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EXPANDING HORIZONS: A PILOT MENTORING PROGRAM LINKING COLLEGE/GRADUATE STUDENTS AND TEENS WITH ASD

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Abstract

A small pilot program of nine youth ages 13–18 with high functioning autism spectrum disorder (ASD) or Asperger's syndrome assessed the feasibility, acceptability, and potential efficacy of an individualized mentoring program. Youth met weekly for 6 months with trained young adult mentors at a local Boys and Girls Clubs. Participants reported improvements in self-esteem, social anxiety, and quality of life. Participants, parents, mentors, and staff reported that the program improved participants' social connectedness. While the pilot study was small, it provides preliminary data that mentoring for youth with ASD has promise for increasing self-esteem, social skills, and quality of life.

Keywords

adolescence; autism; mentoring; self-esteem; socialization; social skills; quality of life

Introduction

Youth with autism spectrum disorders (ASD) face significant and unique challenges, which can include difficulties with social interaction, communication, atypical repetitive behaviors, and restricted interests (American Psychiatric Association, 2000). Considerable clinical and research attention has focused on addressing the language, sensory, and behavioral challenges in ASD. Less attention has been directed to the social difficulties that these youth experience, although these problems can have a serious impact on their quality of life (Kroeger, Schultz, & Newsom, 2007). Youth with ASD may be excluded from peer groups (Loomis, 2008) and may be socially rejected (Chamberlain, Kasari, & Rotheram-Fuller, 2007). The development of social competencies is critical for independence in adulthood, along with academic and vocational skill development. Moreover, positive social

relationships are important for the development of self-confidence and interpersonal competence (Chamberlain, Kasari, & Rotheram-Fuller, 2007). Thus, programs designed to help youth with ASD to develop self-esteem and social competence are critically important for successful transition to adulthood and overall quality of life.

Mentoring may have promise for facilitating social confidence and self-esteem for youth with ASD. Research on mentoring has focused primarily on at-risk children with family and social disadvantages, and has shown that the presence of a trusted and caring individual can confer important benefits for youths' social and emotional development (DuBois, Holloway, Valentine, & Cooper, 2002; Grossman & Tierney, 1998; Karcher, 2005; Keating, Tomishima, Foster, & Alessandri, 2002; King, Vidourek, Davis, & McClellan, 2002; Rhodes, 2008). Youth involved in mentoring have shown improvements in educational achievement, health, safety, social/emotional development (Jekielek, Moore, Hair, & Scarupa, 2002), and in peer and family relationships (Grossman & Tierney, 1998; Sword & Hill, 2003). Additionally, mentoring has demonstrated effectiveness in fostering the motivation, knowledge, skills necessary for successful transitioning from high school to adulthood (Sword & Hill, 2003), and in improving problem-solving, social and interpersonal skills, self-determination, and community integration and participation (Britner, Balcazar, Blechman, Blinn-Pike, & Larose, 2006; Bruce et al., 2014).

In contrast to programs that focus on providing friendship or companionship, mentoring programs provide a structured experience for target youth. Through the development of a caring and supportive relationship and specific discussion about goals, mentees are helped to achieve their fullest potential and to develop their own visions for the future (National Mentoring Partnership, 2005). Several mentoring program practices have been shown to predict stronger outcomes for youth (DuBois, Holloway, Valentine, & Cooper, 2002). These include program procedures for systematic monitoring of program implementation, use of community-based settings (vs. school settings), involvement of mentors who have backgrounds in helping roles/professions, clearly established expectations for the frequency of contact between mentors and mentees, continuous training for mentors, structured activities for mentors and youth, and support for parent involvement. The magnitude of the effects have been shown to be associated with the number of these practices implemented, suggesting that these practices each make an independent contribution to youth outcomes.

