

*Research Articles*

**REFLECTIONS ON FACE-TO-FACE AND ONLINE  
SELF-HELP GROUP PARTICIPATION: COMPARING  
THE VIEWS OF PERSONS WITH AUTISM WITH  
THOSE OF PARENTS SPEAKING FOR THEIR  
AUTISTIC CHILDREN**

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**ABSTRACT**

Autism affects people according to a range of mild to severe symptoms and with varying challenges in the areas of social interactions, communication, and behavior. Can self-help groups become a resource for persons with autism in these problem areas? The researchers explore and compare the views of persons with autism with those of parents speaking on behalf of their autistic children regarding their respective experiences and/or attitudes with face-to-face and online self-help group participation through 10 audio-taped interviews and other methods common to the qualitative method. The authors identified two types of participant: persons with autism who spoke on their own behalf and the parents who spoke on behalf of autistic children. All participants agreed that online groups presented a greater level of challenge in terms of providing the opportunity for social involvement than did face-to-face groups. However, while parents focused on concerns regarding social skills training, persons with autism who spoke on their own behalf stressed the need for opportunities to develop friendships. This research is significant for facilitators and practitioners when creating self-help group strategies to promote social interaction in that it distinguishes between the different priorities of children with autism and their parents.

**Key Words:** face-to-face self-help groups, online self-help groups, persons with autism, parents of children with autism

## INTRODUCTION

In 1996, the prevalence of autism among 3 to 10 year olds living in metropolitan Georgia (U.S.) was reported as having been 3.4 per 1000 children (Yeargin-Allsopp, Rice, Karapurkar, Doernberg, Boyle, & Murphy, 2003). At the time, autism was considered one of the most common of the developmental disorders. Partly due to increased awareness of the disorder, reports of autism have increased significantly in the past decade (Hadjikhani, 2010). Recent prevalence estimates indicate 1/1000 to 4/1000 for individuals diagnosed within the narrow definition of autistic disorder and 6/1000 to 9/1000 for those diagnosed within the broader definition of autism spectrum disorders (Fombonne, 2009; Williams, Brayne, & Higgins, 2006). Although research indicates that genetics does play a significant role (Rapin, 2002), the full etiology of autism remains unknown.

Individuals with autism display mild to severe symptoms in regard to social interactions, communication, and behavior, as well as delays or abnormal functioning in social interaction, language as used in communication, and imaginative play (American Psychiatric Association, 2000, p. 75). Other concurrent disorders include mental retardation in 70% (Fombonne, 2003) and anxiety and depression in 43% of adults with autism (Sterling, Dawson, Estes, & Greenson, 2008). Based on a person's overall IQ score, the autistic spectrum comprises four subgroups: IQ scores: Asperger Syndrome, high-functioning autism (IQ of 85 or above), medium-functioning autism (IQ of 55-84), and low-functioning autism (IQ of 54 or below; Baron-Cohen, 2006). Asperger syndrome is often associated with high functioning autism on the basis of the presence of cognitive abilities without learning difficulties.

The researchers explored and compared the views of persons with autism with those of parents speaking for their autistic children. A qualitative methodology employing interviews revealed both similar and differing views between persons with autism and parents of autistic children regarding the effectiveness of face-to-face and online self-help groups. Participants who understood the purpose of the study and spoke on their own behalf were identified as having high-functioning autism (referred to here as HFA) and the participants whose parents (referred to here as PLF) spoke on their behalf because they were unable to understand the purpose of the study or to speak for themselves were identified as having low-functioning autism. Typically, persons with autism in self-help groups have sought opportunities to make friends while parents have often promoted the importance of teaching social skills. In confirming the usefulness of various configurations and functions of self-help group types for persons with autism, this research identified the importance of separating the needs of persons with autism, as they themselves described them, from those that were described by their parents who spoke on their behalf.

## LITERATURE REVIEW

Self-help groups for autism have flourished, playing a major role at the national level in the United States, Canada, and Great Britain (Autism Society of America, 2010; Autism Society Canada, 2011; The National Autistic Society, 2010). Local, state, and provincial chapters which are supported by larger umbrella organizations promote support and interventions for persons with autism. Two-thirds of families with children with autism take part in self-help or support groups (Mandell & Salzer, 2007).

