



**Exploring the Social Benefits of Face-to-Face and Online Groups for Persons with Asperger Syndrome**

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# Exploring the Social Benefits of Face-to-Face and Online Groups For Persons with Asperger Syndrome

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*Irene Carter, Rob Wilson, and Andrew Wilson*

## Introduction

This qualitative research study seeks more in-depth knowledge about the potential and actual use of face-to-face and online self-help/support groups as a form of informal social support by persons with Asperger syndrome. Self-help groups are “voluntary associations of non-professionals who share common needs or problems and meet together for extended periods for the purpose of mutual support and exchange of information about activities and resources that have been found useful in problem solving” (Barker, 2003, p. 388). Self-help groups provide mutual aid that is supportive, educational, and change-orientated, and which usually addresses a single life problem or condition that all members share (Borkman, 1999; Kurtz, 1997; Reissman & Carroll, 1995). Similarly, support groups involve “a structured ongoing series of meetings among people who share a common problem and who give advice, encouragement, information, and emotional sustenance” (Barker, 2003, p. 424). Several scholars describe the concept along a continuum, with support groups that involve professionals at one end and “pure” self-help groups at the other end (Kurtz, 1997). As the terms ‘self-help group’ and ‘support group’ both represent forms of intervention that seek solutions to identified problems, often empowering their membership in the process, and are often used interchangeably, the term “group” refers to either in this paper.

Social support involves both formal and informal supports. Formal support may include education, health care, and access to hospitals, health clinics, and professionals, such as physicians, social workers, and therapists. Formal support is

formally organized to provide aid and assistance to persons with specific and defined needs (Dunst, Trivette, & Deal, 1988). Informal support, accessed through family and social groups, serves an important role by substituting or supplementing formal support. Informal support, such as self-help groups (Ben-Ari, 2002), provides a means to help address the complex needs of persons with Asperger syndrome by providing social interaction and feedback that allows for the adoption of appropriate roles and behaviors. Through the perceptions and experiences of persons with Asperger syndrome, this study explores some of the potentially helpful aspects of the informal supportive strategies provided by face-to-face and online self-help or support groups. Participants were asked about their experiences with face-to-face and online groups and were encouraged to further comment on the contributing factors that would render these experiences either negative or positive.

## Literature Review

Asperger syndrome is a pervasive developmental disorder with sustained impairment in social interaction (American Psychiatric Association, 1994). Common behaviors include repetitive and inflexible patterns of behavior and difficulty generalizing knowledge and skills to other social situations (Attwood, 2007). There is debate in the literature regarding whether or not Asperger syndrome is distinct from high-functioning autism (Matson & Wilkins, 2008). Both diagnoses are associated with intellectual disability and share similar characteristics (Dissanayake, 2004). Also, the evidence indicates there are few differences between high-functioning autism and Asperger

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syndrome during the middle years and beyond, allowing us, at present, to use both terms interchangeably (Attwood, 2007). Most persons with Asperger syndrome live with family or in assisted living arrangements. Isolation is a considerable problem for children, youth, and adults living with autism (Mullins, Aniol, Boyd, Page, & Chaney, 2002). Persons with Asperger syndrome need varying amounts of social support to help with the activities of daily living and to relieve their stress and social isolation.

Growing out of the frustrations which were experienced as a result of the lack of social support, self-help groups for people with disabilities flourished in the 1970s. Members of face-to-face groups experience decreased stress, greater levels of knowledge and understanding about their situation, and an increase in self-advocacy efforts (Mandell & Salzer, 2007). More recently, participation in online groups also provides an alternate means of accessing support and connection for individuals with Asperger syndrome.

The World Wide Web has broadened our ability to communicate with each other instantly and to share information over great distances. Persons with disabilities have benefited greatly from this relatively new means of communication (Braithwaite, Waldron, & Finn, 1999) through the development of online self-help groups. Individuals access information and social support online, and the Internet also provides them the opportunity to engage in advocacy. Online self-help groups use a computer connected to the World Wide Web as a means of initiating communication through a variety of formats, including newsgroups, chat rooms, bulletin boards, and electronic mailing lists. Chat rooms function with interactions occurring in real time. Newsgroups and bulletin boards involve postings, and electronic mailing lists function through e-mail.

