Authors

Irene Carter

University of Windsor,
Windsor, ON

Correspondence

icarter@uwindsor.ca

Positive and Negative Experiences of Parents Involved in Online Self-Help Groups for Autism

Abstract

This paper explores the Internet-based self-help group experiences of 22 parental advocates who have children with autism. The Internet is a particularly useful method for families, who are stretched to the limit for time and resources, to find ways to help their children as well as to establish social supports for themselves. Furthermore, in this study the Internet was found to be a more effective and less restrictive vehicle through which to undertake advocacy work than were face-to-face self-help groups. Positive experiences that arose from Internet-based groups included support, empowerment, and effective strategies for advocacy. Negative experiences included receiving confusing, overwhelming and unreliable information and other disappointing outcomes.

This paper focuses on parental involvement of 22 parents with Internet-based self-help groups for children with autism. Parents with children with autism, a complex disability, express concerns about support and interventions for their children. Experiencing high levels of stress and realizing they could not solve their concerns independently, parents with children with disabilities, since the 1970s, joined self-help groups seeking support, information, and advocacy. The benefits and challenges of self-help group participation are outlined, followed by a consideration of the Internet as a useful self-help group tool for parents to obtain needed information about their children and support for themselves. A qualitative methodology explores the Internet-based self-help group experiences of 22 parents of children with autism. The data examined in this paper was acquired in the process of conducting interviews for a larger study on the experiences of parental advocates in self-help groups for autism (Carter, 2007). While the larger study concentrated on the face-to-face group experiences of education, support, and advocacy, this study made use of superfluous data to explore positive and negative experiences of parental discovery and use of online self-help groups. The positive and negative experiences of the parents are outlined, applying particular attention to the use of the Internet as an effective advocacy tool.

Literature Review

Autism is one of the most common of the severe developmental disorders, and affects 1 in 65 children (Chakrabarti & Fombonne, 2005). It is characterized by delays or abnormal functioning in social interaction, communication and behaviour as well as language, as used in communication, and imaginative play

(American Psychiatric Association, 2000, p. 75). Early, individual, and intensive behavioural therapy in a structured environment provides the most potentially effective intervention (Kabot, Masi, & Segal, 2003; Rapin, 1997). Parents' primary concerns have been related to early diagnosis, societal acceptance of their children, and access to ongoing medical, behavioural, and respite interventions. Public agencies also face challenges in meeting the needs of children with autism (Bryson, Rogers, & Fombonne, 2003). It has been noted that because of frustrations resulting from inadequate responses to their needs by professionals and agencies, some parents have decided to seek support, education, and changes in social policy through participation in self-help groups and advocacy (Wituk, Shepherd, Slavich, Warren, & Meissen, 2000). Knowing that many professionals refer parents of children with disabilities to self-help groups as an adjunct to professional services, one has to wonder whether current research can shed light on the question of which factors are predominant as motivation to seek self-help.

Parents of children with autism are likely to experience higher levels of stress (Sivberg, 2002) and isolation than parents of other children with developmental disabilities (Bromley, Hare, Davison, & Emerson, 2004). Parents often experience grief and frustration in struggling with their child's behaviours and unfulfilled needs. Stressed parents seek access to medical, educational, and social interventions that alleviate the challenging symptoms of autism, and help children learn functional and academic skills (Bryson et al., 2003). Parents expressed difficulty in evaluating interventions with respect to effectiveness, accessibility, and cost (Carter, 2007). When government agencies failed to sufficiently respond to the parental need for support and information that helped children and their parents manage autism, the parental need for support, information, and advocacy led to parental participation in self-help groups.

Parents initiate contact with self-help or support groups in response to the lack of resources and the realization that the problems and solutions they face cannot be resolved independently. Support groups and self-help groups share similar characteristics. Kurtz (2004) points out that originally support groups were led by professionals while self-help groups were driven by a shared membership need for personal or social change. Both self-help and support groups "herald individual empowerment and citizen involvement" (Kurtz, p. 139), forming hybrid groups that mainly reflect self-help characteristics while being supported by large organizations. In this paper the words, self-help groups and support groups are used interchangeably with an emphasis on self-help as an intervention that seeks solutions to identified problems, empowering the membership in the process.

