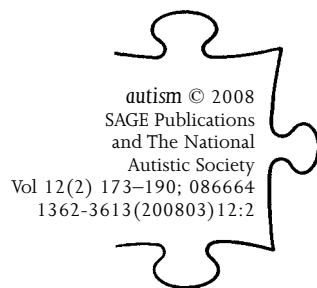


Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities



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ABSTRACT The study describes the perspectives of individuals with Asperger syndrome and other autism spectrum disabilities (ASDs) regarding social challenges and supports. Eighteen adults with ASDs were individually interviewed. They were asked to describe their experiences navigating their social worlds, and recommend effective social supports and strategies for improving social connectedness. Qualitative analyses of the interview transcripts revealed a number of common experiences including a profound sense of isolation, difficulty initiating social interactions, challenges relating to communication, longing for greater intimacy, desire to contribute to one's community, and effort to develop greater social/self-awareness. Commonly recommended social supports included external supports (e.g. activities based on shared interests, highly structured or scripted social activities, and small groups or dyads); communication supports (e.g. alternative modes of communication, explicit communication, and instruction in interpreting and using social cues); and self-initiated strategies for handling social anxiety (e.g. creative/improvisational outlets, physical activity, spiritual practice/organized religion, and time spent alone).

KEYWORDS

Asperger syndrome; autism; social challenges; social supports

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An extensive body of literature documents the significant social challenges associated with autism spectrum disabilities (ASDs) (e.g. Attwood, 1995; Frith, 1989; Sigman and Capps, 1997) as well as the effectiveness of a variety of social skills interventions for individuals with ASDs (e.g. Gray and

Garand, 1993; Koegel and Koegel, 2006; Nikopoulos and Keenan, 2004; Quill, 1995; Wolfberg and Schuler, 1993). Only a handful of studies, however, have been based on the perspectives of individuals with ASDs themselves (examples include recent interview-based research by Carrington and Graham, 2001; Howard et al., 2006; Hurlbutt and Chalmers, 2004; Jennes-Coussens et al., 2006), and none have specifically addressed issues pertaining to the unique nature of individuals with ASDs' social experiences – specifically how they experience their social worlds, and what types of social skills strategies they find most effective.

Several researchers within the field of special education have noted the absence of voices of individuals with disabilities, and have recommended that the perspectives of these individuals be included routinely as part of any intervention-oriented research (e.g. Meyer et al., 1998; Morris, 1998; Turnbull et al., 1998; Ward, 1997). Although not all individuals with ASDs are capable of describing their social worlds and generating meaningful recommendations, individuals with Asperger syndrome and high-functioning autism are increasingly speaking out articulately about their experiences and offering important insights into the workings of their inner worlds (e.g. Grandin, 1995; Nazeer, 2006; Williams, 1992). This study seeks to add to this growing body of literature by interviewing 18 adults with Asperger syndrome and other ASDs about their social experiences and inviting them to address the question of appropriate social supports for individuals with ASDs.¹ Participants were asked to (1) describe their experiences navigating their social worlds, and (2) recommend effective social supports and strategies for improving social connectedness. To the greatest extent possible, participants' thoughts and suggestions are presented verbatim.

Methods

Participants

Criteria for participation in this study included: (1) minimum 18 years of age, (2) self-reported difficulties with social cognition, (3) a formal diagnosis of Asperger syndrome or other ASD or an informal diagnosis of Asperger syndrome based on DSM-IV criteria (from either a mental health professional or a medical doctor), and (4) no diagnosed mental retardation. Participants were 18 individuals from diverse backgrounds in terms of age, age at diagnosis, gender, marital status, education level, and whether or not they received special education services while in school (see Table 1 for participant characteristics). Thirteen participants were formally diagnosed with Asperger syndrome, two were informally diagnosed with Asperger

