A CONSIDERATION OF AMBIVALENCE AND ADVOCACY IN SELF HELP: THE CASE OF AUTISM

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ABSTRACT

Self-help groups contribute to social welfare by providing continuing support to their members and through proposing changes in social policy. Society also benefits from self-help groups that create community initiatives to help meet the needs of children with disabilities. In a study of 22 parental advocates involved in self-help groups for autism, it was found that participants developed ambivalence about membership when they experienced incongruence between individual and group goals. Although many members felt personally empowered as a result of membership, they expressed frustration about wanting to advocate for needed interventions and services. Disappointment resulted in ambivalence about membership and reduced participation. Participants identified the need for self-help groups to preserve a clearer group focus that would meet both therapeutic and social action needs. These findings suggest that social workers need training on how to avoid creating a situation of disempowerment while trying to promote individual and collective empowerment.

Historically, parents involved in self-help groups for autism were interested in accessing information and services that could help their disabled children. Autism is one of the most common and severe developmental disorders (Chakrabarti & Fombonne, 2005). Autistic symptoms include difficulties with social interaction and communication, and restricted, repetitive, and stereotyped patterns of behavior in "(1) social interaction, (2) language or (3) symbolic or imaginative

play" (American Psychiatric Association, 2000, p. 75). There is no cure for the core symptoms of this disability (Alexander, Cowdry, Hall, & Snow, 1996, p. 118).

Early intensive one-on-one behavioral intervention given within a structured environment provides the most effective intervention (Rapin, 1997). Ideally, a wide range of trained practitioners delivering a variety of behavioral interventions are the most effective in addressing the symptoms of autism (Bryson, Rogers, & Fombonne, 2003). Parents often experience difficulty in accessing appropriate and costly interventions. Self-help groups will play an increasingly key role as a source of support and empowerment for families, and as a way of providing an important forum for the promotion of increased services and interventions for people living with autism (Autism Society Canada, 2066).

As parents shared experiences of support, they became personally empowered. As their knowledge and confidence increased, they expressed the need to act collectively to improve conditions for their children. This study of parental advocates in the Greater Toronto area illustrates the importance of support to both personal and collective empowerment. The following discussion considers ways through which to avoid disempowerment and the implications of these strategies for social workers.

LITERATURE REVIEW ON SUPPORT AND EMPOWERMENT IN GROUPS

Self-help groups are diverse and range from support groups to political self-help groups. Support groups are largely therapeutic, while self-help groups provide varying degrees of support, education, and advocacy (Wituk, Shepherd, Slavich, Warren, & Meissen, 2000). Self-help groups for children with disabilities originated when parents, influenced by the civil rights movement in the 1960s, voiced their concerns about the welfare of their children (Foulks, 2000). Throughout the 1970s, parents strove to influence social policy through advocacy, which was undertaken to protect their children with disabilities from abuse and rights violations. It consisted of "purposive efforts to change specific existing or proposed policies or practices" (Ezell, 2001, p. 23). With increased budgetary constraints on social welfare, self-help groups have resurfaced as an important vehicle through which to advocate for the needs of vulnerable populations (Wharf & McKenzie, 2004). A study by Jurkowski, Jovanovic, and Rowitz (2002) found that families with members who were advocates in self-help groups were nearly 11 times more likely to receive health care than those who did not take part in groups.

Parental self-help groups for children with disabilities provide promising opportunities to become both personally and collectively empowered. Empowerment involves gaining a critical level of awareness of one's environment, and can be experienced at an individual, organizational, or community level (Linhorst,

2006). It is a continuing process that enables parents of autistic children to become self-advocates or to improve their abilities of self-advocacy. However, members within self-help groups often struggle regarding how much group advocacy they should take part in. This creates incongruence between personal and group goals for self-help group members. Without opportunities to aim for both collective and individual empowerment, some self-help group members risk disempowerment and ambivalence about participation. In order to address the reasons for attrition in self-help group participation, we need to achieve a greater understanding of the balance between members' needs for support and advocacy, and of the value of opportunities for both personal and collective empowerment.

STUDY OF PARENTAL ADVOCATES IN SELF-HELP GROUPS

In a qualitative study of parental advocates in self-help groups for children with autism (Carter, 2007), 22 parental advocates reaffirmed the limits of current social policies and service delivery to help children with autism. The main research questions included:

- 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?