Two thirds of families with children with autism take part in self-help or support groups, suggesting that this high degree of participation indicates families need more than available professional services (Mandell & Salzer, 2007). In addition to providing support from other parents, Mandell and Salzer found participation in self-help group results in feeling less distressed and alone, reducing the sense of isolation. Thus, members experience self-help groups as therapeutic, allowing them to develop new coping strategies. Gaining more control over their lives, members became more resilient (Gitterman & Shulman, 2005). Parents of children with developmental disabilities who shared their fear, guilt, and family turmoil as a result of the birth of a developmentally disabled child feel less alone and less distressed (Bloch, Weinstein, & Seitz, 2005). Empowerment as an outcome of self-help group membership happens at both the personal and collective levels, reflecting a strengths-based niche (Saleebey, 2006) that empowers people to address problems they could not manage themselves.

Advocacy, as a form of personal and collective empowerment, is another important benefit of self-help groups, considering advocates involved in self-help groups are nearly 11 times more likely to receive health care than those who did not take part in groups (Jurkowski, Jovanovic, & Rowitz, 2002). In areas where services are less widely available, parents' efforts at advocating for their children remain impressive (McCabe, 2007). Since the 1970s self-help groups for parents of children with disabilities have influenced social policy through their work in advocacy (Foulks, 2000; Freddolino, Moxley, & Hyduk, 2004). Maintaining a sense of collective empowerment depends on the ability of the self-help group to listen to their members and to incorporate their concerns. Challenges arise in self-help groups when group goals became incongruent with members' interests (Wituk,

Tiemeyer, Commer, Warren, & Meissen, 2003). For example, when group members who are personally empowered, fail to create self-help group goals for social empowerment, members often become ambivalent about participation (Carter, 2009). As one alternative, parents turn to online groups to address their need for social change, as well as support and information.

The Internet allows parents access to information about symptoms and interventions which may be useful for their autistic children (Fleischman, 2005). The Internet is a useful tool in linking people with specific concerns and is available to anyone who has a computer and an Internet connection. Typically, online groups engage through Listservs, newsgroups, and websites (Meier, 2004). Listservs allow members to send and receive messages delivered to their e-mail addresses and to all those on a subscription list. Newsgroups store messages on a computer in a central location which can be read and replied to by users. Websites provide interactive message boards or real-time chat meetings.

Some obstacles that confront face-to-face groups are overcome in computer-based groups. Online group participants are not dependent on geographic location. For those incapacitated, online groups offer convenience, flexibility, and accessibility. Research suggests that online groups are most suitable for people who cannot or will not attend face-to-face therapeutic groups because they are living with stigmatized conditions or are isolated due to restricted physical mobility or caregiving (Meier, 2004). Considering Internet-based groups mask social cues and norms, Meier suggests anonymity encourages more open expressions, leading to more rapid group cohesion. Conversely, he suggests anonymity may lead to premature disclosure, making participants vulnerable to insensitivity of others' responses. Despite this possibility, participants reported high levels of satisfaction, noting online groups were positive and constructive and promoted emotional bonding.

Groups meet on the Internet to share coping strategies and offer encouragement and support to others. Beder (2005) describes how one can use various technologies to provide solace, that is, caring or emotional support. Beder uses the term, cybersolace, to describe technologies which promote building emotional ties and offering solace between individuals. When there are few opportunities for parents to talk to other parents or professionals and a sense of isolation ensues, Internet self-help groups offer an option (Scharer, 2005). As a study by Fleischmann (2005) indicated, "the Internet allows stressed parents of children with autism to forge ties among themselves and extricate themselves from their isolation." Thus, as Scharer proposed, electronic-based self-help groups have the potential to meet parents' identified needs for increased levels of social support.

Parents who meet online create ties with others who share similar experiences and concerns, thus forming strong online supports for each other, often resulting in more formal online self-help groups. The Internet-based groups permit parents to voice their perspectives, specifically allowing members to aim to effect change through policy advocacy. Continually, Internet parental advocacy for autism plays a major role in countries like the United States (Autism Society of America, 2009), Canada (Autism Society Canada, 2009) and Great Britain (The National Autistic Society, 2009) as well as other countries such as, China, where fewer services are available for parents (McCabe, 2007). However, despite the widespread use of the Internet, there is little evidence within the literature about its effectiveness (Mandell & Salzer, 2007). This paper, as part of a larger study on the positive and negative experiences of parents involved in self-help groups for autism, helps to fill this gap.

Methodology

The application of an interpretive, qualitative methodology explored the Internet-based experiences of parental advocates for autism. As little is known about the complex nature of the Internet experiences of parental advocates for autism, the subject area is suited to a qualitative methodology. It allows the researcher to focus on the complexity of the lives of the parents. It seeks "answers to the questions about the what, how, or why of a phenomenon, and then explores, rather than measures or tests, aspects of it" (Holosko, 2006, p. 59). Practical, qualitative methods in-cluded developing the research questions, select-ing the relevant site and subjects, collection and interpretation of data, and writing up of the findings, conclusion and implications.