Table 1 Participant characteristics

| Participant | Age | Sex | Diagnosis | Age at diagnosis | Education level | Special education | Marital status |
|-------------|-----|-----|---|------------------|--------------------------------------|-------------------|----------------|
| 1 | 18 | F | High-functioning autism | 16 | High school student | Yes | S |
| 2 | 19 | M | Asperger syndrome | 15 | Some college | Yes | S |
| 3 | 19 | F | Asperger syndrome | 15 | High school student | Yes | S |
| 4 | 25 | M | High-functioning autism | 21 | Some college | Yes | S |
| 5 | 25 | F | Asperger syndrome | 21 | Some college | No | S |
| 6 | 26 | F | Asperger syndrome | 24 | AA Math. | No | M |
| 7 | 29 | M | Asperger syndrome | 25 | AS Nat. Science Computer Science | Yes | S |
| 8 | 30 | M | Asperger syndrome | 23 | AA Gen. Studies | Yes | S |
| 9 | 32 | M | Asperger syndrome | 32 | AA Accounting | No | S |
| 10 | 38 | M | Asperger syndrome | 30 | BA Sociology MBA Marketing | No | S |
| 11 | 43 | M | Asperger syndrome | 41 | BA Philosophy MA Philosophy | Yes | D |
| 12 | 43 | M | Asperger syndrome | 40 | BA Geography | No | S |
| 13 | 45 | M | PDD-NOS | 41 | BA Forestry Massage School | No | S |
| 14 | 47 | M | Asperger syndrome Informal diagnosis | 40 | PhD Program Neurology | No | D |
| 15 | 50 | M | Asperger syndrome Informal diagnosis | 49 | BA Math. MA Comp. Science | No | S |
| 16 | 59 | M | Asperger syndrome | 58 | MA Chemistry PhD Plant Physiology | No | D |
| 17 | 60 | M | Asperger syndrome | 53 | BA Math. | No | M |
| 18 | 62 | F | Asperger syndrome | 55 | MFA | No | D |

AA: Associate of Arts degree. AS: Associate of Sciences degree.

syndrome, two were formally diagnosed with high-functioning autism, and one was formally diagnosed with pervasive developmental disorder not otherwise specified (PDD-NOS). Participants were recruited via telephone calls and personal contacts. The research team sought nominations of potential participants by contacting ASD and parent support groups throughout the San Francisco Bay Area, as well as families, teachers, and therapists. If nominees were interested in participating, members of the research team contacted them directly to determine whether or not they met the general eligibility criteria. Participants were given a small stipend for their time.

Instrumentation

Three members of the four-member research team collected data for this study via 18 semi-structured individual interviews. The interview protocol included a series of open-ended questions designed to elicit information relating to participants' social experiences – both positive and negative – as well as recommendations for social supports designed to facilitate greater social connectedness. After drafting a copy of the interview protocol, researchers invited stakeholders (i.e. individuals with ASDs, parents, and professionals) to provide input, and to comment on the social relevance of the study. These recommendations were then incorporated into a final version of the interview protocol.

Data collection

Interviews took place in locations of each participant's choice (e.g. participants' homes, researchers' homes, or small conference rooms at local universities). Each interviewee participated in one semi-structured interview ranging from 1 to 2 hours in length. Before each interview, participants were told that they could end the interview at any time, and that they could refuse to answer any questions that made them feel uncomfortable. Several participants requested one or more 'breaks' during their interviews. All interviews were audiotaped and later transcribed verbatim.

Analysis

The research team conducted analysis of major and minor themes in two phases. First, all members of the four-member team developed a preliminary coding structure by selecting four of the most comprehensive interview transcripts. Each member read the transcripts independently, and identified and labeled any statement pertaining to (1) positive and negative aspects of participants' social experiences, and (2) recommendations for effective social supports and strategies for improving social connectedness (Strauss and Corbin, 1990). The team then met to compare and consolidate findings, and to develop a preliminary coding structure – i.e. a master

list of major and minor themes (Strauss and Corbin, 1990). Differences of opinion were resolved via consensus. During the second phase of analysis, the first author used ATLAS.ti 4.1 – a software program for the organization and coding of qualitative data – to refine the coding structure and complete the coding process for the remaining interview transcripts. The rest of the research team provided feedback as well as confirmation of coding accuracy. Major themes were identified as themes mentioned by at least 50 percent of participants (i.e. nine or more), and minor themes were identified as themes mentioned by at least 25 percent of participants (i.e. five or more).