Most people with autism live either with family or in assisted living arrangements. Both persons with autism and their parents require social support to help with the stressful symptoms and social isolation associated with autism. As public agencies face challenges in meeting the needs of persons with autism (Bryson, Rogers, & Fombonne, 2003), self-help groups complement agencies' efforts to address the full scope of their needs. Many persons with autism and their families responded to the challenges of their circumstances by forming self-help groups which provide the support and information that is not otherwise available. By sharing challenges and developing coping strategies (Ben-Ari, 2002), self-help groups also ease the isolation of the parents and the individuals with autism, by allowing both groups to better manage the challenges associated with disabilities (Carter, 2009).

### Parental Self-Help Groups for Autism

Through self-help groups, parents of children with developmental disabilities have the opportunity to share their fear, guilt, and family turmoil as a result of the birth of a child with a developmental disability. Through their involvement, they typically report experiencing less loneliness and distress (Bloch, Weinstein, & Seitz, 2005; Mandell & Salzer, 2007). As a therapeutic experience, self-help groups allow parents to gain more control over their lives and develop new coping strategies. At both the personal and collective levels, parents became more resilient (Gitterman & Shulman, 2005) and empowered (Saleebey, 2009) in addressing problems they could not otherwise have managed themselves; advocacy became a tool through which to access interventions for their children. Parents involved in self-help groups were 11 more times likely to receive health care than those who did not take part in groups (Jurkowski, Jovanovic, & Rowitz, 2002).

The capacity of a self-help group to respond to their members and to incorporate their concerns reflects on how well its members will be able to maintain a sense of collective empowerment. Challenges arise in self-help groups when group goals become incongruent with members' interests (Wituk, Tiemeyer, Commer, Warren, & Meissen, 2003). As an alternative, parents sometimes turn to online self-help groups to address their need for social change, as well as support and information.

Parents who reported high levels of stress and isolation found online self-help groups offered social support (Scharer, 2005) as well as a means for them to connect with others in similar positions (Fleischmann, 2005). Parents speaking on behalf of their children advocated for interventions based on behavioral or educational approaches (Fleischman, 2005). Self-help groups for persons with autism which were developed by parental self-help groups were often based on what parents considered to be the best options for the children who were rarely consulted.

### **Self-Help Groups for Persons with Autism**

Persons with autism often find it challenging to adjust to varying circumstances, and are socially awkward because their ability to integrate information and apply meaning to stimuli is limited (Berger, Aerts, Van Spanendonck, Cools, & Teunisse, 2007). As a result, adolescents and young adults with autism spectrum disorders, even when they have good cognitive and communication skills, often experience social isolation (Hillier, Fish, Cloppert, & Beversdorf, 2007). "Self-help groups" for persons with high functioning autism are usually support groups run by public agencies and have focused on teaching social skills, reducing anxiety, improving social interaction with peers, and self-advocacy.

#### *Teaching Social Skills*

While there were several support groups for persons with autism (Gray, 2000; Howlin & Yates, 1999; Jerome, Frantino, & Sturmey, 2007), no genuine self-help groups were reported. Most interventions focus on maintaining a structured environment, such as TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children; Van Bourgondien & Schopler, 1996) and require support staff. Because of the nature of the disability, it may be possible that a genuine self-help group could only evolve from a support group.

#### *Reducing Anxiety*

Gillott and Standen (2007) found that persons with autism benefited significantly from groups designed to reduce the symptoms of panic and agoraphobia, separation anxiety, obsessive-compulsive disorder, and generalized anxiety disorder. Persons with autism were found to be three times more anxious than individuals with other intellectual disabilities (Gillott & Standen, 2007) and if left unaddressed, these disorders could develop into clinically diagnosable disorders.

Interestingly, online groups offer the relief of anonymity to persons with autism who often experience difficulty with face-to-face communication (Finn, 1995; Meier, 2004). Anonymity encourages more open expressions, leading to more rapid group cohesion (Meier, 2004). Jordon (2010) found many persons with autism viewed online conversation as a means for socializing without experiencing the demands and anxiety encountered in face-to-face conversation.

*Improving Social Interaction with Peers*

Examining the social lives beyond childhood of individuals with autism, Orsmond, Krauss, and Seltzer (2004) found that only 8% of adults with autism had social friendships with same-aged peers. They did note that 74.5% of adults with autism had weekly routines of either exercise or walking, 38.5% participated in weekly recreational activities, 22.6% participated in weekly socializing activities with relatives, and 20.9% spent time with friends on a weekly basis. However, almost 50% of individuals with autism reported that they did not have any peer relationships outside of pre-arranged settings. Again, the existence of genuine self-help groups is somewhat suspect; the literature most frequently describes support groups and/or facilitators.