Online group participation serves both as a source of information and as a means of encouraging friendships that ease isolation and provide social support (White & Dorman, 2001; Griffiths, 2005). Existing online groups include support groups for parents of children with autism (Boyd, 2002; Huwes, Jones, & Ingledew, 2001), siblings of children with autism (Tichon & Yellowees,

2003), and both adolescents and adults living with Asperger syndrome (Fleishmann, 2005). Wiede, Bolme, and Hoeyland (2006) found that adolescents with autism saw online groups as being helpful vehicles through which to share experiences and information. Some adolescents particularly valued this helpful vehicle through which they could share experiences and information, as it was their only form of social contact. For some persons with Asperger syndrome, online self-help groups have become a tool for practicing self-advocacy where they can represent themselves, and which function as supportive communities, lessening autistic symptoms (Jordon, 2010).

An online group is not dependent on geographic location and is available to anyone who has a computer and Internet connection. Online groups offer convenience, flexibility, and accessibility to anyone living with a stigmatizing condition (Meier, 2004). Fleischmann (2005) found the Internet offers a way for stressed and isolated individuals to connect and feel supported. Using the term cybersolace, Beder (2005) describes how one can use technology to provide solace, that is, emotional support, education, shared experience, empowerment, and advocacy support.

Persons with Asperger syndrome often have difficulty with face-to-face communication (Meier, 2004). Persons with Asperger syndrome viewed online conversation as a way to socialize without experiencing the demands and anxiety encountered in face-to-face conversation (Jordon, 2010). The anonymity found on the Internet is believed to encourage greater levels of open expression which in turn lead to more rapid group cohesion (Meier, 2004). Although the anonymity that the Internet provides encourages higher levels of open expression leading to more rapid group cohesion, anonymity may lead to premature and inappropriate disclosure, rendering participants vulnerable to the insensitivity of others' responses (Meier, 2004).

Because social cues and norms are often misread by people with Asperger syndrome, online communication presents them with added challenges. Moreover, since persons with Asperger syndrome tend to understand communication literally, messages can easily be misinterpreted

(Benford & Standen, 2009; Jordon, 2010). A group moderator can help to alleviate this situation by intervening skillfully to catch inappropriate and hurtful comments. In a moderated group, when participants log into a specific online site and post their thoughts and follow-up messages, postings are read and approved by the moderator before being distributed to the group at large (Lampe & Johnston, 2005). Although the process is not instantaneous, members benefit from reduced concerns about the appropriateness of postings, especially inappropriate postings of a sensitive or private nature (Backstrom, Kumar, Marlow, Novak, & Tomkins, 2008). The moderator can then use their knowledge of the dynamics of such situations to work with participants regarding how they might manage their postings differently in the future.

Although online self-help group activity for persons with autism has flourished in Canada (Autism Society Canada, 2009), there are financial and other challenges to accessing online self-help groups. Those most affected financially include the poor, women, minorities, older people, and persons with disabilities, such as Asperger syndrome (White & Dorman, 2001). People with the necessary skills who don't own a computer can access an online group by going to a library and logging into Hotmail, Yahoo, or Gmail. However, home users access the Internet from a computer or Internet-capable device for a fee. Additionally, the costs of hosting a distribution group include obtaining the necessary hardware (computer and firewall for security) and software (available at no cost by using Open Source software). Ongoing costs include a monthly Internet connection fee and a yearly domain name registration fee. A domain name provides participants with the benefit of a friendly, simple, and easy-to-use name to type into their web browser (Pang, Hendricks, Akella, De Prisco, Maggs, & Seshan, 2004).

The option of setting up an online discussion group through a nonprofit agency is a more affordable choice for a small user group. If the user group and the nonprofit agency share an interest—for example, Asperger syndrome-hosting the dis-

ussion group on the agency's website ensures ease of use and promotes accessibility. Once the service is set up, it is easy to replicate elsewhere to other chapters of the organization. To prevent potential intruders by restricting access, each online group user is set up with a unique login ID and a strong password. Password policies need to be implemented and enforced as a measure to help prevent attacks on user accounts. To address privacy and security concerns, guidelines need to be implemented regarding the things that are or aren't appropriate to share online.

To summarize, the goal of this research is to explore the use and benefits of both face-to-face and online group activity for persons with Asperger syndrome, and to suggest strategies for overcoming obstacles and mitigating the potentially negative aspects of participating in face-to-face and online groups. The potential support that face-to-face and online groups might offer has far reaching prospects for informal support, and offers hope for reducing some of the isolation experienced by persons with Asperger syndrome. Thus, exploring the challenges to group participation, as voiced by persons with Asperger syndrome, is a useful approach to promoting informal support through various forms of groups.