Social validation

The research team made several efforts to ensure the social validity of the study. In addition to including the input of individuals with Asperger syndrome and other ASDs during design of the interview protocol, an individual with Asperger syndrome served as one of the core members of the research team. Also, following completion of data analysis, participants were invited to be part of a ‘member check’ (i.e. a meeting during which findings were presented, and participants confirmed their accuracy).

Results

Findings yielded a number of themes, 15 major and 11 minor, common across participants (see Table 2 for a summary of themes). These themes can be divided into two major categories, based on the two focal questions guiding this study: (1) social experiences, and (2) recommendations for social supports and strategies to improve social connectedness and alleviate social anxiety.

Overview of social experiences

Six major themes emerged in response to questions concerning participants’ experiences navigating their social worlds: (1) intense isolation, (2) difficulty initiating social interactions, (3) challenges relating to communication, (4) longing for intimacy and social connectedness, (5) desire to contribute to one’s community, and (6) effort to develop greater social/self-awareness.

Isolation

All but one participant reported that intense isolation was a defining feature of his/her experience living with an ASD. Most described being isolated throughout both childhood and adulthood, with the pain of isolation increasing as they grew older and became more conscious of being ‘different’, ‘alone’, or ‘out of place’. In recalling their childhood experiences,

Table 2 Major and minor themes

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| <p><i>Features of social experience</i></p> <p>Intense isolation (major)</p> <p>Difficulty initiating social interactions (major)</p> <p>Communication difficulties (major)</p> <p>Desire for intimacy and social connectedness (major)</p> <p>Desire to contribute to one's community (major)</p> <p>Effort to develop greater social/self awareness (major)</p> <p><i>Recommended social supports</i></p> <p>External supports (major):</p> <ul style="list-style-type: none"> Joint focus and shared interest activities (major) Structured social activities (major) Small groups and dyads (major) Facilitated social interactions and opportunities for 'tracking off' others (minor) Opportunities to observe/model socially appropriate behaviors (minor) <p>Communication supports (major):</p> <ul style="list-style-type: none"> Alternative modes of communication (major) Explicit communication (minor) Instruction in interpreting and using social cues (minor) <p>Self-initiated supports (major):</p> <ul style="list-style-type: none"> Creative and improvisational outlets (major) Physical and/or outdoor activity (minor) Spiritual practice and/or organized religion (minor) Mediating objects (minor) Alone time (minor) <p>Attitudinal supports (major):</p> <ul style="list-style-type: none"> Patient and caring attitude (minor) Tolerance of and respect for differences (minor) Willingness to initiate social interactions (minor) |
|---|

several described watching other children play and simply failing to grasp the social mysteries of how to join in. The workings of the social world seemed incomprehensible to them. Although several participants described a slow and painful learning process, whereby they were eventually able to establish one or two relationships with peers, most described ongoing social frustration. In the words of one, 'I still feel too isolated from people, just as I did when I was little.'

Several participants reported having no real friendships. When asked about this, one participant responded that his relationships 'can more accurately be called *acquaintanceships*, but [they] can actually stay at that point for many years without progressing'. While some participants actively sought to improve their social situations, many seemed resigned to their lack of relationships, and a few even attempted to embrace their feelings

of isolation. One man, for example, proudly described himself as ‘something of a lone wolf’.

Several participants employed vivid metaphors to describe their experiences of social isolation. For example, one described feeling as if he were ‘at the bottom of a remote abyss, removed from everything, and not developing the normal peer relationships I perceived everybody else as experiencing’. Another said, ‘I almost feel like I’m on a different planet.’ Several described themselves as depressed and/or anxious as a result of their social isolation.

