



**Perceptions of Professional Intervention by Parental Advocates for Autistic Children: A Need to Improve Practice with Self-help Groups and Those with Developmental Disabilities**

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# Perceptions of Professional Intervention by Parental Advocates for Autistic Children: A Need to Improve Practice with Self-help Groups and Those with Developmental Disabilities

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*Irene Carter*

## **Introduction**

Recent budget constraints on government social welfare spending have resulted in increases in the activity levels of self-help groups for those suffering from autism. Some individuals whose families have been touched by a diagnosis of childhood autism choose to focus their efforts on voluntarily taking part in support, education, and policy advocacy work through self-help groups for autism. Currently, some self-help groups for children with developmental disabilities propose social policy initiatives that would increase the ability of social welfare programs to meet their needs, which would benefit society as a whole.

Self-help groups originated in the 1970's when parents of children with disabilities began an effort to influence social policy through advocacy (Foulks, 2000). Although support and self-help groups have similar characteristics, self-help groups, besides offering support and education, aim to effect change (Kurtz, 1997). Historically, support groups, assisted by a larger organization, involved social workers while self-help groups, independent of professionals, promoted change. However, self-help groups and support groups have common characteristics. To clarify this construct, several scholars have suggested viewing the various groups as being part of a continuum, with "pure" self-help groups at one end and support groups involving social workers at the other (Schopler & Galinsky, 1995). Parents of autistic children need the benefits provided by both support and self-help groups to continue their supportive, educational, and advocacy efforts.

The author's study of 22 parental advocates of children with autism in the Greater Toronto Area has revealed several unmet needs and sources of frustration with regard to governmental support for developmental disabilities, self-help group dynamics, and parental experiences with profes-

sionals. Referring to key findings in this study, the author will survey the literature in order to examine relevant issues more deeply and to come up with suggestions for possible solutions.

This article begins with an overview of autism and the history of difficulties faced by families of children with autism. It will then consider the role that self-help groups have historically played for these families, as well as the traditional role and contributions of professionals working with self-help groups. Following from the information gleaned, an outline of suggestions will be made regarding ways in which professionals could more effectively support families touched by a member with a disability as well as support for the self-help groups in which they are involved.

## **Autism – Symptoms and Interventions**

Autism is a developmental disability that presents an absence or delay of speech development and a lack of normal interest in others. Although the etiology is unknown, current studies show that genetics play a role (Rapin, 2002). Prevalence rates vary and could be as high as 60 to 70/10,000 (Chakrabarti & Fombonne, 2005). People with autism often display mild to severe symptoms of stereotypical, repetitive, purposeless movement, and self-injurious behaviors, and includes concurrent mental retardation in about 70% of cases, a male/female ratio of 4:3:1, and other disorders (Fombonne, 2003). To lessen symptoms, parents seek a range of behavioral interventions, which vary in intensity, that focus on teaching the afflicted child certain skills. Applied Behavior Analysis [ABA] (Lovaas, 1987) changes autistic symptoms with up to 40 hours of instruction weekly and a reliance on reinforcement and discrimination-learning. Other treatments, such as the Treatment and Education of Autistic and Related Communication-Handicapped Children

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[TEACCH] (Schopler, Short, & Mesibov, 1989) adapt the learning environment to the child's needs. Professionals and parents consider the severity of the child's condition as well as human and financial resources when making intervention choices.

### **Challenges Faced by Families with Children with Autism**

Families with children touched by autism face many challenges. Historical attitudes, beliefs, and values ostracized and rejected people with disabilities (Mackelprang & Salsgiver, 1996), isolating and institutionalizing them. Some of this behavior extends even into the twenty-first century. Oppressive beliefs created obstacles to public awareness, intervention, support for families, and progressive social policy. The rise of the labor movement, the post World War II United Nations Declaration of Human Rights, and the civil rights movement of the 1960s all helped to humanize persons with disabilities. Advocacy of services for children with disabilities in the United States resulted in the *Individuals with Disabilities Education Act* of 1975 (Kotler, 1994), and continued improvements in American legislation into the 1980s and 1990s (Foulks, 2000). American trends have influenced other countries, including Canada. In Canada, legislated recognition for the rights of full citizenship for people with disabilities came into effect through the Canadian Charter of Rights and Freedoms (1982).