The main research questions were:

• What positive experiences have you encountered with regard to the use of the Internet for self-help group support and advocacy?

• What negative experiences have you encountered with regard to the use of the Internet for self-help group support and advocacy?

For practical reasons, the Greater Toronto Area (GTA) was chosen as the research site. The participants in the GTA met the criteria that included experience of the phenomenon being explored, the ability to articulate their conscious experiences, and the willingness to participate in a lengthy interview. Although parents for children with autism with these capabilities maintain membership in self-help groups in every Canadian province, larger numbers of parents in the Greater Toronto Area focus on improving interventions for children with autism. For example, over 100 GTA families had lodged formal human rights' complaints against the Ontario government for discrimination against autistic children over the age of six.

Purposive sampling, snowball sampling, and advertising were all used to locate potential participants for the interviews. Purposive sampling permitted the researcher "to locate all possible cases of a highly specific and difficult-to-reach population" (Neuman & Kreuger, 2003, p. 563). Snowball sampling located participants, based on the information gained from initial participants, fellow members at the Geneva Centre for Autism and participants at Toronto conferences on autism. Advertising permitted posting of a recruitment letter about the study on the Ontario Autism website, indicating approval by the University of Calgary Conjoint Faculties Research Ethics Board. These recruitment techniques resulted in 22 in-depth interviews with parental participants, experienced with autism, self-help groups, and advocacy, ensur-ing the likely collection of sufficient data. All but 4 of the 22 participants came from the Greater Toronto Area (GTA). Two lived south of the GTA and two lived east of the GTA. The interview process involved a recruitment letter, verbal consent, and a written, signed consent and a small honorarium of 50 dollars to assist

with attendant care responsibilities for the time allocated for the interview.

A semi-structured interview guide helped to focus the queries, but the participants largely directed their audio-taped responses according to their interests. The participants shared more information than was required to address the experiences of parents in face-to-face self-help groups (Carter, 2007). Information, initially set aside, on the experiences of online self-help groups, is analyzed in this paper in a two-step coding process. The first step involved the transcription of interviews, identification of units of meaning and assignment to codes, and allocation of codes to broader categories (Strauss & Corbin, 1998). Atlas.ti software (Scientific Software Development (1997–2003) aided the process of creating, changing, and merging codes into categories. Analysis at the second level looked for meanings, in developing themes, by comparing the similarities and differences in categories, organizing the meanings into themes, and integrating these themes into the findings and discussion. The themes did not simply reflect frequency counts of categories. Theme development occurred through a process of creating research questions, conducting, recording and transcribing interviews, line-by-line coding, and grouping categories into themes.

Credibility was provided though the collection of data from different sources, engagement with participants over a long period of time, consultation with colleagues, the search for, and inclusion of data sources that contradicted the study's themes and findings, the keeping of complete and accurate records, and the carrying out of member checks. However, several limitations to this research study have been noted. First, since all participants had some financial means, the results may not be representative of all families in the GTA with children with autism. Second, a longitudinal study would perhaps better reveal the long-term concerns, successes, and challenges of families with children with autism. Third, limiting the study to the GTA, including east and south of the GTA, restricted the research area. Fourth, the study did not include all parental advocates in self-help groups within the research area. Fifth, three of the interviews, done by telephone, hampered the researcher's ability to respond to nonverbal visual cues, carrying the risk

that participants made responses that were not picked up by the researcher. Finally, the identified themes represent only some of the categories of coded data which were created.

Results

The participants in this study consisted of a largely homogeneous group of Caucasian families who were Christian, and where either one or both parents had a community college or university education, where one parent was employed full-time, and where the family income was over $50,000 dollars a year. Participants consisted of 17 mothers, 3 mother and father dyads, 1 mother and grandmother dyad, and 1 divorced father. Seventeen mothers, 5 single and 12 married, took part in the interviews. Nineteen participants were Caucasian, 1 was Asian, and the racial background of 2 others was not known. Three participants had immigrated from Asia, Eastern Europe, and England respectively. Three participants received income assistance from government and family. Six of 8 participants with a psychological diagnosis were on long-term disability. Most participants had significant levels of family support. Regarding Internet use, 12 participants described consistent use of the Internet for 4 or more hours a day while 9 participants used it 1 to 4 hours a day and 1 participant used it less than 1 hour a day.