In the interest of clarity and to help prevent ambiguity, the following concepts, found in the literature and research questions, are defined: parents, children with autism, support groups, self-help groups, advocacy, parental advocacy, and empowerment. Parents, in this study, are those parents who live with a child diagnosed with autism, including participants from both two-parent and lone-parent families. Children with autism are defined as those children, diagnosed with autism, and who are viewed by their parents as needing medical, social, or educational interventions. Support groups provide emotional support and education, usually with the help of a professional. Self-help groups have minimal professional involvement and offer advocacy as well as support and education (Kurtz, 1997), advocating for social policy and legal changes (Foulks, 2000). Advocacy is a method to plead the case of another to affect changes in policy, practice, or law for needed interventions. Parental advocacy represented the assertiveness demonstrated by parents in continually pointing out the needs of their autistic children to the people who could meet them. Empowerment,

viewed as an ongoing process of enabling parents of autistic children to become advocates, reflected the acquisition of a critical awareness of one's environment, experienced on an individual, organizational, or community level (Boehm & Staples, 2004; Linhorst, 2006).

Limitations of this study included the restriction of the research site to the Greater Toronto Area and southern and eastern Ontario. The views of parental advocates in self-help groups located outside the research site are not represented. Second, three of the interviews, as well as two follow-up interviews, were conducted by telephone, possibly hampering the researcher's ability to respond to non-verbal, visual cues. Third, with respect to the analysis, the themes identified in this study do not represent all of the categories of coded data created. In the analysis, the need to make choices determined what would be reported. Although this research promoted increased understanding of parental advocacy, the findings are limited by the above considerations.

Of the 22 participants, 18 came from the Greater Toronto Area (GTA), 2 from south of the GTA, and 2 from east of the GTA. Parental advocacy in self-help groups in the Greater Toronto area has focused on advocating for improvement in interventions for children with autism. Participants in the study met two sample criteria:

1. they were parents of children with autism; and
2. they had experience with self-help groups and advocacy.

The age of the participants ranged from 35 to 54 years of age. The interviews involved participants who were either one parent (a mother or father), two parents (a mother and father), or a parent and grandparent (a mother and grandmother). In the case of two of the two-parent interviews, both participants had been raised in a foreign country with cultural differences. However, on the whole, the participants represented a homogeneous group. This group consisted primarily of individuals who were Caucasian, Christian, married, had a post-secondary education, and who belonged to families where at least one parent was employed full-time and whose family income was over $50,000 per year. Despite the stress and financial obligations associated with parenting a child with autism, most of these families possessed the means and support to advocate for improved services for children with autism.

Data analysis involved transcription of the interviews, use of the software program Atlas.ti for coding, and creation of the main themes. In the first main theme, *finding self-help group involvement to be necessary,* participants perceived self-help group involvement as necessary, feeling a need to do something following their child's diagnosis, as evident in the quotation, ". . . and after we, sort of got over the initial shock, we started researching like crazy." Due to waiting lists for assessment, several participants experienced the need to be assertive, as illustrated in the following quotation:

> I wanna get on this waiting list. Oh, we can't put a name on the waiting list till you have an official diagnosis . . . I got my appointment moved up. So, uhmm, which was a matter of calling every day, is there a cancellation today. . . .

Main theme 2, *supporting and protecting children with autism,* illustrates how, reflecting supportive, protective, and vigilant attitudes, several participants switched their focus to advocacy as they became more aware of the interventions for autism and their children's rights. As one participant noted, ". . . as a group becomes more educated and finds out what's out there, [they] form a united front to do the advocacy work, to go after the service." Most participants focused on the acquisition of behavioral interventions as a reason for advocacy, experiencing behavioral interventions as costly, with waitlists and limited availability. The following quotation illustrates participants' frustrations with service delivery that imposed eligibility criteria that had a cutoff age of six:

> . . . So the provincial government on one hand say we don't actually have to provide ABA therapy for children over the age of six because they are going to go to school and the school system will meet their needs. The school system on the other hand turns around and said, we're not doing ABA therapy. . . . And it's not that they don't believe it works. You know, it's a resource issue.

After experiencing disappointment with self-help groups that refused to take an advocacy position, many participants began independently advocating for their children by fundraising, seeking legal resolutions, and joining informal Internet-based groups. As one participant remarked: "I knew that this was going to be a very, very long-term situation for us and we needed to have this funded as medically necessary services, which is what it is." Participants suggested that self-help groups should place additional focus on advocacy to gain access to behavioral interventions and funds, recommending groups include advocacy in their purpose or mission statements.