Despite increasing levels of awareness and protective legislation, families dealing with developmental disabilities still often experience isolation, rejection, a lack of support, as well as difficulties in accessing needed information regarding issues of concern to them. Circumstances that currently create obstacles for families managing developmental disabilities include the following:

- lack of a comprehensive agency to provide service delivery
- limited access to services for individuals with chronic symptoms
- deinstitutionalization without enough support
- increasing dependence by government on women to provide care in families

- development of programs for general rather than particular needs
- allowing those who can afford it to pay for services beyond basic care for all
- the lack of user contributions in planning and developing programs

Budget constraints on government social welfare spending have resulted in increased activity by self-help groups. In line with conflict theory, self-help groups responding to perceived oppression have reacted by striving to influence social policy through advocacy and by proposing social policy initiatives that would increase the ability of social welfare programs to meet their needs.

### **An Overview of Self-Help Groups for Families Touched by Developmental Disabilities**

Presently, several national and international self-help organizations provide information, resources, and advocacy for those with developmental disabilities. Emerging during the civil rights movement of the 1960s, self-help groups for children with disabilities concentrated on support and education (Foulks, 2000), and they also had an influence on social policy through advocacy. The concept of "self-help groups" belongs to a largely analytical category that varies significantly according to place, culture, and historical time, as well as by size and intended role. The size of self-help groups varies from small primary groups to large bureaucratic organizations. The literature has produced few comprehensive analyzes of self-help groups. However, Wituk, Shepherd, Slavich, Warren, and Meissen (2000) found that the goals of the members of self-help groups included emotional support (61%), education (96%), and advocacy (70%).

Self-help groups provide services and means of addressing social issues through social action, consciousness-raising, and advocacy (Cossom, 2005). Parental advocates embraced the minority model or social model (Oliver, 1990) of disability in focusing on the removal of unjust limits to interventions and services for their children. Based on conflict theory and related to the civil rights movement, this model views people with disabili-

ties as an oppressed minority in that they are kept from fully taking part in society by negative, environmental, and societal causes (Bickenbach, 1993). Bickenbach credits this model of disablement for bringing about many of the legislative developments in the last twenty years. He explains that the minority model takes the view that negative social factors, and not the disability, restrict participation, and that progressive social policy can reduce and address oppression (Goodley, 2000). As an approach that directs policies to lessen oppression, it needs knowledge and skills in policy advocacy. However, the minority model provides a means to understand how social policy, and the social attitudes that influence it, created and continued the lack of interventions, services, and social support for children with developmental disabilities. Taking action, based on a theory of oppression, created opportunities to empower parents (Linhorst, 2006; Mullaly, 2002), self-help group members, professionals, and policy makers.

### **History of the Relationship between Self-help Groups and Professionals**

Historically, organizations called “friendly societies” promoted self-help during and before the nineteenth century (Green & Gromwell, 1984). Gosden (1973) traced the first friendly society to 1643, when a group of mariners created a coalition to provide insurance against old age, death, and widowhood. Friendly societies flourished after the 1840s in Great Britain (Gosden); however, accurate figures are not available because many friendly societies remained unregistered. These societies provided insurance for sickness and death. Calculating liabilities was not reliable, and many friendly societies collapsed financially. By 1918 the state began to regulate the societies. Friendly societies remained prominent until the 1940s when they ceased to function as insurance programs.

In recent decades, self-help groups have provided an alternative to formal, professional help. During this time, the relationship between self-help group members and professionals evolved from therapeutic to dualistic to conflictive (Lee,

1999). In the therapeutic model, professionals organized groups and directed the therapeutic process. In this model members viewed professionals as professionalizing self-help, and thought the professionals were unlikely to go against the service system. In the dualistic model, members and professionals filled different, respectful, complementary roles, focusing on the exchange of knowledge, resources, social policy, and advocacy. This model allowed members and professionals to act independently or to collaborate as partners. In the conflict model, group members viewed professionals suspiciously as disabling the strength and power of citizens, as providing questionable interventions, and as being unable to change existing policy. The historical relationship between professionals and self-help groups explained in these models created an environment that made it difficult to integrate professional and experiential knowledge.

Now, many self-help groups view partnership with professionals as informative, useful, and desirable (Ben-Ari, 2002), replacing contradictory relationships between self-help groups and professionals. Political coalitions that united professionals and non-professionals to lobby legislators proved effective (Foulks, 2000). Ben-Ari recommended discussion between professionals and self-help groups to improve professional involvement with self-help groups.