### Methodology

A qualitative research design explores what persons with Asperger syndrome found positive and negative about communicating in face-to-face and online groups. A qualitative research design is "concerned with understanding the meaning of human experience, from the subject's own frame of reference" (Holosko, 2006, p. 13). It further refers to social context and depends on the subjective interpretations of particular people in a specific social setting (Bryman, 2004). Common practices consistent with a qualitative research design include developing general research questions, selecting relevant sites and participants, collecting relevant data, interpreting data, and writing up the findings.

### *Main Research Question*

The primary research question being addressed in this study is, “What are the experiences and perceptions of persons with Asperger syndrome about participation in face-to-face and online groups?” This paper focuses on this research in aiming to gain a better understanding of the benefits and challenges of engaging in face-to-face and online groups from the perspective of persons with Asperger syndrome.

Definitions of the key words in the main research questions help us to add clarity and avoid ambiguity. For example, in this study, “individuals with Asperger syndrome” represents youth or adults diagnosed with Asperger syndrome who have participated in a group and who speak on their own behalf. “Face-to-face groups” are groups that meet face-to-face and address particular challenges associated with the need for support, education, and advocacy. “Online groups” are groups that provide access to information, support, and advocacy by using a computer to gain entry to the World Wide Web.

### *Sample*

Typically, in qualitative research, the sampling procedures are purposive, employing sample specificity rather than a representative sample. Thus, participants have specific characteristics that provide useful and reliable information based on their personal experiences. Employing the purposive sampling method involved advertising the study in the newsletters of several local agencies which focused on autism and Asperger syndrome and requesting interested individuals who had autism to contact the researchers to arrange an interview. Individuals with Asperger syndrome and parents with children with autism from metropolitan Windsor, Ontario, located directly across from Detroit, Michigan, who inquired about the research, received a letter with information about the research as approved by the Research Ethics Board, University of Windsor. The criteria for participating included an age span of youth to middle age, a diagnosis of autism with-

out specific diagnostic criteria, and experience with a face-to-face or online group. Snowball sampling, as a secondary strategy, allowed the researchers to ask each participant if they knew of others who may be interested in taking part in the research. Snowball sampling is a method where the researchers begin with one case and based on interaction with that case, identifies other cases.

The researchers conducted ten interviews. Six of the participants who declared that their diagnosis was Asperger syndrome and spoke on their own behalf demonstrated they understood the concept of consent at the beginning of the interview. Four participants had autism with significant cognitive limitations. In these cases, the parents spoke on their children’s behalf and described parental experiences with face-to-face and online groups. The unit of analysis for this paper is the perceptions and experiences of high functioning persons with Asperger syndrome who responded to the interview questions independently. The data on the parents who spoke on behalf of their children with autism who displayed cognitive limitations was set aside as it is not part of the analysis in this paper.

### *Data Collection*

An interview was scheduled to take place at either the researcher’s office or the participant’s place of residence, depending on the participant’s preference. Participants received a honorarium of \$30.00 dollars for the time earmarked for the interview and agreed to, and provided, an audio-taped interview. One researcher interviewed all the participants and used a semi-structured interview guide that allowed the interviewer “to provide a general focus to the interviews without too narrowly defining the evolution of the interviews” (Ames & Diepstra, 2010). Participants were asked the following questions, as listed on the interview guide:

- How has autism, high functioning autism, or Asperger syndrome affected you?
- When did you become involved with a face-

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to-face self-help group?

- When did you become involved with an online group?
- What experiences have you had with face-to-face groups?
- What experiences have you had with online groups?
- What factors contribute to positive effects in face-to-face groups?
- What factors contribute to positive effects in online groups?
- What are the negative effects for individuals in face-to-face groups?
- What are the negative effects for individuals in online groups?

The interviews took about 90 minutes. Audio tapes of the completed interviews were transcribed word-for-word and stored in a Word program in two locations. Additionally, a self-reflective journal, maintained by the primary researcher, supplemented the interview process, providing the researchers with opportunities to review the data and ensure accuracy.