Despite the documented benefits of mentoring for at-risk youth, research on mentoring youth with developmental disabilities is scarce. Powers and colleagues (1995) found that youth with physical disabilities who participated in a structured mentoring relationship expressed higher levels of self-efficacy and confidence as well as increased community knowledge compared to youth in the control group. A handful of case studies and review articles have called for mentoring programs for individuals with disabilities but empirical evidence is limited about outcomes for youth with disabilities in mentoring programs (Stumbo, Blegen, & Lindahl-Lewis, 2008; Stumbo et al., 2010; Whelley, Radtke, Burgstahler, & Christ, 2003; Wilson, 2003). We know of no similar demonstrations of the benefits of mentoring for youth with ASD. In that there are few known therapeutic modalities for these adolescents, mentoring programs may be a promising means for providing this population of youth with regular social contact and the opportunity to develop

and practice problem-solving, self-motivational, interpersonal, and social skills. Toward that end, we designed a pilot study to evaluate the feasibility of providing one-to-one mentoring for adolescents with ASD based in a community recreation program setting.

Method

The goal of the pilot mentoring program was primarily to assess the program's feasibility and acceptance by parents and teens. In addition, we sought to pilot-test several measures that might be useful to assess evidence of program efficacy in addressing social skills, confidence, and self-esteem. Specifically, we sought to determine: (1) the extent to which mentors and mentees attended the sessions as scheduled; (2) adolescents' reports on their self-esteem, quality of life, and communication skills using standardized instruments; and (3) the satisfaction of youth, their parents, mentors, and recreation center staff with the program.

The program was designed to maximize its likelihood of success based on previous literature about mentoring (described above). The program was implemented in a community-based setting that included structured activities, was continuously monitored by program leadership, had clearly established expectations regarding the frequency and length of contact between mentors and mentees, included training and ongoing support for mentors, and supported parent involvement.

We used a pre-post design to assess our outcomes of interest; participants completed assessment measures at baseline before the mentoring intervention began and again within three weeks after program completion. In addition, adolescents and their parents were asked to complete a satisfaction questionnaire to evaluate the program following its completion.

Program Setting

The Partners Exploring Education and Recreation (PEER) mentoring program was developed by Partners for Youth with Disability (PYD), an organization in Boston, MA that provides individualized and group mentoring programs for youth with a wide variety of disabilities. The PEER program paired adolescents with ASD ages 13–18 years with undergraduate and graduate students to meet on a weekly basis at a local Boys & Girls Club (BGC). BGCs are community-based recreation centers where mentors and mentees can choose from a menu of activities including Arts, Education, Leadership, Life Skills, Sports, Fitness & Recreation, and Technology. That the mentoring sessions all took place at the BGC standardized the setting and range of activities available to participants. Additionally, the availability of pre-planned activities provided mentors with the opportunity to focus more closely on supporting their mentee without the added pressure of seeking out and selecting activities.

Participants

The program was targeted for adolescents ages 13–18 with Asperger syndrome (AS) or high-functioning autism (HFA). Participants were recruited by outreach to various community organizations that serve youth with developmental disabilities and their families. Youth were included if they were between the ages of 13 and 18 years and had received a

previous diagnosis of AS or HFA by a qualified professional. Participants were excluded if they had a history of aggressive behavior, running away, or psychosis. Parents who were interested in the program for their adolescent called and spoke with a staff member who explained the structure, activities, and requirements of the program, and conducted a brief phone screen.

Mentors were identified from local area colleges and universities. They committed to meeting with their mentee for 2 hours per week for 20 weeks. Mentors completed a six-hour training program preparing them for their role as mentor to a teenager with ASD. The training covered an overview of ASD, including a review of typical strengths and challenges. Mentors also received training in communication skills, behavior management, using visual supports to facilitate communication, role-modeling proper social behavior, encouraging active participation, and the person-environment-activity occupational therapy model (Law et al., 1996).

Participating youth were matched with mentors, based on personality types and common interests. An in-person meeting was then arranged that included program staff, mentor, mentee, and at least one parent or guardian. During this meeting the policies, goals, and procedures of the program were explained in detail, and all participants signed contracts stating their agreement to abide by program policies. Additionally, the parent and adolescent gave consent (or assent for those under 18 years) and completed a set of pre-intervention questionnaires.