*Self-Advocacy*

Youth and adults with autism responded to their own concerns by developing self-advocacy groups calling for the acceptance of persons with autism as they are and without attempts to alter the way they think and express themselves. The official diagnostic view of autism as a mental disorder requiring intervention is being challenged (Canadian Broadcasting Corporation, 2010). Advocates are working to have autism re-conceptualized as a genetic deviation that occurs naturally, and are promoting the positive aspects of living a life with autism.

**Face-to-Face and Online Self-Help Groups**

The literature indicates that both face-to-face and online self-help groups are useful tools for helping parents and persons with autism find information, support, relief from isolation, and collective action. Parental self-help groups on autism express concerns regarding the challenging symptoms of autism and access to continuing medical, behavioral, and respite interventions (Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004). Parents initiate contact with self-help groups in response to the lack of resources and the realization that the problems and solutions they face cannot be resolved independently. Thus, they begin to seek access to interventions through engaging in advocacy (Wituk, Shepherd, Slavich, Warren, & Meissen, 2000). Parents also point out that youth and adults with autism experience few opportunities for socialization, and highlight the need for social skills training.

Persons with autism agree with parents of autistic individuals that isolation is one of their greatest challenges but promote acceptance by others as a primary solution (Mullins, Aniol, Boyd, Page, & Chaney, 2002). In some cases, persons with autism believe interventions suggested by parents to be invasive and call for the right to be accepted for who they are (Canadian Broadcasting Corporation, 2010).

For individuals and their families who find it difficult to attend face-to-face self-help groups, online self-help groups offer an alternate means of connecting with others and deriving some of the benefits connected to face-to-face groups as was found in other research (Bjerke, 2009).

Jordon (2010) explored the evolving virtual communities initiated by persons with autism and described the Internet as a medium of self-advocacy for individuals with autism who were “seizing the opportunity to represent themselves” (p. 222); participants presented their opinions on their blogs and websites. Jordon found that online discussion forums functioned as supportive communities and lessened autistic symptoms.

Challenges include:

1. accessibility, since many people still do not have the means to access the Internet;
2. aspects of communication, such as the ability to recognize social cues and norms, particularly challenging for persons with autism as they often have the tendency to interpret what is communicated literally (Benford & Standen, 2009); and
3. anonymity which can lead to premature disclosure, rendering participants vulnerable to the insensitivity of others’ responses (Meier, 2004), and more susceptible to the influence of people with mal intent (Jordon, 2010).

Despite these challenges, the Internet can be a source of information and support that provides positive and constructive experiences for members of online self-help groups.

## **METHODS**

The researchers used the accepted procedures and techniques found in qualitative research (Bryman, 2004). All participants lived in metropolitan Windsor, Ontario, Canada and the research was in compliance with the University of Windsor Research Ethics Board. Ten qualitative interviews (six HFAs and four PLFs) were tape recorded. The researchers were concerned with understanding the participants’ experience from their perspective (Holosko, 2010).

### **Selection of Site and Participants**

Employing sample specificity rather than a representative sample, the researchers looked for participants with specific characteristics who would provide useful information based on their experience (Goodman, 2001). Employing the purposive sampling method involved advertising the study in the newsletters of four agencies that focused on autism in Windsor, Ontario. All prospective participants who inquired about the research received a letter and consent form with information about the study. Participants contacted the primary researcher

directly. Once the prospective participant confirmed that they (either HFA or PLF) had self-help group experience and lived in metropolitan Windsor, an appointment place and time designated as appropriate and convenient by the participant was arranged.

The self-help group experience of participants included parental groups for support, education, and advocacy groups that provided support, recreational, and life skills training for persons with high functioning autism. 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.

### **Interviews**

The interviews averaged 90 minutes and reflected on the participants' face-to-face and online self-help group experiences. Audio tapes of the completed interviews were transcribed word-for-word by research assistants. The primary researcher also maintained a journal related to recruiting and interviewing participants. In the interviews, participants spoke about their positive and negative experiences with both face-to-face and online self-help groups. HFAs or the PLFs received a small honorarium of \$30.00.