The third main theme, *viewing self-help group participation as enabling,* reflects how most participants considered other parents as the best source for learning about autism, illustrated by the participant who said, "I think sharing. Sharing personal stories, information, sharing resources, sharing experiences, all those factors bring about a positive effect." Several parents found sharing social activities with parents and children especially helpful when misunderstood behaviors by their autistic children made them feel judged as deficient in their parenting. Many participants commented that they could not have sustained their sense of self-esteem, empowerment, and motivation over the long term if it were not for the support of other parents. Attributing an improved sense of self-esteem to self-help group participation, one commented: "I probably have a higher self-regard for myself now, self-esteem wise, than I did six years ago."

The fourth main theme, *experiencing ambivalence about group participation,* portrays participants as finding advocacy and self-help participation as overwhelming and stressful. Participants reported that although their children were eligible for government funding, those under the age of 6 often received less than the eligible 2 years of behavioral interventions or no behavioral interventions at all, prior to being removed from a waiting list on their sixth birthday. Although behavioral interventions were available privately, the yearly cost of $50,000-$80,000 prohibited access to the average family. As participants raced to secure behavioral interventions, the following comment describes their frustration:

> . . . 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.

Several participants felt they had gotten "too involved," affecting the family negatively. Advocacy for self-help groups also created conflict with employers. Explaining advocacy with professionals is necessary from nine to five as the only time they are generally available, they risked consequences similar to the following participant:

> I was terminated from my work. . . . For inappropriate use of company phone and e-mail. . . . And I did a lot, a lot of things for autism because I have to admit it's against the company policy, I admit. And I didn't tell my boss about it because I thought I could do it at lunch time . . . they printed out all my calls, incoming, outgoing when they investigated my inappropriate use. . . . I had a special folder at work called AUT. . . . I was on a distribution list of other parent groups fighting for relative IBI [Intensive Behavioral Intervention] therapy to be covered. . . .

Fearing consequences of advocacy, many participants cautioned that ". . . you have to make sure that you just don't become seen as this negative, wailing parent rather than a parent to be appropriately addressed and dealt with." The negative outcomes of stress and disappointment in self-help group advocacy and the fear of reprisals from professionals "for speaking out" contributed to the development of ambivalence about self-help group participation.

The fifth main theme, *appreciating group support, education, and advocacy,* relates to participants' positive experiences with self-help, as evident in the following quotations on receiving information and communication skills:

> So they handed out, you know, copies of certain sections of acts. There's a regulation on ABA [Applied Behavior Analysis] that's really important for anyone who has a special needs child in the school system. These are all things that nobody gives you.

> Last fall when our MPP [Member of Provincial Parliament] announced some more money to autism, the information went out and autism advocates contacted their media contact and by the 6 o'clock news we were downplaying the announcement that had been made at 10 or 11 o'clock in the morning. It really made a strong impact on this announcement that it is not good enough, and here's the pitfalls.

Many participants learned to negotiate respectfully and use their knowledge strategically, striving to employ strategies that offered feasible alternatives.

The sixth main theme, *discovering group practices that need improvement,* highlights the ineffective aspects of self-help groups. Many participants experienced a lack of self-help group advocacy, as illustrated by the following quotation:

> What I found in the groups that I deal with . . . is that the advocacy is not there. That you're one parent in a group doing the best that you can to advocate which will change the situation for your son but results hopefully in a positive for every other child. But what I've seen is next to zero advocacy.

This statement is reflective of many applicants who identified the need to improve the practices of self-help by focusing on advocacy as a group goal.

Among the findings, participants listed increased self-esteem and personal empowerment as positive experiences associated with their involvement in self-help groups. Negative experiences included increased stress associated with decreased time for family and work, and frustrations and disappointments in outcomes. While appreciative of the support, education, and advocacy that their group provided them, most study participants also noted several group practices in need of improvement. Their suggestions for improvement included the use of professional help, enhanced feedback mechanisms, and the development and upholding of a clearer group focus.

DISCUSSION ON AMBIVALENCE
AND ADVOCACY

Gaining Personal Empowerment

Most participants viewed the emotional support they received from the group as the factor that provided them the strength and ability to become a group that experienced and provided support and hope. Participation provided most of them a feeling of "relief" that they were not alone. In the company of people who understood, they enjoyed being social without worrying about the impact of their children's behaviors. In an environment that was understanding, patient, and tolerant, many participants accepted their children's limits as less frightening. They noted how participation in their self-help group allowed them to develop a greater sensitivity toward those who are different. Many participants described how they shared frustration, tears, resources, and laughter with their self-help

group peers. Others expressed that "it's so great to talk to someone who gets it." Validation and "positive affirmation" of their experiences made them feel less "despondent."