Self-help groups provide opportunities through which new perspectives and coping strategies can be developed (Bloch, Weinstein, & Seitz, 2005). Gitterman and Shulman (2005) describe how self-help group members become more resilient as they gain “greater personal, interpersonal, and environmental control over their lives” (p. xiv), confirming the value of support (Saleebey, 2006). Johnson and Johnson (2003) noted participants’ views of social support as being the most important aspect of group membership. Self-help group members organize around a common need for help and support from others in order to address problems they cannot manage by themselves. Thus, self-help groups provide important and powerful conditions that promote functionality and self-esteem.

Similarly, O'Connor (2002) found that caregivers became enabled "to advocate more effectively for the support they required" (p. 49) when they had access to a better understanding of available services and rights. O'Connor found that the group experience connects to the promise of achieving social empowerment. O'Connor further suggested that we reexamine groups to ensure that their purposes are consistent with their desired outcomes and that we explore ways of integrating support and empowerment. It was further revealed that while participants valued personal empowerment, they also voiced the need for an approach that focused more on collective empowerment and social justice. According to the theory of oppression, self-help group participants strive to take action to create opportunities for themselves and others to become empowered (Linhorst, 2006). Lastly, the literature suggests a positive correlation between advocacy and the receipt of services for people with disabilities. A study by Jurkowski, Jovanovic, and Rowitz (2002) found that family advocates in self-help groups were nearly 11 times more likely to acquire health care resources than those who did not take part in groups.

### Methodology

An interpretive, qualitative, grounded theory method (Straus & Corbin, 1998) provided the means for gaining knowledge about the experiences of 22 parents living in the Greater Toronto Area. A qualitative approach transformed the complex experiences of parents in self-help groups into a written account, using research questions that sought and explored answers about parental experiences. The primary research question -- "What are the positive and negative effects of parental advocacy in self-help groups?" -- resulted in the following related research questions:

- What circumstances lead to parental participation in a self-help group?
- How important do parents think the role of advocacy is in a self-help group?
- What are the positive effects for parents involved in self-help groups?

- What are the negative effects for parents involved in self-help groups?
- What factors contribute to positive effects of participation in self-help groups?
- What factors contribute to the negative effects of participation in self-help groups?

Participant experience and willingness to take part in a lengthy interview decided the site, type, and size of the sample. All participants came from the Greater Toronto Area (GTA), Ontario, except for four participants, two who lived south of the GTA and two who lived east of the GTA. The GTA had significant parental advocacy in self-help groups that focused on improvement in interventions for children with autism. Contacting potential participants and arranging interviews involved purposive sampling, snowball sampling, and advertising.

Only those parents of autistic children who confirmed they had experience with self-help groups and advocacy took part in the interviews. Participants ranged in age from 35 to 54. They consisted of either one parent (a mother or a father), two parents (a mother and a father), or a parent and grandparent (a mother and a grandmother). In two of the two-parent interviews, the individuals involved were raised in another country with significant cultural differences from North America. These varying characteristics are consistent with qualitative research, in which diversity of individual experiences is valued. All recruiting efforts resulted in 22 participants, a reasonable assurance there would be enough data for the research. Before the interview, verbal and signed consent ensured fully informed consent. The research was approved by the Research Ethics Board, University of Calgary.

The research participants provided transcribed, tape-recorded data by verbally responding to a semi-structured interview guide. The participants received a small honorarium of \$50 to help with attendant care responsibilities for the time earmarked for the interview. The use of pseudonyms

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protected the confidentiality and anonymity of participants. The interviews averaged two hours in length and took place in the GTA, and east and south of the GTA, between April 2003 and July 2003. A self-reflective journal supplemented the interviews and provided an opportunity to review the data and ensure accuracy, clarifying how researcher biases and assumptions affected the research.