The main themes which emerged through the coding of categories from the replies to the research questions included:

Main Theme 1: Seeking and Receiving Information

Category 1:   Searching for Information
Category 2:   Seeking Services
Category 3:   Accessing Professionals and Services
Category 4:   Confusing Information
Category 5:   Overwhelmingly Negative Information
Category 6:   Unreliable Information

Main Theme 2: Connecting to Others

Category 7:   Easing Isolation
Category 8:   Joining Self-help Groups

Main Theme 3: Promoting Advocacy

Category 9:   Boom in Advocacy
Category 10: Sacrificing Time with Family
Category 11: Resenting Loss of Time
Category 12: Discouraging Ineffective Practices

The first main theme reflects how many participants felt that online self-help group participation was necessary for seeking and receiving information. The second main theme describes how several participants thought Internet-based group participation provided them opportunities to connect with others. The third main theme reaffirms that most participants view online self-help groups as promoting advocacy. The main themes and categories that were identified include:

Theme 1: Seeking and Receiving Information

One main theme that emerged throughout the interviews focused on how the Internet was used as a primary method for seeking out and receiving information about autism and interventions for autism. The following comments regarding Internet use suggests that most families used the Internet for access to information and interventions:

> It's the best tool they've ever come up with for this kind of thing. Number One, we've got instant communication with each other, with hundreds, perhaps even thousands, of people…I just checked this morning, two hundred and thirteen were the number of contacts…So as much as I am sending out two hundred plus e-mails, I know its going out to a multitude more than that, that's why I say it may be getting into the thousands and actually receive my e-mails within a day or two. Uhmm, instant tool…When it comes to trying to arrange something quickly or respond to something quickly, it's been amazing.

> …It's like almost international. They're based in the US but there are many parents from Canada who are active on the, on the list…there is discussion on how we teach the child, uhmm, like, potty training and things, how we teach them math, how we teach them reading, and there are other things like…the IEP [Individual Education Plan], you know, how to, be an advocate for the child to be integrated in the regular class, you

know, with special help. How do we get the help the child needs because of the, uh, the funding restricts…

Many parents explained that their busy family lives seldom allowed them to meet face-to-face with other parents in similar situations. The Internet was described as a particularly useful tool in its ability to increase accessibility to information for those who are housebound, lack transportation, or live in rural areas. As another participant remarked, "… we've done a lot of research online because it's convenient. I can do it. I work evenings. I get home from work at midnight. I'm often on there till 2 am." Most parents' initial experiences with Internet-based self-help groups happened through reading information and e-mails. They found it comforting to have the information available to read without necessarily feeling obliged to reply.

For many parents, making use of the Internet also meant improved access to professionals. One participant noted in the following quotation that the Internet allowed them access to professional websites such as those of the Ministry of Education, school boards, and government websites:

> …It actually is very easy now for getting information to, uhmm, people in the school board because all the people in the school board have e-mail addresses… I don't even have to fax, I can e-mail and e-mail is just so instant and it's wonderful…

Participants also relayed negative experiences stemming from their use of the Internet. As indicated by the following typical quotation, many families found the information they got through the Internet to be confusing:

> … I mean on the one hand the e-mail is a godsend because it allows you to participate when you can. On the other hand you can get bombarded with these e-mails, uhmm, and there is so many groups you don't know which to choose …

Some participants found the sheer volume of information to be overwhelming:

> … And new parents should get on the Internet but you have to be careful because there're 20,000 places with autism and parents get overwhelmed. When I first found out, I went on the Internet. It was like, "Whoa." I was just bombarded.

> … parents also get very downtrodden and depressed when they go on the Internet. Some places will say, "There is no definitive treatment and nothing will help your child, or you need $60,000 [per year] to take care of your child …"

A few parents found the information gained from the Internet to be unreliable:

> So what I did was I went to a workshop and I took all, I took some of the things that were on the Internet and I took them with me to ask them, you know, what they thought of these different things to see if they were accurate. And some of them weren't …

Several indicated that they used Internet-based discussion boards. These discussion boards were reported to have helped to fulfill the need for information and support (Scharer, 2005), while also addressing the subjects of behaviour management and educational needs.