### *Analysis*

The researchers used line-by-line coding in each transcribed interview to extract units of words, sentences, and paragraphs about participants' experiences and perceptions regarding face-to-face and online groups. Atlas.ti software (Scientific Software Development, 2003) was used to extract significant statements while coding the transcribed interviews line-by-line. The units of words, sentences, and paragraphs were assigned to a code. Once the coding was complete for all ten transcribed interviews, similar codes were assigned to categories. Clustering statements into codes and categories of codes assisted the

researchers in making inferences and suggesting themes that related to the research questions. Data analysis followed a straightforward, systematic, step-by-step process where smaller units were examined first, and then similarities and differences between them were identified. This process led to the assemblage of similar smaller units into general themes. This approach was chosen in order to allow the themes to emerge from the data (Tutty, Rothery, & Grinnel, 1996), and reflects a common practice in qualitative research (Bryman, 2004).

Theme is the sense we are able to make of something - a means through which to get at the underlying concept and describe the content. As such, the main themes do not simply reflect frequency of codes or categories. Theme development occurred through the process of creating research questions, conducting, recording and transcribing interviews, line-by-line coding using Atlas.ti software (Scientific Software Development, 2003), and developing main themes analytically. Interpretation of the data was an ongoing process that moved back and forth as one progressed through these stages of the research. Clustering statements into codes and categories of codes assisted the process of making inferences and suggesting themes that related to the research questions.

After completing the analysis and the development of themes, summaries of the findings were shared with the participants. The responses obtained from the participants helped the researchers further verify the data. Three participants with Asperger syndrome responded to the summaries of the findings. All thanked the researchers for letting them take part in the research, mentioning the data was sufficient and that they did not have further comments to make regarding the project.

### **Findings**

The ages of the six male participants with Asperger syndrome who spoke on their own behalf were 15, 18, 20, 23, 37, and 38. Three of the participants with Asperger syndrome had attended university or college programs, and two were

employed part time. One participant lived independently, while the other five participants with Asperger syndrome resided with their parents. All six participants with Asperger syndrome expressed concern about the ability to earn a satisfactory income now or in the future, and all had incomes of \$40,000.00 or less. With respect to persons with Asperger syndrome, three had participated in only a face-to-face group, one had participated solely in an online group, and two had participated in face-to-face and online groups. Their participation was restricted to less than two years. As the perceptions of persons with Asperger syndrome is the unit of analysis for this paper, the three main themes and six sub-themes which emerged from the responses of persons with Asperger syndrome are outlined in the following themes.

In Theme 1: Social Support and Social Interaction in Face-to-Face Groups, participants recalled the benefits and challenges of involvement with face-to-face groups for autism. Subtheme A: Benefits of Face-to-Face Group Contact, illustrated how the participants especially appreciated the social activities and opportunities for social interaction provided by the face-to-face group, as noted in the following quotation, "Well there was this boys club at the Regional Centre...I met, a couple friends...we got to go to a lot of places like...we went to the Squash and Fitness Gym...very helpful."

Participants noted that making friends through social activities, independent of group activity, was possible while attending school. As one participant remarked, "Well I have...uh...been in the drama club in high school before...they got me into...acting in a school play." Most participants experienced fewer opportunities to engage in social activities following graduation from high school. However, participants who were employed spoke positively about being associated with staff, including attending social events associated with their work environment. One participant's work was in the context of a volunteer position at an organization that served people with disabilities, and another participant worked at a large grocery store, collecting shop-

ping carts, packing groceries, and other tasks. These work positions created opportunities for social interaction. One participant expressed their appreciation of social contact at work by stating, "I know it's good, meet some good people and all that, and I'm having some good co-workers that work in other areas."

Other persons with Asperger syndrome voiced experiences about the lack of social contact. The participant who lived alone was especially affected by isolation of his experience as expressed in the following quotation:

I think the isolation...it's hurting my career...it is hurting my sense of um...being able to have a good reputation, how I am seen, how I view myself, how much I get out of the house, how my family sees me...

When asked about the possibility of taking part in a face-to-face group, the participant quoted above responded, "I wish I could say that I would have that hope...If there is one, please, I would be happy to [join]..."

In Subtheme B: Reservations about Face-to-Face Group Contact, participants described how they encountered challenges to face-to-face group participation. A primary concern involved arranging transportation back and forth to meetings. As one participant noted, "You know you've got the problem of transportation...and where to meet, and people who may live in the county some distance away...so I can see it as more of an occasional thing."