Mentoring Program Design

Once matched, the mentors and mentees met once a week for two hours at one of two BGCs over a 6-month period. Mentors and mentees established individual goals at the beginning of the program, related to the mentee's interest in one of five core areas: self-esteem, healthy relationships, independent living, community involvement, and education/vocation. Mentees were encouraged to work on these goals with their mentor through the process of choosing and engaging with their mentor in recreational and social activities offered by the BGCs. Mentors helped mentees to break down the broad goal areas (e.g., improve social relationships) into smaller steps. For example, one mentee identified early on that he would like to initiate plans with friends, and learn to be more at ease during phone conversations. His mentor helped him to create a list of people at school that he would like to know better and to identify some ways he could contact them and make plans with them. The mentor practiced talking on the phone with him and also arranged for him to call some of her friends as a way to help him practice talking to new people.

Project staff provided regular follow-up support to matches through checking in on a monthly basis in accordance with recommendations for effective mentoring programs (National Mentoring Partnership, 2005) and reviewed mentor logs on a weekly basis to provide ongoing support. Follow-up support was conducted via phone, email, and site visits throughout the duration of the program.

Measures

Mentee outcomes—Three standardized instruments, Pediatric Quality of Life Scale (PedsQL) (Varni, Seid, & Kurtin, 2001) the Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1965) and the Social Worries Questionnaire (SWQ) (Spence, 1995) were administered within one month prior to the start of the program and again within three weeks after the 6-month mentoring period was completed. Comparisons focused on differences between pre- and post-intervention scores on all measures. The PedsQL assesses the quality of life of adolescents in four domains: physical, emotional, social, and school functioning. The PedsQL was completed by adolescents, and the parent proxy form was completed by parents. The RSES is a short, self-administered scale of self-esteem that has been used successfully with adolescents with autism (Shipman, Sheldrick, & Perrin, 2011) The SWQ is a 13-item questionnaire that assesses anxiety about social situations that are typical for adolescents. The SWQ was completed by adolescents and also by their parents as proxy reporters.

Program outcomes—Feasibility and acceptability of the program were assessed by evaluating attendance, i.e., whether the participant attended 80% or more of the scheduled mentoring sessions, and by participants' responses to a satisfaction questionnaire. They were also asked report on the extent to which the goals they set at the outset of the program were met. In addition, at the end of the program, participants completed the *Youth Survey: Measuring the Quality of Mentor-Youth Relationships* (Jucovi, 2002) which consists of 20 questions that evaluate mentees' perceived closeness to their mentor and other dimensions of the mentor-mentee relationship. Parents completed a questionnaire designed for the study to report their satisfaction with the program and their perceptions of the value of the mentoring relationship and activities for their son or daughter. Specifically, they were asked to rank their teen's experience with his or her mentor and their teen's progress on goal-setting on a 5-point scale ranging from very negative to very positive, and to write in additional comments or feedback.

The study was reviewed and approved by the Tufts University School of Medicine Institutional Review Board.

Results

Mentee Outcomes

Participant demographics are shown in Table 1. Ten youth enrolled in the project. One dropped out before being matched because of transportation difficulties. Thus, our final sample consisted of nine youth with AS or HFA.

Table 2 shows the scores for the structured survey instruments that were administered pre- and post-intervention to assess quality of life, self-esteem, and social worries. Ratings by the teens on the on all instruments suggested trends toward improvement in each domain. Parent responses on the proxy form of the PedsQL showed a similar trend to those of the adolescents' responses. The sample size is too small for meaningful statistical analyses, but

it does appear that these outcome measures are acceptable to teens and parents and can yield meaningful scores when used in this population.

Four mentees chose to work on educational/vocational goals, and five mentees identified working on healthy relationships and community involvement. Specific goals included: working on trying new activities at the club; inviting peers to play games and find ways to form stronger relationships; basketball skills; time management and improved study habits; giving compliments; getting an A in a science class; arranging an outing with friends; learning to tie shoes; money skills, reading skills, and public speaking; and starting conversations with peers. Qualitative data collected from both mentors and mentees at the end of the program about whether they worked on goals together indicate that in most cases the mentor-mentee pairs worked on the goals the mentees had set for themselves. With the exception of one mentor who indicated that although she and her mentee talked about goals but she was unsure of her mentee's follow-through, the other mentors reported that they worked on skills such as assertiveness, activity planning, learning new games or skills, fitness, academics, and future planning. Similarly, seven of the nine mentees identified specific goals that they worked on including exercise, getting prepared for exams, social skill development such as complimenting others, and telephone skills. Two mentees reported, *I don't know or sort of*.