Theme 2: Connecting to Others

A second theme, connecting to others, emerged from the interviews, indicating most parents found the Internet offered them opportunities to connect with others. Participants described themselves as feeling isolated from society at large because of behaviours displayed by their autistic children that were not well understood by the public. The emotional support they received through the Internet eased their isolation, as is made obvious in the following quotations:

> … I can't imagine and then if you don't have the Internet, how much more isolating, because I think for many of us it's our only means of socialization sometimes or the phone …

Theme 3: Promoting Advocacy

A third theme centered on the employment of the Internet as a tool for supporting advocacy work. One participant described their use of the Internet for advocacy in the following way:

> …I think that the advent of the Internet such a tremendous, uh, boom to advocacy and support of autism because of the availability of information in all those facets, you know…I think the Internet quite honestly has saved my child because of the

amount of information that's out there that ten years ago, even five, six years ago wasn't there. Thank God for technology…

And one of the parents really opened up with all the stats, all the issues, and you could tell MPP Elliott was just bombarded by this person. She said, "Are you an organized group? Could I speak to a leader here?" And then we all looked at each other. Who was going to step forward and be the leader? We aren't that organized. And we need to be. So with the e-mails that I collected from organizing that group that day, I started an e-mail group to keep us organized, to keep us focused…

Participants engaged in Internet-based groups as a means of seeking and launching community action. Frustrated about the limited nature of programs and services, and the difficulties encountered with being unable to take an active role in decision-making regarding their autistic children, participants took part in advocacy efforts on the Internet (Autism Society Canada, 2009). Parents often remarked, such as in the following quote, that they felt the Internet and e-mail was "…just wonderful because it was a very good way of, of trying to feel like there was some sort of a community that was advocating together." Internet-based members successfully sought to organize participants to collectively advocate by creating opportunities for themselves and others to develop advocacy, based on collective empowerment.

Although many participants believed their work was important, expressing that "it really needs to be done" and that they did "not want to miss out on anything," they complained about the time work on the Internet took away from family life. Parents resented the time lost to using the Internet by reading and answering thirty or forty e-mails a day. Adding to this discontent, participants reflected on discouraging outcomes that they had experienced through their Internet correspondences:

> … the type of criticism that I was going to open myself up to, from these people who basically I didn't even know. Ah, actually the other day, people took a lot of shots at me after I went public and you know, I would hear a lot of stuff, and, uh, you know, there were people, there were some people who weren't so polite about how they felt about me and had no problem saying things to

me in e-mails. And I didn't know some of these people. And so that, that was not very pleasant…

These findings suggest that Internet use resulted in both positive and negative experiences for participants. Participants viewed Internet use as providing them with opportunities to gain needed information, but also found that the information was often overwhelming, negative, and unreliable. Although it provided an opportunity to promote advocacy, many of the parents in the study experienced disappointing outcomes with regard to Internet advocacy. Despite these limitations, the Internet provided opportunities to ease isolation and to form and take part in self-help groups.

Discussion and Implications

The following positive findings indicate that the Internet is a useful tool for helping parents and families who are touched by autism to:

- Find information about autism

- Access professionals

- Acquire social support and relieve isolation

- Create collective action

Internet self-help groups help to relieve stress with access to both information and professionals. Participants valued the relief from isolation and the social support acquired through online self help groups. Social support encouraged some online participants to pursue social change through collective action.

The following negative findings indicate that the Internet has challenges and limitations as a useful tool for helping parents and families who are touched by autism:

- Internet accessibility

- Internet maintenance and security

- Internet etiquette and confidentiality

- Internet lists of unknown and costly interventions

- Internet advocacy outcomes

Several issues with online self-help groups suggest the need for improvements. The first issue involves accessibility to the Internet. Accessing support through the Internet is restricted to those who can afford computer equipment and accessories. Public libraries provide the service of linking parents to the Internet, but the access and time available is limited. Next, Internet consultants are often needed to develop and maintain self-help group websites, often requiring resources not readily available. Minimally, passwords need to be used when accessing self-help group websites in order to insure adequate security for members. Also, training in e-mail etiquette for self-help group participants is needed to minimize the potential for offensive comments. As well, confidentiality guidelines should be developed and disseminated to those in discussion groups. Essentially, online self-help groups need to list proven interventions based on research to avoid confusing and frustrating members. Lastly, online groups collectively acting to bring about required services for children with autism need training to improve their approaches to empowerment and advocacy.

The Internet provided a forum through which parents and family members received information and social support. It also allowed participants to collectively voice concerns about needed interventions and work together positively to initiate positive change for children with autism. Despite the challenges involving Internet maintenance, security, and etiquette, misinformation, costly interventions, online self-help groups transformed personal empowerment into collective empowerment. With government cutbacks to professional and human services, self-help groups continue to provide needed support, information and a means to generate collective action. As face-to-face group participants may decrease in number with the challenges of time and access, increasing use of the online self-help group is likely. However, professionals may be reluctant to refer clients to or engage with online groups due to a lack of evidence about their effectiveness. Therefore, professionals need to support further research on the benefits of online self-help groups and gain the technological skills necessary to assist in creating and maintaining online groups.

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