Another concern centered on the availability of groups for specific ages. Participants noted that face-to-face groups concentrated more on younger children. As one participant noted, "So I was the oldest...The only one." Several individuals also related there was a lack of individuals within a specific area of the autism spectrum, such as, groups that focused only on people who were high functioning. Participants also recommended face-to-face groups be organized around an age span of four to five years, and that they further support members by taking personal interest into consideration. Participants questioned

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whether or not group relationships would be helpful if participants' interests differed. As one participant voiced:

Like they'd be playing games and I wasn't really into that so...I didn't really socialize with them, and then in the other group, I don't know they were more like the athletic type, you know the...how do I say it? ...I'm not really like that either, so... really I didn't really fit in well with that group...

Lastly, several participants expressed concern about conflict between members in groups, as illustrated by the following quotation:

But, with an Aspergers group, face-to-face, uh...the bad thing is that everybody [differs]...there's too much conflict at first, we have to really get to know each other...confidence...will be built as we get to know each other... you know, you build [relationships] slowly...

In Theme 2: Social Interaction in Online Group Activity, participants indicated they were familiar with how to use the Internet for school projects, e-mail, and conversations, illustrating their familiarity in the following quotation:

I had a Facebook account, and you know how people on Facebook they like to form these groups ...and I would sometimes, you know, if I really strongly support a group, you know I'll write on...it's a thing called a blog... basically, you write comments and you respond to other people's comments and what not...

Three of the participants with Asperger syndrome related benefits to online group activity but focused on the perceived tradeoffs of using online groups.

In Subtheme C: Benefits of Online Group Interaction, participants described how participants used the Internet to stay socially connected in

groups using e-mail, e-mail distribution lists, and Facebook, as outlined in the following quotation:

I talk about how things are and all that. And I was talking to Xxxxx about what Taiwan was like, when she was there. It's uh... interesting to hear about them even though it's not quite the same as the phone voice, or in person, but still it's, can be still a good way to talk about it there... At least, least I get a response immediately ...Better than, at least a lot better than at least snail mail...

The three individuals who participated in online groups noted that sometimes online groups function to assist shy individuals in voicing their opinions more boldly because of the anonymity that the Internet provides. As such, through the Internet, online groups are used as a tool for communication. Support for this idea is provided by one participant:

Another thing for being anonymous is that you don't have to worry about what other people might think of you, or how people might judge you...you have no identity, so therefore people can't judge you in real life, right?

With regard to online group activity, persons with Asperger syndrome generally appreciated the convenience, social opportunities, and anonymity that access to online group activity provided.

In Subtheme D: Tradeoffs to Online Group Participation, one participant spoke of the difficulties in maintaining online participation, clarifying he would need a job to find the money to buy a computer and pay the monthly cable bill. This participant had access to a face-to-face group; however, he also wished to join the online community but found income to be an obstacle to such participation. He remarked, "I've got a buddy that had an Internet site...but I've got to have a job first."

Participants identified some of the challenges to providing social skills training in the context of an online group. Expressing reservations about



using the Internet, they stated, “it’s just so much easier...to state your opinions” [face-to-face]. Participants cautioned, “overall it’s just not the same” [as face-to-face communication]. Many participants stated that using the Internet as a communication tool was inferior to face-to-face interaction, as illustrated in the following quotation:

I don’t normally go for Internet conversation...It’s really not my style...I prefer the telephone more than anything...Basically, it’s just too much of a hassle for me...I’m going to need way more than just brief sentences to explain myself...

As described by one participant, Internet-based communication is much like typing, where one has to write, then stop and wait for a response, potentially leading one to lose one’s original train of thought. In contrast, talking was found to be preferable as it is more instantaneous.

Participants doubted that online groups provided the social interaction necessary to communicate effectively. As one participant remarked:

...I think there’s definitely an advantage... face-to-face...you understand group facial features, and expressions of other people, and what they are truly like. Online, you don’t know what they’re thinking, you don’t even know if they’re being sarcastic...

Participants placed an emphasis on meeting face-to-face, indicating a greater likelihood of relationships progressing to shared social experiences, such as “going to a movie or meeting for a coffee.” Three participants also expressed concern about the potential loss of privacy and abuse by Internet predators such as Internet hackers and criminals. They worried about the risks associated with dealing with strangers, as opposed to the familiar contacts made in face-to-face groups. Participants suggested they might be vulnerable to individuals who may electronically enter their group with mal intent. They recommended guidelines and procedures be put in place to maintain

the security of online group members.