Difficulty initiating

Almost all participants reported that initiating social interactions posed a significant challenge. In the words of one participant, ‘I’m not very outgoing on my own, in terms of taking the initiative.’ For many, understanding how to initiate was the fundamental problem. For example, one participant reported that her mother suggested she initiate more interactions with others, and, in the participant’s words, ‘It sounded really good, but I didn’t have the slightest clue how to do it.’ For others, the main problem was that initiating interactions with others was a source of tremendous anxiety and stress.

Communication challenges

Participants described a variety of communication challenges contributing to their social difficulties, including participating in impromptu and/or unstructured dialogue requiring improvised responses, understanding implicit as well as explicit meanings of messages, drawing social and emotional inferences, and interpreting and using gesture and tone of voice (e.g. sarcasm, irony or innuendo). As one participant noted, ‘I can’t pick up on body language or hidden meanings, or what people are really saying when they’re saying that in-between-the-lines stuff.’ Others described how they dreaded having to engage in ‘chit chat’ with colleagues, schoolmates, or peers, because such conversation can be bewildering in that it doesn’t appear to follow a predictable set of rules.

Longing for intimacy

All but three participants expressed a longing for greater emotional intimacy – both romantic and otherwise. Several participants were married or divorced; and a few described past or present involvement in romantic relationships; but the majority of participants expressed distress as a result of their inability to find and sustain such relationships. In the words of one participant, ‘One of the biggest things I struggled with was not being married at my age or having that significant other . . . And sometimes that’s

still a struggle . . . I went through a long period where that whole issue almost *shredded* me emotionally.'

In addition to their desire for romantic fulfillment, almost all participants discussed their desire for more and deeper friendships. In the words of one, 'It's emotional intimacy that I really crave from other people,' and in the words of another, 'I would really like to be the sort of person who could have a bigger circle of friends.'

Several described the fragile nature of their nascent relationships, which were often marred by miscommunication and confusion regarding how to read and use social cues. One participant, for example, described trying to befriend a woman at work: 'One day I made eye contact with her, and it seemed like she might have been interested in being friendly, but I didn't know how to deal with it, and so now she is aloof.' This pattern of missed or broken connections was described repeatedly.

Some participants also stressed the limits of their own tolerance for intimacy as one of the obstacles to developing meaningful friendships. For instance, one said he was looking for 'a little bit more . . . closeness and friendship without getting too close, because I myself have a very limited tolerance of closeness in relationships'. This ambivalence about intimacy was a recurring theme – with several participants stressing both their desire for greater closeness, and their hesitancy and fear about what that might mean.

Desire to contribute

In spite of the challenges inherent in social interactions, the majority of participants expressed a desire to contribute in some way to the betterment of the world around them. For example, several reported volunteering for non-profit, religious, or service organizations. A number of younger participants described working with small children or assisting schoolmates with their homework. Several older participants worked as teachers at one time or another, and described the pleasure they took in aiding others. Many also described their desire to help individuals with ASDs by organizing support and/or advocacy groups, speaking about their experiences at ASD-related conferences and/or special education teacher preparation classes, volunteering at summer camps for youth with ASDs, or raising money for ASD-related research.

Effort to develop social awareness

The majority of participants described ongoing efforts to compensate for the effects of their ASDs by developing greater social/self-awareness. Some accomplished this by reading books and articles about ASDs; others joined autism support groups; still others signed up for social skills groups

intended for individuals with social cognition deficits. These activities appeared to help participants identify and address areas of weakness, such as reading body language, or using pitch and intonation to communicate affect. One participant described his efforts in the following words, 'I'd have a really . . . straight face, and . . . straight tone of voice. And so people [were] confused [by] me. And I understand that more . . . I try to work on it. I try to be more lively.' Another reported, 'I [try] to push myself to be a little bit more understanding of facial expressions and things.' Several made efforts to develop their conversational skills. In the words of one, 'I know that a lot of times when I talk, I bore people, because I talk too much, and go into too much detail. So I've been working to try and make things more brief.' Participants also described deliberate efforts to improve personal relationships. In the words of one, 'What I'm trying to work towards is feeling socially at ease with more than one person at a time.' For all participants, improving social/self-awareness seemed to be a highly intentional process, involving deliberate effort. Significantly, although participants described themselves as possessing varying levels of social skill, most reported that their social understanding continued to improve with time and effort.