Program Outcomes

As shown in Table 1, program participation was very high; all of the adolescent mentees attended 80% or more of the scheduled sessions with their mentors.

Feedback from youth, parents, mentors, and BGC staff all indicated a high level of satisfaction with the program and indicated that in their opinion the PEER program was feasible and successful. Following the intervention, 100% of parents described their teen's relationship with their mentor as *very positive*. Seventy-five percent (75 %) of parents reported their teen's progress on set goals as *somewhat* or *very successful*, and that the mentoring experience had been very powerful for their child. Many parents noted that their child looked forward to the meetings and had built a positive relationship with his or her mentor. For example, one parent noted that her daughter was "*more relaxed and happier, especially right after meeting. She seems more spontaneous to emotional response and expression at home.*" Another parent observed that

[her son] is much more willing to take social risks and make plans with friends via Facebook. He is much more comfortable picking up the phone to call [his mentor]. He can text now and does with his friends. He has made friends at school and approached kids at the Boys & Girls Club.

Parents indicated an appreciation of the fact that their teen was accessing a community that he or she likely would have not otherwise independently navigated. As one parent expressed,

the best part of the program was witnessing my son look forward with anticipation to his weekly match. The fact that the mentor program was a springboard into an

inclusionary environment of acceptance and little to no socially penalizing behavior due to facilitation/supervision is a god-send!

Many parents indicated a desire for a longer-term program, more varied locations, having older teens at the BGCs, and some desire for more structure around the goal-setting component of the program.

Mentees themselves also reported a high level of satisfaction with the program. As shown in Table 3, mentees reported feeling excited and happy when they were with their mentor and indicated that they perceived that their mentor was someone to whom they could relate and talk, and who helped them grow stronger relationships with other people. Notably, following the completion of the PEER program, eight of the nine mentees chose to continue mentoring through the PYD's regular mentoring program.

For many of the youth, mentoring was a new experience, and it was important for the mentors to clarify their roles, especially since these youth had the social difficulties associated with ASD. For example, a mentee asked if he and his mentor were dating. In consultation with program staff, the mentor explored what "dating" meant to the mentee and then explained that the role of a mentor is a trusted guide, similar to a coach. She explained that her role was to support him as he worked towards goals and to be an older role model for him. She elaborated that in her role as a "coach", she could explain dating or give advice on dating, but the mentoring relationship itself is not dating. While this situation was successfully resolved, it does suggest that role clarification needs to be made very explicit for this population of youth.

Feedback from BGC staff indicated that the program was very successful and that they observed positive changes in mentees' behavior. In particular, staff indicated that at the beginning of the program, they perceived that the PEER participants appeared to be a bit shy in their interactions with other club members, but after a few weeks they became a part of the Club community. They reported observing that teens quickly gained more confidence in themselves and in their place in the Club. They noted that the PEER program raised the comfort level of everyone involved – the mentee, the parents, the Club staff, etc. Staff witnessed the mentors serving as good role models and helping the teen mentees know where to go and what to do at the Club.

All of the mentors reported that the PEER program was a positive experience for them as well. Qualitative comments obtained from the mentors indicated that they observed their mentees' identifying social goals and improving significantly in their ability to approach peers at the club. The mentors indicated that they enjoyed forming a connection with their mentee and watching them grow. One mentor noted, "[She] was an amazing mentee and friend. I will miss her very much." Another expressed that she

loved watching [her mentee] grow. He had a great sense of humor, and the times when I got him to laugh were really special for me. Knowing I was making a difference in his life, while he was making a difference in mine, was a very powerful thing.

All mentors reported feeling that they were helpful to their mentee.

Discussion

The results of this small pilot study suggest that a program in which trained undergraduate and graduate students provide supervised one-on-one mentoring to adolescents with AS and HFA can be feasible, acceptable, and helpful. The small sample size (n=9) precluded statistical analyses but the data suggest some promising trends worthy of future exploration. In particular, the trends toward the adolescents' improvements in quality of life, self-esteem, and social skills are encouraging. Likewise, the high rate of participant retention in PYD's regular mentoring program beyond the study further underscores participants' satisfaction with the program, enthusiasm for mentoring, and desire for the social connectedness that the program fostered. The high degree of satisfaction indicated by the participants suggests that a larger trial would be worthwhile in order to identify facilitators and barriers to important changes.