### **Coding and Developing Themes**

Analysis of the data involved reading all the transcribed descriptions and using Atlas.ti software (Scientific Software Development, 2003) to code transcribed interviews. Clustering statements into codes and categories of codes assisted the process of making inferences and suggesting themes that related to the research questions. Theme development occurred throughout the stages of the research. Each theme had to be explored from two main vantage points: that of the person with autism who spoke for themselves; and that of the parents who spoke for a person with autism. After analysis and the development of themes, summaries of the data were shared with the participants; responses from the participants helped the researchers further verify the data.

## **FINDINGS**

All 10 persons with autism were male and ranged in age from age 9 to 38. One participant lived independently; the other nine lived with their parent(s). Parents spoke on behalf (PLF) of four persons with autism who showed a limited capacity to participate independently in the interview while six persons with autism (HFA) were able to speak for themselves.

The type of self-help group participation and length of engagement by participants varied. HFAs reported experience with face-to-face groups ( $N = 3$ ), online groups ( $N = 1$ ), or combined face-to-face and online groups ( $N = 2$ ); none of their experience exceeded 2 years. PLFs participated in a face-to-face

group ( $N=1$ ) and in combined face-to-face and online groups ( $N=3$ ); nearly all of their experience exceeded 2 years. No parents participated in online groups only.

Ten themes emerged based on participants' responses to interview questions and the subsequent data analysis: Real Life Interaction, Acceptance, Intervention, Lack of Resources, Support, Primary and Secondary Tools of Support, Fear of Being Judged, Learning Tool, Insecurity about Meanings and Intent, and Age Differences.

### **Real Life Interaction**

HFAs suggested face-to-face groups heightened their opportunities to have social interactions and make friends. Youths and older adults spoke positively about possible future group involvement with face-to-face self-help groups, making comments such as, "I would be happy to . . . If you have any contacts. . . I'm open, I'm willing, absolutely." Most participants preferred face-to-face interaction, expressing reservations about using an online self-help group, indicating "it's just so much more easier . . . to state their opinions [face-to-face]." One parent preferred face-to-face interaction to online communication explaining that regardless of what people online type, "it's not personal."

### **Acceptance**

Participants expressed different concerns regarding acceptance. One HFA related an experience of being in a group of people where he "felt estranged . . . like an alien." A few HFAs remarked that they gravitated to social environments where they experienced "acceptance" [for their natural selves]. PLFs longed for societal acceptance of their autistic children, but viewed self-help groups as being particularly useful in getting their autistic children to connect and find socially acceptable ways of learning "how to talk, how to act, how to react, and how to socialize." Parents thought that social skills training in self-help groups was essential to facilitating their children's acceptance.

### **Intervention**

Most parents expressed concern about the effects of unusual behaviors displayed by their children and placed greater emphasis on the function of intervention in self-help/support groups which could be valuable in providing the social skills training that they believed their children required. They described those who advocated for acceptance without intervention as "cruel," and as failing to take into consideration that persons with autism may want help to learn social skills. In fact, one HFA was receptive to intervention in self-help groups if it helped him to "know how to be a more effective employee, . . . how to communicate better on the job."



### **Lack of Resources**

For all participants, the primary obstacle to participation in face-to-face groups appears to be transportation. HFAs also suggested that starting an online group required resources that were often difficult for them to attain. “I’ve got to have a job first.” “I’ve got to find the money to buy a computer and to pay the monthly cable bill.”

### **Support**

HFAs expressed very little about finding self-help groups supportive; but PLFs stressed the value of emotional support provided by members of face-to-face self-help groups:

And for me, that is my circle of friends, it’s mainly people who have kids with disabilities, or work with kids with disabilities. So you’re on the same level, and you get ideas, and you share ideas, and, it’s just to help each other out.

Parents suggested persons with autism should also have opportunities to share similar experiences. Parents envisaged that supportive self-help relationships for persons with autism might progress to shared social experiences such as “going to a movie, meeting for a coffee.”

### **Primary and Secondary Tools of Support**

Parents viewed face-to-face and online self-help groups as primary and secondary means of support for themselves. While HFAs remained skeptical about the support provided by face-to-face and online communication, PLFs viewed a face-to-face group as a source of primary support for their children with the opportunity to realize secondary support by maintaining friendships and connections over the computer. As one parent suggested, “It’s nice to have the, the networking, so we think a combination of the two, would be really effective [for persons with autism].”