Recommendations for social supports

Recommendations for social supports were grouped into four major themes: (1) external supports, (2) communication supports, (3) self-initiated supports, and (4) attitudinal supports.

External supports

All participants emphasized the importance of externally implemented supports. These external supports were grouped into the following themes: joint focus and shared interest activities; structured social activities; small groups and dyads; facilitated social interactions and opportunities for 'tracking off' others; and opportunities to observe/model socially appropriate behaviors.

Joint focus activities Participants most commonly stressed the importance of joint focus and shared interest activities. All described current and/or past membership in one or more groups based on a common interest such as chess, jogging, Buddhist meditation, hiking, vintage Volkswagens, vampires, electronics, or disability rights. All agreed that special interest groups provided much-needed social opportunities, and several noted that these groups created natural opportunities for thematically focused interactions based primarily on the exchange of information. The majority of participants also stressed the importance of membership within

ASD-related groups, since these groups not only provided a joint focus, but also enabled participants to meet others like themselves. One participant noted how relieved he was to find 'that I'm . . . part of this group, and there are other people like me'.

In addition to groups, participants described enjoying activities that created a shared focus, but required minimal interaction with one's companions, such as listening to books on tape, or watching TV or a movie together. Significantly, many participants reported that joint focus activities were also important when they were children. For instance, several noted that their happiest social memories revolved around 'parallel play' with peers – i.e. engaging in the same activity side-by-side with someone else, such as swinging or playing on the monkey bars. One participant said of playing on the jungle gym, 'Being with [other children] didn't have to be talking with them, just them being there, doing something I was doing, made me feel like they were my friend.'

Structured social activities Participants also described structured social activities as ideal contexts for interaction. One man, for instance, described how he enjoyed the structure of the Catholic mass, and how 'comfortable' the ceremony made him feel. This was in marked contrast to the way he felt *after* the mass, when parishioners engaged in unstructured conversation and 'subjective talk'. Another participant described enjoying 12-step programs because he could 'relate to people in a slightly autistic way, [since] they don't have cross talk' during meetings. Toastmasters International – a public speaking club that follows the same strict protocol each week – was mentioned by some, and several participants recalled that they had enjoyed participating in school choirs and bands, or taking part in dance classes, where interaction required minimal social negotiation, but created a sense of community nonetheless. All of these activities have predictability in common, as well as a high level of social scripting.

Small groups and dyads Almost all participants noted that one-to-one dialogue was their favorite medium for socializing. Most participants also noted that small groups – particularly in academic settings – could serve as an effective means of enabling positive social interaction. In contrast, participants often described feeling lost in big classrooms and on large college campuses.

A number of participants described how small groups served as natural 'laboratories' for learning about and mastering group dynamics, with several noting the importance of study groups and discussion groups. In the words of one, these groups 'provided sort of a minimal framework, and then having these ideas to discuss led to more connection'.

Participants also described their pleasure when working in small groups that shared a common goal or task such as dissecting a fish. In the words of one, he liked it best ‘when something is goal-oriented, and we’re as a group trying to get something done’. Several stressed that creating intentional groups within an academic context would help to include the people who are not ordinarily included. Participants agreed, however, that as much as they appreciated small groups, it was usually necessary for someone else – e.g. a teacher or another student – to convene and sustain the group.

Facilitated social interactions Participants frequently mentioned the importance of facilitated social interactions, as well as opportunities for ‘tracking off’ of more socially competent peers. They described following the social lead of siblings, and taking advantage of what one participant described as other people’s ‘organizational energy’. One woman described a childhood friend who served as a sort of social ambassador for her, helping to initiate social activities with others, inviting her to come along, and thereby easing the pain of not knowing how to join in on her own. Other participants stressed the importance of having other, more socially capable peers, generate activities and set the agenda.