From an analytical perspective, most participants experienced self-help groups as therapeutic (Cox, 1991) and as opportunities to develop new perspectives and coping strategies (Bloch, Weinstein, & Seitz, 2005). Parents felt less alone and distressed when they saw that other families also experienced fear, guilt, and family turmoil as a result of the birth of a developmentally disabled child (Bloch et al., 2005). Gitterman and Shulman (2005) described how group members become more resilient as they gain "greater personal, interpersonal, and environmental control over their lives" (p. xiv).

Self-help group members are organized around a common need for help and support in order to address a problem they cannot manage by themselves (Johnson & Johnson, 2003). In this process, self-help groups provide important and powerful aspects that promote self-esteem. Many participants commented that they could not have maintained their sense of self-esteem, empowerment, and motivation over the long-term if not for the support of other parents. The literature also confirms the value of support (Cossom, 2005; Saleebey, 2006). Johnson and Johnson (2003) noted the importance of views of social support to group membership.

Most participants experienced empowerment as an outcome of self-help group participation at both the personal and collective levels (Askheim, 2003; Boehm & Staples, 2004; Linhorst, 2006; Shulman, 1999). Individual empowerment provides the opportunity to achieve a greater sense of self-esteem, self-control, and reduced feelings of guilt and self-blame (Cox, 1991). Parental advocates in this study reflected this experience. Many participants experienced a sense of empowerment, gaining control over their lives and developing a critical understanding of their environment. O'Connor (2002) found that caregivers, aided by a better understanding of services and rights, became enabled "to advocate more effectively for the support they required" (p. 49).

Most of the participants personally experienced increased self-esteem, a sense of purpose, and increased hope for the future. Similarly, Saleebey (2006) identified these results in a strengths-based approach. He explained that "the central dynamic of the strengths perspective is precisely the rousing of hope" (p. 8). Self-help groups provide a strengths-based niche that empowers people to address their own problems in the company of others who have had or are having similar experiences (Heinonen & Spearman, 2066). From a strength perspective, family and community members view themselves as having the strength to face challenges and to develop their own problem-solving skills to deal with misfortune and stress. Based on the principle of self-determination (Heinonen & Spearman, 2006), the strengths approach helps individuals, families, and communities develop a portfolio of coping competencies (Saleebey, 2006).

Experiencing their problems as something larger than a personal issue encouraged participants to develop a greater collective voice. As noted in Shulman (1999), groups can engage "the client (individual, family, group, or community) in developing strengths to personally and politically cope more effectively with those systems that are important to them" (p. 17). Personal empowerment, essential to consciousness-raising, inspired many participants to become collectively empowered. Participants found that the difficulties they faced while trying to influence social institutions benefited collective action as well as individual strengths. Participants viewed collective empowerment as a means to address oppression and to influence external organizations. Their perspective reflects conflict theory. The minority model of self-help groups (Lee, 1999), supported by conflict theory, addresses the need to remove injustice and inequality and includes advocacy as an instrument to change the structures that oppress people (Mullaly, 2002).

Experiencing Ambivalence

In contrast to the positive results noted above, many participants experienced personal stresses which were heightened by their participation in self-help groups. They viewed participation as "a lot of work" that "takes away from family life." Participation in self-help groups was viewed as exacerbating the problems of the lack of time spent with family members, invasive strains associated with in-home behavioral interventions, difficulties faced in working full-time, continuing health problems, and the negative self-images experienced by advocates. Women of both single-parent and two-parent families, who assumed most of the responsibility for child care and self-help group participation, voiced frustrations with upholding group participation. Despite these challenges, many of the participants made self-help group activities, such as advocacy, a priority since they thought it would improve circumstances for their autistic children.

Some participants noted a distinct lack of advocacy work in self-help groups that received funding from government sources. These participants explained how they had been unsuccessful in getting advocacy letters from self-help groups because, as charitable organizations, registered self-help groups faced governmental limits on advocacy. Many participants experienced disappointment with self-help group leaders who expressed caution about advocacy since they feared funding cuts. Revenue Canada restricts the advocacy activities that registered charitable organizations can participate in (Canada Revenue Agency [CRA], 2003). Revenue Canada does allow charitable organizations with an income of less than $50,000 to devote up to 20% of their resources to political activities in a given year. However, participants believed that these checks limited the role of advocacy for self-help groups. Many participants assumed that such policies severely restricted the support for legal efforts to promote social action for behavioral interventions for their children.