In Theme 3: Interfacing Face-to-Face and Online Group Activity, participants offered suggestions for improving the combined functions of face-to-face and online groups for persons with Asperger syndrome. Participants believed “face-to-face encounters apparently have more of an impact” and would make you “feel like you were a part of something.” Moreover, they believed it would be easier to understand “facial features and expressions of other people” in a face-to-face group setting. However, participants also displayed enthusiasm regarding the opportunity to partake in online discussions with people who share an interest in autism without worrying about “how people might judge you.” As one participant explained:

...we also tend to judge people based on appearance...And when you’re face-to-face, the other person, say, has a disability for example, one may think, “Oh that person is not very intelligent” or that person is this or that...

Participants felt emotionally safer and less vulnerable in an online environment, as indicated in the following quotation:

Where as in face-to-face, people really get...like argue more...like they become really aggressive? Online doesn’t seem that way... they don’t get that aggressive...I think there’s definitely an advantage to online communication...

Alternately, as one participant explained, online communication is unlikely to “change the fact that I feel isolated and disconnected.” Some participants concluded that creating an online group was useful as a secondary tool, as “a more focused reason for the group.” Participants made suggestions regarding how to link face-to-face

groups with online groups. They suggested the use of visual cues, such as posting pictures of the participants on email connected to a distribution list associated with an Internet site, and employing the use of camcorders or Skype when conversing online. They believed that such innovations would help address the need for visual cues to assist them in interpreting and responding to social situations since their common tendency is to accept statements literally. Participants favored the concept of using face-to-face and online groups in combination, suggesting that they attend online groups "once or twice a week and getting together face-to-face once a month." In summary, the participants' responses helped confirm our present understanding regarding the use of face-to-face and online groups and suggested new questions that need to be further examined.

### Discussion

The participants viewed groups as having the potential to provide social support by easing their isolation, especially if they had limited opportunities to engage socially with others. Participants included the following obstacles to face-to-face group involvement: issues associated with transportation, anxiety about face-to-face interaction, and the lack of matching participants in the areas of age, ability, and interests. Participants' perceptions about online groups agreed with prior research that indicates online groups provide access to social support where obstacles to meeting face-to-face occur (Mesec & Mesec, 2004, p. 421).

Participants identified the need to implement strategies and procedures to block access to online groups by uninvited intruders. Maintaining privacy and security is a challenge that is shared by all online groups, and can usually be successfully navigated by installing a firewall or piggybacking on a host organization with strong security features already in place. Although persons with Asperger syndrome mentioned concerns about potential intruders to their online groups,

this research revealed no incidents of this having happened in the experiences of the participants. In any case, standard online security precautions need to be implemented to lessen potential risk even though unwanted malicious intruders are less likely to be attracted to smaller sites than larger, more public sites.

Whether using face-to-face or online groups, persons with Asperger syndrome indicated they are vulnerable to risks associated with miscommunication. Communication is a challenge for persons with Asperger syndrome since they often interpret statements by others literally. Although persons with Asperger syndrome may be highly verbal, they demonstrate difficulties with nonverbal aspects of communication that include conveying emotion, modifying meanings, and engaging in supportive conversation (Benford & Standen, 2009).

As evident in research, the participants found the anonymity on the Internet attractive, as it lessens the anxiety and demands of face-to-face conversation (Meier, 2004; Jordon, 2010). However, certain methods of online communication are potentially confusing, difficult, and vulnerable to miscommunication without visual cues (Jordan, 2010) for persons with Asperger syndrome. For example, a standard e-mail distribution list in which everyone on the list receives and replies to all emails can be confounding to persons with Asperger syndrome and lead to misunderstandings. Compared to e-mail, a moderated discussion group would reduce the risk of miscommunication since the moderator's job is to intervene where the content of a posting may be inappropriate or offensive (Backstrom, Kumar, Marlow, Novak, & Tomkins, 2008). When a group member sends a message to the distribution list, the moderator reviews the message content before releasing the e-mail to the distribution list members. A moderated group also offers the opportunity for the moderator to assist participants with learning how to interpret messages and respond appropriately.

Despite the risk of miscommunication associated with face-to-face or online groups, group activity is considered to be potentially useful for providing social support and easing the isolation

of persons with Asperger syndrome. However, due to the nature of Asperger syndrome and associated communication challenges, assistance may be required in setting up and maintaining a group. The use of a group moderator who ensures group autonomy and participants' interests would help to manage the risks of miscommunication.