Observing/modeling social behaviors Several participants described the importance of observing how non-autistic individuals, or ‘neurotypicals’, interact socially, and trying to learn from this. One participant described ‘a combination of watching other people and listening to them’. In the words of another participant, ‘to some extent, I’ve copied other people’. One participant described learning via observation that there were particular ways of dressing in order to fit into his dance group. Another described learning from a colleague how to use eye contact, and a third recalled how her younger sister coached her in the rules of communal play, teaching her some conventional ways of playing with dolls.

Communication supports

Almost all participants recommended some type of communication support. Recommendations were grouped into the following three themes: alternative modes of communication; explicit communication; and instruction in the use and interpretation of social cues.

Alternative modes of communication Because conversation can be so stressful (both face-to-face and on the phone), most participants described the importance of alternative modes of communication. Many described the value, for example, of Internet-based relationships – e.g. relationships

established via e-mail, chat groups, listservs, or online 'role-playing' clubs. One participant explained that these alternative modes were preferable to conversation because 'people often say one thing with their voice, and seem to be saying the opposite with their tone . . . And when you write . . . the tone's not there, so you can't have a conflict between tone and what's written.'

Participants suggested a number of creative alternatives to conventional conversation. For example, one woman described experiencing such intense social stress that she could not talk with anyone around her: 'I would communicate by notes. We were in the same room, but I wanted to write notes back and forth.' Another participant described sitting down at a typewriter with somebody else and conversing via typewritten messages. Several participants described the importance of being gently touched while conversing with others, and one described talking on the telephone inside a dark closet in order to avoid sensory over-stimulation.

Explicit communication The need for explicit communication was a common theme. In the words of one participant, individuals with ASDs are 'just going to need you to spell it out literally. Not metaphorically. Not in a roundabout way. They're going to need a literal explanation.' Participants also noted the importance of clarity and specificity. For example, when giving instructions, one participant suggested that teachers tell individuals with ASDs, 'First you do "a", then you do "b", then you do "c"', breaking tasks down into their component parts whenever possible. She also suggested that teachers be clear about their priorities: 'If it's more important to get this right than to get that right, tell them that. Out loud. Totally spell it out.'

Instruction in use of social cues Several participants recommended direct instruction in the interpretation and use of social cues. Some recalled that a parent, sibling, or teacher had provided them with needed information about how to use body language, facial expressions, and tone of voice. One participant described being taught by a teacher how to give compliments to peers. A number of participants described being unaware of offending the people around them, and wished people would let them know directly when they had been hurt. Participants suggested that one-on-one instruction and/or small groups that focused on social skills development would have been very beneficial.

Self-initiated supports

Most participants stressed the importance of self-initiated supports for coping with day-to-day social stress, including: creative and improvisational outlets; physical and/or outdoor activity; spiritual practice and/or organized religion; mediating objects; and alone time.

Creative and improvisational outlets In light of the fact that most participants described stress when engaged in unstructured social interactions, it was surprising that most also described creative and improvisational outlets as either a way of practicing social skills or a means of reducing social anxiety. Several participants, for instance, played instruments in orchestras or jazz bands, participated in theater or dance groups (including contact improvisation), or engaged in communal art projects. Some tried to explain their attraction to theatre – including the writing of dramatic scripts, improvisational theater classes, voice workshops, or role playing games (e.g. ‘Dungeons and Dragons’). In the words of one, ‘by doing [improvisational theater], you realize that it’s actually possible to be spontaneous, to just go with an impulse (laugh)’.

Physical and outdoor activities Another common theme was finding respite from social stress in physical and outdoor activity. In the words of one participant, ‘If you take me and throw me into the wilderness, I feel at home. Give me rocks and clouds and birds and tigers . . . and a big chunk of my mind feels that this is home.’ Others described exercise routines that helped reduce social stress, including hiking, running, yoga, bicycling, snowboarding, rollerblading, backpacking, skiing, swimming, kayaking, and sailing. According to one participant, ‘I dealt with my [social] frustration by starting up with the physical fitness thing.’ Several participants also noted that engaging in physical activities with others enabled them to connect socially without need for much conversation.