The reported connectedness mentees experienced with their mentor supports evidence that the social difficulties experienced by individuals by ASD are not rooted solely in a lack of desire for social relationships, but rather in a need to develop effective social skills (Bauminger, Shulman, & Agam, 2003). As one mentee reported, the best part of the PEER program was *"having a friend all to myself."* Another described that he felt his mentor was

very helpful and [I liked] her a lot. We [played] board games together and [invited] other people to play if they wanted to. I've also had my mentor help me socially and strategize what I can do to grow stronger relationships with people.

The guidance of a mentor appeared to help participants increase their level of social comfort and navigate a new environment. The mentoring relationships not only promoted growth in the mentees, but the mentors reported high levels of satisfaction as well. Mentors may have an important role to play in facilitating increased social skills, initiative-taking, self-confidence, and quality of life in the lives of youth with ASD. A larger randomized trial to evaluate further the potential benefit of mentoring for youth with ASD is indicated. Future research on mentoring youth with disabilities should include structured methods for tracking and supporting goal setting and goal adherence activities.

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Table 1

Participant characteristics

Characteristic	n
Age in yrs – Mean (SD)	15.4(13)
Race	
Black/African American	1
White, Non Hispanic	5
Asian/Asian American	3
Gender	
Male	7
Female	2
Attendance	
Attended 80% or more mentoring sessions	9

Table 2

Mean (SD) change scores pre and post-intervention on structured questionnaires

Questionnaire	Pre-Intervention Mean (SD) Score (n=9)	Post-Intervention Mean (SD) Score (n=9)
Pediatric Quality of Life Scale (PedsQL) – Teen Report (Score range: 0–100) ^a		
Health & Activities	66.8 (18.6)	73.9 (16.4)
Feelings	61.7 (21.8)	72.2 (17.7)
Getting Along	72.8 (20.9)	74.4 (16.7)
School	62.8 (21.2)	65.6 (15.7)
Pediatric Quality of Life Scale (PedsQL) – Parent version (Score range: 0–100) ^a		
Health & Activities	65.5 (21.3)	70.1 (23.1)
Feelings	58.9 (24.2)	66.1 (18.3)
Getting Along	47.5 (29.0)	61.4 (20.1)
School	66.0 (19.3)	72.2 (12.8)
Rosenberg Self-Esteem Scale (Score range: 10–30) ^a	20.2 (3.4)	23.3 (4.6)
Social Worries Questionnaire – Pupil version (Score range: 0–26) ^b	10.2 (5.1)	7.2 (4.1)
Social Worries Questionnaire – Parent version (Score range: 0–26) ^b	10.1 (6.6)	8.8 (5.1)

^a higher score indicates improved functioning^b lower score indicates improved functioning

Table 3

Mentee satisfaction ratings with their mentor (n=9)

Questionnaire item	Very True	Sort of True	Not Very True	Not at all true
Knows my name	9	0	0	0
Makes fun of me in ways I don't like	0	0	0	9
My mentor always asks me what I want to do.	8	1	0	0
When I'm with my mentor, I feel special.	6	3	0	0
Sometimes my mentor promises we will do something; then we don't do it.	0	1	2	6
My mentor is always interested in what I want to do.	7	1	0	1
When I'm with my mentor, I feel excited.	6	3	0	0
When my mentor gives me advice, it makes me feel stupid.	0	1	1	7
My mentor and I like to do a lot of the same things.	8	1	0	0
When I'm with my mentor, I feel sad.	0	0	0	9
I feel I can't trust my mentor with secrets – my mentor would tell my parent/guardian.	1	1	1	6
My mentor thinks of fun and interesting things to do.	8	1	0	0
When I'm with my mentor, I feel important.	7	2	0	0
When I'm with my mentor, I feel bored.	0	1	2	6
I wish my mentor asked me more about what I think.	1	2	0	6
My mentor and I do things I really want to do.	8	1	0	0
When I'm with my mentor, I feel mad.	0	0	0	9
I wish my mentor knew me better.	0	2	2	5
When I'm with my mentor, I feel disappointed.	0	0	1	8
When I'm with my mentor, I feel happy.	8	1	0	0