Analyzing data included reading transcribed descriptions, using Atlas.ti software, and extracting, clustering, and integrating themes into a written account. Initially, the coding phase involved

identifying meaning units, assigning them to codes, assigning codes to categories, and documenting coding rules. Second, coding entailed comparison of likenesses and differences in categories and interpreting underlying meaning. Theme development occurred throughout the processes of creating research questions, conducting interviews, transcribing and coding, matching categories to research questions, and analytically developing themes. The participants shared more information than was required to address the experiences of parents in face-to-face self-help groups (Carter, 2007). This paper focuses on the

Table 1: *Main Themes and Quotations for Parental Advocates in Self-Help Groups for Autism*

Themes	Quotations
1. Self-Help Group Participation as Necessary	I became involved when he was about four years of age. And I received a letter from, I don't remember which group, saying that the Xxxxxx chapter, that our regional chapter of the Autism Society Ontario, there was a ship sinking and they were calling out for, ah, members, volunteers to come. There was a big turnout for this meeting and that's how I got involved, because, I just cannot bear not doing anything for my child, when I can.
2. Supporting and Protecting Children with Autism	No one taught me how to advocate. There, as far as I know, I wish there was someone that said you're child's autistic, this is what you need to do, this is how you go about fighting the government, this is how you go online, these are the places you can go to, these are the people you can talk to, there isn't anything like that.
3. Viewing Self-Help Involvement as Enabling	I think sharing. Sharing personal stories, information, sharing resources, sharing experiences, all those factors bring about a positive effect. Ah, sharing in the group, sharing in the joy, just, sharing our stories in general just seems to be a positive experience and seems to have a positive effect upon people.
4. Experiencing Ambivalence in Self-Help Groups	...the main thing is the stress that it, it creates because it is significant. And when you're having to advocate continually and it doesn't stop and you're unsuccessful. I mean you get yourself up for the battle and you lose it. It's, it's a tough go.
5. Appreciating Self-Help Group Support, Education, and Advocacy	... We also decided that, ah, that she [a professional] would be present and if there was a parent that entered the group that day that was extremely upset over whatever is sue that she would be there to take her outside of the group and just be with them on a one to one level. So the group could carry on [with advocacy], ah, as a group.
6. Discovering Self-help Group Experiences that Need Improvement	Some, some have a lot of complaints but they don't care to share the solution process... they don't seem to have a goal... There's a despondency there and, and we see enough depression that, you know, if, they need to share that... maybe there're getting what they need from the meeting that way to if, if they can, if they can share. And no one, no one can feel restricted in coming in and pouring out their heart. That's not what I'm trying to say but I, I think you need to, have been hurt, you know, obviously but each meeting should have a theme or a purpose and if you can come away with something to work with instead of more bad news.



experiences of self-help group members with professionals.

Although this study provided insights into the experiences of parental advocates in self-help groups, it has limitations. First, the researcher restricted the site to the Greater Toronto Area and eastern and southern Ontario. The study does not include all parental advocates or all self-help groups in this area. Participants' experiences varied in type and number of years. Five participants had less than two years of self-help group experience. Using a prepared interview guide with set questions may have limited participant responses. Conducting three interviews and two follow-up interviews by telephone may have hampered the researcher's ability to respond to nonverbal, visual cues. Lastly, this research does not reflect the views of professionals who provide interventions for children with developmental disabilities.

### Findings

The data analysis revealed that parents viewed access to policy advocacy and professionals, when appropriate, as important to the members of self-help groups. This paper focuses on these perspectives, as illustrated by the quotations, in each of the main themes, outlined in Table 1: Main Themes and Quotations for Parental Advocates in Self-Help Groups for Autism.

Most parents experienced limited access to suitable behavioral interventions due to age limits, long waiting lists, the prohibitive cost of private therapy, and a lack of properly trained professionals. In the first main theme -- Self-Help Group Participation Involvement as Necessary -- participants noted a continuing need to locate, provide, develop, fund, and maintain programs and services for their children by affiliation with self-help groups. In the second main theme -- Supporting and Protecting Children with Autism -- several participants voiced the need for to protect children with autism. Many participants described how they learned to challenge, repeatedly, the government about its discriminatory and exclusionary practices against their children. They strived to create public awareness, to break