### Implications for Professionals

As persons with Asperger syndrome tend to misread and misinterpret messages (Benford & Standen, 2009; Jordon, 2010) and disclose prematurely and inappropriately in online groups (Meier, 2004), professionals who interact with persons with Asperger syndrome must have an understanding of how they uniquely communicate and the challenges it presents. Second, given these communicative challenges, it may be necessary for professionals to play a role in setting up and maintaining groups for persons with Asperger syndrome. As participants in this study suggested, professionals may need to consider initially organizing a face-to-face group followed by the supportive strategy of a moderated online group.

Third, professional facilitators need to consider group members' age and areas of interest, important points made by the participants in this research. Making the area of interest the main focus creates opportunities to work collaboratively with other agencies in forming groups of peers with, or without, other disabilities. Fourth, professionals that work with persons with Asperger syndrome need to support the autonomy of the group members. A group designed by those it intends to serve focuses on acceptance and offers its members an opportunity for empowerment as well as social interaction (Saleebey, 2009). For example, in this study participants were primarily interested in making friends rather than interventions such as training in social skills. It is necessary for professionals to gain the approval of members when making decisions about the steps to take when designing group activities and when providing or managing the functions of a moderator for online groups. Last, as the knowledge of the communication strategies used by persons

with Asperger syndrome progresses, professionals will need to update their knowledge and practice accordingly.

### Limitations and Future Direction

Limitations of the study included a small sample, restriction of the research site to a relatively small geographic area, and the noticeable absence of gender, race, or ethnic diversity. As well, using a semi-structured interview guide can be considered to have placed the research at risk by preparing and defining questions before the interview. Pursuing a general understanding of the participants' experience is often preferable so as to ensure that the responses reflect their personal experiences (Tutty, Rothery, & Grinnell, 1996, p. 12). Also, although participant experience with various types of groups and the length of time as members in groups usually vary, the time participants spent in groups was less than two years.

More needs to be known about what communication strategies are best to employ in groups with persons with Asperger syndrome and the usefulness of employing moderators and helpers to promote appropriate communication opportunities. Research is needed to investigate the potential role that recent technologies, such as video chat systems, Skype, and cell phones that display a front picture, play in enhancing communication between persons with Asperger syndrome. Lastly, future studies on the benefits of using face-to-face and online groups for persons with Asperger syndrome need to include larger populations in quantitative studies over a wider geographical area.

### References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- Ames, N., & Diepstra, S. (2010). In B. Thyer (Ed.), *Oral history studies* (pp. 397-414). Thousand Oaks, CA: Sage Publications, Inc.