### **Fear of Being Judged**

A few HFAs suggested conversing in online groups might help shy individuals voice their opinions more boldly as a result of the anonymity it affords. One participant remarked:

You don’t have to worry about what other people might think of you, or how people might judge you because, basically online, you have no identity, so therefore people can’t judge you in real life, right?

### **Learning Tool**

HFAs reported they used the Internet as a learning tool for such tasks as school projects, e-mail, and MSN conversations. However, as a form of conversation, they were skeptical about how to manage online conversations, indicating that “you don’t know what they’re [other party] thinking . . . you don’t even know if they’re being sarcastic.” In particular, one HFA said;

I don’t normally go for Internet conversation. . . . I’m going to need way more than just brief sentences to explain myself. . . . 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.

Some parents also questioned how their children might learn to respond properly in an online group. They suggested the importance of having a trained organizer or coach facilitate group activity on the Internet by ensuring that participants receive adequate computer training and technical help.

### **Insecurity about Meanings and Intent**

Both PLFs and HFAs stressed the need to address issues regarding the vulnerability of youths and adults, particularly in online groups. HFAs felt concerned about dealing with strangers online, as opposed to the familiar contacts made in face-to-face groups. Both PLFs and HFAs voiced concern regarding the reactions that persons with autism may experience in both face-to-face and online self-help groups when resolving feelings of rejection and anger.

Both HFAs and PLFs expressed concerns that some online group members might post comments that could compromise members’ privacy and potentially place them at risk. HFAs worried about privacy issues and protection from individuals with mal intent such as Internet hackers and criminals, while parents emphasized the vulnerability of their children and the risks posed by potential Internet predators. Reflecting on how to make online activity more secure for their children, parents suggested the use of visual cues such as posting pictures of the participants on e-mail and Internet sites, and suggested the use of skilled help, whether volunteer or paid, in the maintenance of any type of group.

### **Age Differences**

Parents viewed participation in a self-help group as likely more important both for them and their children when their children were younger. Noting that self-help groups concentrate more on serving parents of younger children, a major parental concern centered on the lack of focus on self-help groups for their older children. Both HFAs and PLFs indicated that “we’re lacking that high functioning only age [group].” “There’s nothing above the age of 10.”

### **Varying Views about the Functions of Self-Help or Support Groups**

Parents viewed self-help group participation as generally helpful and potentially supportive for persons with autism. The six HFAs both agreed and disagreed with their parents about the usefulness of self-help groups.

#### *Similarities*

Parents and HFAs agreed that face-to-face meetings supported the important value of nonverbal gestures and behavior in face-to-face communication. Both parents and individuals with autism suggested that interesting age-specific activities should be organized within the format of the face-to-face group. Participants recommended that self-help group membership be restricted to a maximum size of 10 individuals, and that, to encourage communication about age-specific interests, the ages of participants should span a range of only a few years. HFAs and PLFs viewed face-to-face groups as a means to ease social isolation; they agreed that combining an online with a face-to-face self-help group needs “a lot of forethought and organization.” For example, they suggested a knowledgeable helper would need to secure a location, partner with other disability agencies, and organize the group according to the needs of either low or high functioning participants, keeping in mind the benefits of matching individuals according to ability.

#### *Differences*

Most parents promoted the need for social skills training to improve social interaction while HFAs focused on the need to be accepted. Most parents thought the first step involved securing a specific location for the face-to-face meetings followed by setting up opportunities for communication between members through the use of an e-mail list or a discussion group. However, HFAs were puzzled about how they could communicate face-to-face without familiar facial and communication gestures and knowledge about group members. Most parents welcomed an online group that was supported by a face-to-face group as a useful supplementary learning tool while HFAs saw it as an opportunity to make friends with those who shared an interest. Parents expressed concern about the vulnerability of their children and the need for trained help to control for Internet predators while HFAs expressed greater concern about getting emotionally hurt by potentially insensitive comments made by fellow group members.

In summary, parents viewed various groups as personally supportive and as potentially providing companionship for their children. HFAs viewed groups from the perspective of making social connections. Both HFAs and PLFs agreed that face-to-face groups provide opportunities for greater social involvement and communication. HFAs, more so than parents, saw communication in online

groups a great challenge for persons with autism. All participants felt that facilitators are needed and groups need to focus on a specific age span and area of the autism spectrum. Although parents highlighted social skills training as a priority for their children, persons with autism remained skeptical about the purpose of the group and concerned about communication challenges, identifying opportunities for friendship and companionship as their primary needs.