Spirituality and religion For a number of participants, spiritual practice and organized religion played an important role in helping them cope with social difficulties. In most cases, meditation or prayer enabled participants to focus in a deeper way on developing social/self-awareness. One participant said, ‘Meditation allows me to orient my life according to my highest aims and desires in life, and it is among my highest aims and desires to relate socially.’ Another participant reported that Christian spiritual practice ‘allowed me to be more accepting of myself’. In terms of actual religious community, several described the importance of being part of a group that accepts them unconditionally. One participant, for example, described his church as having ‘given me a safe place to practice [social skills]’.

Mediating objects Several participants described using mediating objects as a means of initiating and sustaining social connections. One participant, for example, described bringing musical instruments to parties and sharing them with other partygoers, effectively starting ‘little jam sessions’ as an alternative to more socially demanding conversation. Another participant

described exchanging candy and small gifts as a way of approaching the man she eventually married, and a third participant recalled carrying a pocketful of little toys that he could use as conversation starters with classmates. In each of these instances, mediating objects effectively took the spotlight off the individual with an ASD and redirected attention to the object itself.

Alone time Several participants stressed the importance of alone time. One woman described the need to balance social interaction with time spent in solitude. Others described alone time as an opportunity to decompress. In the words of one, 'Sometimes I need the down time, dead time, silence, and not to do anything . . . and that's how I rejuvenate myself.' Participants repeatedly stressed that teachers and parents needed to recognize and accept this need for alone time as a legitimate coping strategy and not something that needs to be 'fixed'. As one participant noted, 'neurotypicals' often assume that constant social interaction is desirable for everyone – even for individuals with ASDs. In the words of one, 'My mom's always telling me, "Come on, join the party!" But I am having fun, just sitting and listening to the music.'

Attitudinal supports

The majority of participants stressed the importance of attitudinal supports from teachers, family members and peers, including: a patient and caring attitude; tolerance of and respect for differences; and willingness to initiate social interactions.

Patient and caring attitude Commonly used adjectives included 'patient', 'caring', 'understanding', 'empathetic', and 'supportive'. One participant described the importance of others being able to imagine the inner worlds of individuals with ASDs. Another described an effective teacher as someone who 'understood instinctually that I had social relatedness problems'.

Tolerance of differences Participants were in general agreement that a tolerance of differences was critical, and a 'non-judgmental' attitude appeared to go a long way in terms of alleviating some participants' persistent feelings of isolation and social estrangement. Several shared anecdotes about times when a friend, co-worker or family member made them feel accepted for who they were. Many participants felt that friends, colleagues, and relatives should not only tolerate but also embrace their differences. Participants' pride in their autistic identity was frequently apparent, with one noting, 'Someday I hope people will realize what richness we have in our community.'

Willingness to initiate Several participants also talked about how to befriend an individual with ASD, stressing the importance of taking the social initiative and being willing to go beyond superficial chit-chat. Participants also emphasized the importance of having the person without ASDs assume greater responsibility for keeping the relationship going, including taking the initiative in terms of making phone or e-mail contact, and organizing shared activities.

Discussion

This study contributes to a growing body of literature providing suggestions for how individuals with ASDs can better be supported to make meaningful social connections. It is notable for its emphasis on the perspectives of individuals with ASDs regarding how they make sense of social contexts, as well as its identification of a wide range of socially validated supports – including external, communication, self-initiated, and attitudinal supports.

Findings pertaining to participants' social experiences create a complex and nuanced portrait of how individuals with ASDs perceive and navigate their social worlds. Based on the results of this study, it appears that while individuals with ASDs experience serious social challenges – including social isolation, difficulty initiating, and problems with communication – they long for intimacy and social connectedness, and derive satisfaction from making contributions to the wellbeing of others (at both individual and community levels). Furthermore, many individuals with ASDs expend tremendous energy in developing greater social understanding and self-awareness. These findings counter a number of culturally reinforced stereotypes about ASDs – particularly the characterization of individuals with ASDs as socially aloof, deliberately self-isolating, affectively flat, and lacking consciousness of their social skills deficits.