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- Attwood, T. (2007). *The complete guide to Asperger's syndrome*. Philadelphia: Jessica Kingsley Publishers.
- Autism Society of Canada. (2009). Provincial and territorial societies. Retrieved from [http://www.autismsocietycanada.ca/index\\_e.html](http://www.autismsocietycanada.ca/index_e.html)
- Backstrom, L., Kumar, R., Marlow, C., Novak, J., & Tomkins, A. (2008). Preferential behavior in online groups. *Proceedings of the International Conference on Web Search and Web Data Mining* (pp. 117-127). New York: Association for Computing Machinery. Retrieved from <http://doi.acm.org/10.1145/1341531.1341549>
- Barker, R. L. (2003). *The social work dictionary* (5th ed.). Washington, DC: NASW Press.
- Beder, J. (2005). Cybersolace: Technology built on emotion. *Social work, 50*(4), 355-358.
- Ben-Ari, A. T. (2002). Dimensions and predictions of professional involvement in self-help groups: A view from within. *Health & Social Work, 27*(2), 95-103.
- Benford, P. & Standen, P. (2009). The internet: A comfortable communication medium for people with Asperger syndrome (AS) and high functioning autism (HFA)? *Journal of Assistive Technologies, 3*(2), 44-53.
- Borkman, T. J. (1999). *Understanding self-help/mutual aid: Experiential learning in the commons*. New Jersey, NJ: Rutgers University Press.
- Boyd, B.A., (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus On Autism and Other Developmental Disabilities, 17*(4), 208-215. doi: 10.1177/10883576020170040301
- Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication, 11*(2), 123 - 151.
- Bryman, A. (2004). Social work strategies. *Social research methods* (2nd ed.) (pp. 13-19). New York: Oxford University Press Inc.
- Dissanayake, C. (2004). Change in behavioural symptoms in children with high-functioning autism and Asperger Syndrome: Evidence for one disorder? *Australian Journal of Early Childhood - Autism Spectrum Disorder, 29*(3), 48-58.
- Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books.
- Fleishmann, A. (2005). The hero's story and autism: Grounded theory study of bsitesew parents of children with autism. *Autism, 9*(3), 299-316.
- Griffiths, M. (2001). Online therapy: A cause for concern? *The Psychologist, 14*, 244-249.
- Holosko, M. J. (2006). *Primer for critiquing social research: A student guide*. Belmont, CA: Thomson Brooks/Cole.
- Huws, J. C., Jones, R. S., & Ingledew, D. K. (2001). Parents of children with autism using an email group: A grounded theory study. *Journal of Health Psychology, 6*(5), 569-584.
- Jordon, C. J. (2010). Evolution of Autism Support and Understanding Via the World Wide Web. *Intellectual and Developmental Disabilities, 48* (3), 220-227. doi: 10.1352/1934-9556-48.3.220
- Kurtz, L. F. (1997). *Self-help and support groups: A handbook for practitioners*. Sage Publications: Toronto, Ontario.
- Lampe, C., & Johnston, E. (2005). Follow the (slash) dot: Effects of feedback on new members in an online community. *Proceedings of the 2005 international ACM SIGGROUP conference on supporting group work* (pp. 11-20). New York: Association for Computing Machinery. Retrieved from <http://doi.acm.org/10.1145/1099203.1099206>
- Mandell, D.S., & Salzer, M.S. (2007). Who joins support groups among parents of children with autism? *Autism, 11*(2), 111-122.
- Matson, J. L., & Wilkins, J. (2008). Nosology and diagnosis of Asperger's syndrome. *Research in Autism Spectrum Disorders, 2*(2), 288 -300. doi:10.1016/j.rasd.2007.07.003
- Meier, A. (2004). Technology-mediated groups. In C. D. Garvin, L. M. Gutierrez, & M. J. Galinsky (Eds.), *Handbook of social work with groups* (pp. 139-159). New York: The Guilford Press.

- Mesec, B., & Mesec, M. (2004). Conceptualization of the new methods of self-help appearing on the Internet. *European Journal of Social Work*, 7(2), 181-194.
- Mullins, L. L., Aniol, K., Boyd, M. L., Page, M. C., & Chaney, J. M. (2002). The influence of respite care on psychological distress in parents of children with developmental disabilities: A longitudinal study. *Children's Services: Social Policy*, 5(2), 123-138.
- Pang, J., Hendricks, J., Akella, A., De Prisco, R., Maggs, B., & Seshan, S. (2004). Availability, usage, and deployment characteristics of the domain name system. *Proceedings of the 4th ACM SIGCOMM Conference on Internet Measurement* (pp. 1-14). New York: Association for Computing Machinery. Retrieved from <http://doi.acm.org/10.1145/1028788.1028790>
- Reissman, C., & Carroll, D. (1995). *Redefining self-help: Policy and practice*. San Francisco: Jossey-Bass Inc.
- Saleebey, D. (2009). *The strengths perspective in social work practice* (5<sup>th</sup> ed.). Boston: Allyn & Bacon.
- Scientific Software Development. (2003). Atlas.ti The knowledge workbench visual qualitative data analysis management model building (Version 4.1) [Computer software]. Thousand Oaks, CA: Scolari Sage Publications.
- Tichon, J., & Yellowlees, P. (2003). Internet social support for children and adolescents. *Journal of Telemedicine and Telecare*, 9(4), 238-240. doi:10.1258/135763303322225599
- Tutty, L. M., Rothery, M. A., & Grinnell, R. M. (1996). *Qualitative research for social workers: Phases, steps, & tasks*. Needham Heights, MA: Allyn and Bacon.
- Weidle, B., Bolme, B., & Hoeyland, A. L. (2006). Are peer support groups for adolescents with Asperger's Syndrome helpful? *Clinical Child Psychology and Psychiatry*, 2(1), 45-62.
- White, M. & Dorman, S. M. (2001). Receiving social support online: Implications for health education. *Health Education Research*, 16(6), 693-707.