thought it would lessen youth’s feelings of being different and increase the empathy felt by the mentor. Participants discussed the many benefits that come when people with ASD can be together and learn from one another.

It was also noted that this type of mentoring program could increase individual and parental expectations for the youth’s future. The mentors would become models for what is possible in the youth’s lives over time. Individual and family expectations strongly influence outcomes for people with intellectual and developmental disabilities (including ASD, e.g., Carter et al., 2012), so the potential influence on expectations may be integral to the success of this type of mentoring program. Despite overwhelming support for a mentoring program for adolescents with ASD in which adults with ASD provide mentorship, there were some potential concerns (e.g., mentors and mentees sharing similar struggles rendering the relationship too difficult).

Though there were a variety of perspectives represented in the focus groups, participants were recruited through a few programs within one metro area where the proposed mentoring program was anticipated to run. It is possible that individuals not connected to these types of programs or who live in rural communities would have different perspectives on this topic. Furthermore, this is an assessment of need and acceptability in one community, so these results might not be generalizable to other communities. This was also a conceptual exploration in which participants were asked to respond to an idea about a possible program; these same participants might feel differently when responding to the actual implementation of such a program.

As such, a vital next step in this area of research is to explore the development and implementation of the proposed intervention model that includes incorporating feedback from participants in this study. Researchers need to investigate whether such a program is feasible, practical, and likely to improve the well-being of mentors and mentees. Closely studying intervention implementation will help identify what types of structure, support, and training are required to enhance the success of a mentoring program in which both the mentor and mentee are diagnosed with ASD. This is a promising area of inquiry that may open new avenues through

which youth with ASD are supported and through which young adults with ASD contribute to their communities in a way that only they can.

Conclusion

Participants in this study were clear that youth with ASD need social support from non-parental adults beyond what is currently available. All key stakeholders agreed that a mentoring program in which youth mentees with ASD are paired with adult mentors with ASD would be an acceptable model for this. The participants reported that such a program would have potential to benefit both the mentor and the mentee. As this type of program is developed, it will be important to use quantitative and qualitative methods to better understand the potential impacts on participants and the types of supports that are needed to make the model a success.

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