down the barriers to inclusion, and to increase access to behavioral interventions and other supports. Frustrated with self-help group leadership, as well as professionals and government representatives, most participants realized that they would have to engage in policy advocacy (Jansson, 2003) to acquire behavioral interventions for their children. In the third main theme -- Viewing Self-Help Involvement as Enabling -- participants appreciated the sense of hope and self-esteem gained from the support they experienced in self-help groups. Sharing stories gave them opportunities to become empowered at both personal (Saleebey, 2006) and collective levels (Boehm & Staples, 2004; Linhorst, 2006). In the fourth main theme -- Experiencing Ambivalence in Self-Help Groups -- many participants experienced ambivalence when personal goals became incongruent with self-help group goals. Ambivalence about membership surfaced when efforts to promote social change failed as a result of differences between individual and group goals. In the process of becoming personally empowered, many parents realized that oppressive, institutional practices consistent with a minority model (Mullaly, 2002; Oliver, 1990) prevented access to needed interventions and supports. These participants perceived self-help groups as inadequately supportive of individual group members who required interventions. Consequently, many of the participants felt self-help groups provided limited support for legal efforts to promote behavioral interventions. Self-help groups often hesitate to become involved in advocacy for interventions. As registered charitable organizations, they are restricted by government regulations with respect to the amount of advocacy they can do (Canada Revenue Agency, 2009). Parental advocates decided that professional help was crucial to developing collectively empowering practices.

In the fifth main theme -- Appreciating Self-Help Group Support, Education, and Advocacy -- most participants perceived self-help group participation as beneficial to the areas of support, education, and advocacy, causing many participants to suggest professional involvement to en-

hance these interventions. Self-help groups found it challenging to simultaneously support the need for advocacy training for seasoned members and care for the emotional needs of newcomers. Parental advocates welcomed involvement with professionals to help resolve these issues and to work, collaboratively, towards changes in social policy. Many also suggested some members needed professional intervention, identifying complex needs beyond the ability of the self-help group to provide. Most participants identified professionals as especially necessary to provide new members with support and more seasoned members with opportunities for social action.

The sixth main theme -- Discovering Self-Help Group Experiences that Need Improvement -- revealed what participants noted as major ineffective aspects of self-help groups. Although these participants described personal and collective experiences as beneficial, they experienced limited success through self-help groups in the quest for improved behavioral interventions and support for children with autism. As a result, many participants believed self-help groups required a clearer group focus on what the group could and could not do with respect to advocacy.

The main themes revealed that parents viewed policy advocacy and access to professionals as important to parental advocates in self-help groups for autism. Most parents experienced limited access to suitable behavioral interventions due to age limits, long waiting lists, the prohibitive cost of private therapy, and a lack of properly trained professionals. Many participants described how they needed professional assistance in challenging the government about its discriminatory and exclusionary practices against their children. Many also suggested some members needed professional intervention, identifying complex needs beyond the ability of the self-help group to provide. Specifically, most participants identified professionals as especially necessary in providing new members with support and more seasoned members with opportunities for social action. Parental advocates decided that professional help was crucial to developing collectively empowering practices and avoiding reduced participation in self-help groups. Thus, this paper explores how

professionals can interact positively with parental advocates in self-help groups for autism and other developmental disabilities.

### Discussion

#### Professional Involvement in Self-Help Groups

Supported by the literature, the Greater Toronto Area study confirmed that incongruence between individual and self-help group objectives often prevails when the group does not initially set realistic goals (Wituk, Tiemeyer, Commer, Warren, & Meissen, 2003). Self-help groups need a mission, purpose, or vision statement that describes the values of their organization in a clear and precise manner. The values of the organization should be congruent with the roles taken on by group members. To support organizational goals, group members need to perceive organizational values as being clearly in line with the overall values of group members. Ideally, from the time that a self-help group is set up members should make a conscious effort to align the values of their organization with the roles played by their members. It is also important to regularly re-evaluate the congruence between members' values and those of the organization in order to stay on course. Using this strategy would reduce the risk of participants being misled or making false assumptions about the groups' functions or values. Wituk, Tiemeyer, Commer, Warren, and Meissen's study points out that in order to avoid incongruity between values and actions, self-help groups need to encourage feedback and regularly address concerns and challenges. Thus, an appropriate balance between the roles of support and advocacy needs to be developed through setting a clear group focus and through constant evaluative feedback.

Also consistent with the views of parental advocates in the Greater Toronto Area, Ben-Ari (2002) noted the value of professional contributions to self-help groups. Ben-Ari identified and emphasized the need for flexible and complementary interactions between social workers and self-help groups. The most important insight provided by this study is the recognition that self-help



group members who are professionals need to create a flexible relationship that allows both self-help group members and professional workers to integrate their knowledge and experience. Encouraging renewed dialogue between professionals and other self-help group participants provides opportunities to improve the effectiveness of self-help groups.