Recommendations generated by participants for supporting social connectedness should prove useful to teachers, clinicians, and adult service providers – particularly those relating to joint focus activities, structured social environments, and opportunities for tracking off others. Educators and service providers may wish to consider thoughtful groupings that would facilitate greater social connectedness for individuals with ASDs (e.g. assignment to small groups or dyads based on shared interests; membership within topical clubs; enrollment in extension courses at community colleges; and participation in structured social activities such as band, choir, or athletic practice). Participants also provided a number of creative suggestions for alternative modes of communication, and practitioners may wish to consider the use of chatrooms and listservs as ways of leveling the conversational playing field for individuals with ASDs.

Perhaps one of the most surprising findings had to do with the numerous self-initiated strategies via which participants were able to manage social anxiety and stress. These strategies – which include creative/improvisational outlets, spiritual practice and organized religion, physical exercise, and alone time – are remarkable in part because of how similar they are to the ways in which ‘neurotypicals’ cope with stress. The marked emphasis on the role played by these strategies in reducing social anxiety, however, is likely much more common among individuals with ASDs. Furthermore, participants never mentioned relaxing with friends and family, parties, or other types of unstructured social time as a way of unwinding and/or relaxing.

Findings from this study complement the work of Bauminger and Kasari (2000) which found that children with high-functioning autism were lonelier than their typically developing peers and tended to have poorer quality friendships. A second study by Chamberlain et al. (2007) found, however, that elementary-aged children with Asperger syndrome and high-functioning autism, despite their experiences of social marginality, did not report feeling greater loneliness than their typically developing peers. Although this finding appears to conflict with the present study, which found that the vast majority of participants reported intense loneliness, this apparent discrepancy may be explained by the fact that participants in the present study were significantly older than participants in the Chamberlain et al. study, and many reported that their sensations of loneliness intensified as they matured, supporting a developmental approach to understanding the social experiences of individuals with ASDs.

This study’s findings were also consistent with those of Howard et al. (2006) which found that an adolescent boy with Asperger syndrome both desired and enjoyed friendships, as well as with a study by Bauminger et al. (2003) which found that children with high-functioning autism displayed relatively high levels of social awareness – e.g. understandings of both social interaction and the meaning of loneliness. Significantly, this study also provides likely contextual explanations for the high levels of depression and anxiety disorders – including social anxiety – found among individuals with ASDs (e.g. Gillott et al., 2001; Kim et al., 2000; Stewart et al., 2006; Tantam, 2000).

Results of this study should be interpreted with the following limitations in mind. The majority of participants belonged to autism support groups and/or received therapy intended for individuals with social cognition difficulties. As a result, participants selected for this study may represent above-average levels of introspective skills and social awareness. Also, many participants were older adults who did not receive diagnoses of ASDs until later in life. Consequently, a significant number of participants never received specialized autism services – such as are currently available to

students with ASDs. Finally, several social strategies described in this article were identified by fewer than 10 participants (see Table 2 for a summary of major and minor themes), suggesting that recommendations for social supports may not work equally well for all individuals with ASDs.

This study has drawn on the perspectives of individuals with ASDs in an effort to better understand how they experience their social worlds, and the types of social support strategies that have been effective for them. Whenever possible, the research team sought to describe both social experiences and recommended strategies in participants' own words. The research team was particularly impressed by how articulate participants were about both the depths of their social isolation, and the tremendous efforts many have made to compensate for the social skills deficits associated with their ASDs. Also noteworthy were the thoughtful recommendations made by participants, many of which reinforced existing research in the area of explicit social and communication skills training, and some of which suggested new avenues for study – particularly in the area of self-initiated supports. Results of this study suggest that individuals with ASDs should be included in future research efforts to identify appropriate strategies for improving social connectedness.

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Notes

- 1 This study was part of a larger study examining the social challenges faced by individuals with ASDs at school and in the workplace.

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