### DISCUSSION AND IMPLICATIONS

Both persons with autism and parents seek greater social interaction and acceptance for persons with autism. As noted by Bromley, Hare, Davison, and Emerson (2004), parents tend to seek a cure and interventions, such as intensive behavioral intervention or social skills training as pathways to greater acceptance for their children. Persons with autism want social interaction where they are accepted as their natural selves. The literature indicates that while persons with autism also seek social skills training to better manage socially, the findings in this study support their priority in group participation is acceptance (Canadian Broadcasting Corporation, 2010). This has implications regarding how self-help/support groups need to function to meet the needs of persons with autism.

The findings point to the importance of distinguishing between the needs of persons with autism and those as suggested by their parents. HFAs viewed the challenges more critically and the assumed support and communication in both face-to-face and online groups more skeptically. Understandably, given the communication challenges autistic individuals have in social interaction (American Psychiatric Association, 2000, p. 75), HFAs were concerned about being judged negatively in a self-help group environment. Persons with autism have been found to be three times more anxious than individuals with other intellectual disabilities (Gillott & Standen, 2007) and would need training that meets the social and technical challenges of online communication. As noted in the literature, parents extrapolated from their own experiences and deemed self-help group participation as supportive, and online groups as a convenient form of secondary support (Carter, 2009).

To address other self-help group participation concerns, especially in online use, such as miscommunication and threats to privacy and security, guidelines would need to outline appropriate postings in a discussion group. A moderated discussion may be a method to lessen risks associated with online groups. In a moderated group, postings are confirmed by the moderator before being distributed to the group at large. This allows the moderator to delete a message that is rude or which poses a risk before anyone else sees it. Members benefit from reduced concerns about the appropriateness of postings, especially unintentional postings of a sensitive or private nature (Backstrom, Kumar, Marlow, Novak, & Tomkins, 2008). The moderator can intervene skillfully to catch inappropriate,

hurtful comments and use their knowledge of the dynamics of such situations to work with participants face-to-face regarding how they might manage their postings differently in the future.

Weidle, Bolme, and Hoeyland (2006) point out that aiming at multiple support group goals is often ambitious for a monthly meeting format. They suggest that setting the single goal of self-acceptance would be more realistic and manageable.

This research confirmed the value of the independent expression of people with a diagnosis of autism regarding their own needs and interests (Jordon, 2010). Self-help activity offers persons with autism opportunities to share information, support, and advocacy. However, the findings indicate it provides a limited option for individuals with autism who depend on their parents to communicate for them. If parents act on behalf of persons with autism, the individual's thoughts may be stifled and the resulting message may differ from what the individual might have been communicated independently. The literature indicates that self-help groups involving self-advocacy have a substantially different orientation from the focus on interventions typically presented by parents (Jordon, 2010). A self-help group for autism designed by those it intends to serve, with priority given to the attainment of acceptance, offers its members an opportunity for empowerment as well as social interaction (Gitterman & Shulman, 2005; Saleebey, 2009). It also encourages professionals and parents to consider the benefits of promoting acceptance instead of focusing primarily on interventions. This study suggests individuals with autism may need to consider guidance that involves the support of a skilled worker who functions to preserve the autonomy of the self-help group members. To carry out this task, the helper would need to be knowledgeable about autism, parental concerns, and where parents and persons with autism disagree and agree about the roles of self-help groups.

Self-representation by persons with autism is an important concept to explore. It raises questions for parents and professionals regarding when and how others may be speaking on behalf of persons with autism. It further considers the value of consulting with individuals who will be affected by the suggested interventions, or persons with autism whose experience may be helpful.

## LIMITATIONS AND CONCLUSION

Limitations of this study include the geographic area, the small sample size, and variation in the functioning capacity of the individuals with autism who participated. The study was a qualitative survey to gain specific information and did not represent either the views of all participants in self-help groups or those of professionals who provide interventions and services for autism.

This research confirms that as professionals and parents, we need to consider whose interests are being served in creating a self-help/support group. This can be achieved by determining points of agreement and difference between persons with autism and the parents who speak on their behalf. In order to further understand type and patterns of use among self-help group members, a quantitative approach using a surveyor structured interviews with a few open questions for specific populations would be appropriate. Future studies on the benefits and challenges of linking face-to-face and online self-help groups need to include larger populations of persons with autism, and concentrate on the experiences of specific groups.

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