Participants in the Greater Toronto Area study also focused on the need for professional support in policy advocacy training (Jansson 2003). Using various approaches, such as strengths-based or structural approaches, professionals help people with disabilities and their families to develop ways to challenge issues and counter oppression at the micro, mezzo, and macro levels (Rothman, 2003). For example, the strengths perspective advocates the creation of hope through the recognition and maximization of the potential of clients and of the community as a whole (Saleebey, 2006). Furthermore, this approach helps individuals discover and use their resources. The emphasis on human capacity and self-empowerment is consistent with a solution-focused approach and with historically held values regarding personal and social change. Professionals use a strengths-based approach when they encourage clients to get involved in self-help groups and to access other informal supports in order to empower them. Promoting empowerment through a strengths-based approach involves a framework which conceptualizes people as being resilient in making their own choices and decisions (Saleebey).

Although self-help group support allowed parental advocates in the Greater Toronto Area to achieve a level of personal empowerment, obstacles continued to prevent them from accessing interventions needed for their children. As a result, they continued to be marginalized. A structural approach could be employed by professionals when working with a population such as this. The structural approach connects practice with socioeconomic and political environments that promote and cause oppression. Focusing on socioeconomic reasons as the basis for client problems allows professionals to look for opportuni-

ties for change and to move beyond generalist practice into a focus on collective action. According to the literature, professionals are committed to vulnerable populations but they are hesitant to engage in structural practice. Most likely this reluctance is a result of the limited guidance on how to do so.

### **Professionals and Empowerment of Self-Help Groups**

Despite the various approaches to practice generally available to professionals, parental advocates in the Greater Toronto Area study experienced professionals as being limited in their knowledge. Parental advocates wanted professionals to teach them how to navigate the system in order to more effectively access the services they needed. A study by Mansell and Morris (2004) further reflects the frustrations that many of the parental advocates in the Greater Toronto Area experienced in gaining information about services. In Mansell and Morris' study, participants hoped that professionals would point them in the right direction, but after their interactions with professionals they reported feeling improperly heard and abandoned. Participants did, however, state that they believed that this lack of productive help was not the result of callousness, but rather that the professionals were deficient in understanding and training. Research suggests that professionals need specific training in the challenges that families face in having a child with a developmental disability as well as the psychosocial issues related to children with disabilities (Shannon, 2004).

Professionals also lack skills and training related to the area of social policy and disabilities. Haynes and Mickelson (2006) write that "knowledge and skills have been lacking in the policy arena during the past several decades" (p. 65) and proposed using suitable policy models to teach political intervention skills. Hoefer (2006) suggested that the amount of advocacy practiced by professionals depended on their degree of education and skills, and suggested that professionals should take time to do advocacy in non-work related organizations as a way of ensuring the prac-

tice of activism. In order to help promote policy changes and to collaboratively incorporate change within agencies, communities, and legislatures, professionals must be familiar with existing social policies and with a variety of research findings (Jansson, 2003). Developing community initiatives calls for both professionals and government to jointly collaborate with vulnerable populations in mutual aid organizations.

Parental advocates in the Greater Toronto Area experienced ambivalence about membership in a self-help group when their personal empowerment failed to mature into collective empowerment. Empowerment is problematic for professionals who, as gatekeepers, are not in a position to give clients power (Adams, 2003). Adams links empowerment to practice by viewing power on a continuum from individual empowerment to group empowerment, and includes an understanding that interactions with professionals may function to disempower groups or individuals. Recommendations with regard to the issue of empowerment include a continual reformulation of goals as well as the understanding that any specific goal may not be fully obtainable. Van Voorhis and Hostetter (2006) pointed out that we are more likely to assist others in becoming empowered and to acquire needed resources if we perceive ourselves as empowered, implying that the curriculum can aid the development of empowerment.

In the author's study, participants who wanted to focus on collective empowerment had little opportunity to pursue social justice through political advocacy. The incongruence between individual and group goals resulted in frustration and participation decline. When group activity diverged from the goals of individual participants, these participants experienced a lack of support. O'Connor (2002) found that the group experience is connected to the promise of achieving social empowerment. O'Connor has suggested that the goals of groups may need to be re-examined on a regular basis in order to insure that the group purpose is consistent with its stated and desired outcomes.

To avoid disempowerment, Bloch et al. (2005) recommended training professionals in such a way that they become aware of how their actions

could potentially undermine the confidence and self-esteem of parents involved in self-help groups. Holosko, Leslie, and Cassano (2001) stressed that in order to maintain empowerment one must have the knowledge and skills to develop partnerships and collaborations between service users and human service organizations. They stressed that ensuring constant feedback to the service user at all levels avoided the experience of disempowerment. The area focusing on the psychological experiences and outcomes of groups (McDermott, 2003) and ways in which social support and empowerment can be integrated into the group experience needs further research.

### Professionals and Policy Advocacy Practice

The experiences of parental advocates revealed that professionals need to improve their interventions with self-help groups. Additionally, parental advocates suggested that professionals would be more helpful if they increased their level of collaboration with parental advocates in self-help groups for autism. In order to assist self-help group volunteers to become more effective in their group contributions, professionals need access to appropriate training on policy advocacy through their training curriculums. Such training would help make professionals more effective in aiding self-help groups develop strategic alliances.

Advocacy is a part of the professional's ethical responsibilities when dealing with a client who is in need. Research suggests that self-advocacy skills are essential to improving the quality of life of people with disabilities and their families (Huang et al., 2004). Professionals do aid clients to employ self-advocacy and social action in order to help them gain services, change policies or practices that impact clients, and promote new legislation or policies. Jansson (2003) also envisaged the professional as a policy practitioner who aims to change social policy. Powell (2004) has suggested that professionals create a new paradigm for advocacy that is values-driven and that includes an emphasis on leadership and policy-making skills. Training helps professionals to identify and document the need for policy changes, to assist parents who are advocating for ser-

vices, and to promote new legislation or policies (Sherraden, Slosar, & Sherraden, 2002).

Viewing the self-help group as a form of empowerment and self-help group advocacy as a further form of empowerment, Adams (2003) recommended that the role of facilitator was the optimal role for professionals when working with their clients, either individually or collectively. Professionals need to appreciate that the success of a self-help group revolves around both individual and collective needs, and that professionals and self-help groups have a common cause. One possible solution would be to address individual goals under the umbrella of group goals while at the same time upholding the more generalized group goals.

#### Recommendations for Future Action

Eight percent of the general Canadian population is affected by a developmental disability. Yet professionals lack knowledge about the issues and values important to people with developmental disabilities and their families. Burge, Druick, Caron, and Ouellette-Kuntz (1998) found that 79.2% of bachelor and master's level social work field placements did not focus at all on serving people with developmental disabilities. A study by Tower (2003) found that fewer than 40% of social work practitioners recalled any content on disability in their social work training.

Although professionals are familiar with issues of gender, race, and class, an educational gap has been left with regard to issues surrounding disability (Meekosha & Dowse, 2007). Increasing student participation in disability studies calls for a rise in the number of courses on disability, collaboration with disability studies programs, and student placement sites that promote acquiring knowledge and policy-advocacy skills related to disabilities. For example, in examining how Canadian Schools of Social Work have responded to disability issues, Dunn, Hanes, Hardie, and Macdonald (2008) found the need for enhancement, despite some recent improvements. They recommended that social work explore issues of accessibility and accommodation and that it develop best practices to ensure effectiveness in the area of disability. Courses that promote an inclusive

environment, using an interdisciplinary approach, need to be incorporated into the social work curriculum (Leslie, 2008) as well as the programs of other helping professions. Achieving improvements requires a collaborative effort between professional programs and disability studies.

Historically, parents in self-help groups have played an important role in providing support, education, and advocacy. Preserving self-help groups contributes to the possibility that collaborative community initiatives will help meet the current needs of children with disabilities. In addition to being a fundamental professional duty, helping marginalized groups provides positive and varied roles for professionals to play. Skilled professionals can assist self-help group members find ways to resolve ambivalence, avoid disempowerment, uphold a clear group focus, and create strategic pathways towards collaborative community initiatives through practice, education, and research. In order to use policy advocacy strategies effectively and to overcome limits in service delivery, it is important that further research on the effect of professional involvement in self-help groups be conducted. This qualitative study also indicates that further research is required to evaluate present programs that train professionals to work with people with disabilities and the importance of including training on advocacy.

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