Participants met limits to their sense of empowerment when they made efforts to affect social change. Ambivalence about self-help group membership surfaced when attempts at having the group advocate for social change failed. Thus, participants experienced incongruence between what they thought self-help groups should do and what they were doing.

Participants who felt empowered signaled that they wanted to act collectively as well as personally. These participants displayed resilience consistent with a strengths-based model, but had little opportunity to aim for political advocacy (Heinonen & Spearman, 2006). Although Saleebey (2006) has noted that strengths-based practice can address social and political obstacles, he does not aim for resolutions through policy advocacy (Jansson, 2003). While participants valued developing personal empowerment, they also voiced the need for an approach that focused on collective empowerment. Many became ambivalent about their participation in the self-help group when they felt their participation became incongruent with their interests (Wituk, Tiemeyer, Commer, Warren, & Meissen, 2003). The incongruence between individual and group goals resulted in frustration and an eventual decline in self-help group participation among some of the members. This situation created an increased burden and risk of burnout for those who remained, and set the tone ultimately for the possible dissolution of the self-help group.

The literature suggests that the term "empowerment" is problematic because it represents the value of individualism and the belief one can change one's environment (Adams, 2003). As noted by Adams, if participants do not achieve individual and collective goals, they can experience disappointment and develop ambivalence about group membership. The findings of this study reaffirm the impact of support on empowerment, and how ambivalence can develop as a result of disappointing outcomes and incongruent personal and group goals.

Avoiding Disempowerment

So far, the literature has provided limited insight regarding the outcomes of negative experiences on self-help group participation. Identifying the negative experiences of parental advocates in this study has provided the opportunity to analyze some of the difficulties faced by those participating in self-help groups. The participants pointed out that the positive results of self-help group involvement can be put at risk unless a greater understanding is arrived at regarding the negative experiences. The negative experiences included incongruence between individual and group goals, a lack of focus on advocacy, and a lack of professional involvement. Outcomes of negative experiences resulted in the risk of decreased participation, dropout, overworked members, and burnout.

Developing Strategies While Preserving Focus

Knowledge about the motivations for starting a self-help group, identification of needed tasks, and sources of frustration are all crucial factors in avoiding negative outcomes in self-help groups (Wituk et al., 2003). Participant experiences provided the insight that self-help groups need to use leadership in resolving basic group issues. As helpful strategies, most participants stressed the development of conflict resolution skills in communicating and negotiating with government, and motivational leadership skills to help preserve enthusiasm and participation. They also suggested the creation of online, Internet-based self-help groups which complemented their commitment (Mesec & Mesec, 2004) but which did not exercise limits on advocacy. Another strategy included upholding membership in several groups.

Self-help group participants displayed resilience when coming up against negative experiences. In line with resiliency strategies found in the literature, the surveyed participants searched for strategies which involved working with the community at large (Jurkowski et al., 2002). Wharf and McKenzie (2004) noted the need for collaboration; the study participants also cited collaboration as being important. Participants suggested that meeting the needs of their children was so challenging that they needed to form alliances with community agencies.

While the successful self-help group evolves around a common cause, members of self-help groups also need to address the individual needs of their members. There is a concern that if self-help groups fail to address individual needs, a certain number of their members will remain preoccupied with their own needs. Preserving group goals requires addressing individual goals while remaining focused on group goals.

Upholding Empowerment

To avoid undermining confidence and self-esteem and disempowering parental advocates, self-help group members need training (Bloch et al., 2005). However, empowerment should not simply consist of consciousness-raising therapy that places vulnerable participants at risk for disempowerment. Participants needed opportunities to promote collective as well as personal goals. If participants do not achieve both individual and collective goals, they experience disappointment and develop ambivalence (Adams, 2003). Their efforts to create change, collectively as well as personally, displayed resilience consistent with a strengths-based model. However, they had little opportunity to aim for political advocacy.

While participants valued personal empowerment, they also voiced the need for an approach that focused on collective empowerment (Jansson, 2003). This is difficult for some professionals who, as gatekeepers, feel they are not in a position to give clients power (Adams, 2063). 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. Avoiding disempowerment

would involve an anti-oppressive approach (Mullaly, 2002), a continuous reformulation of goals, and an understanding that the perfect goal may not be attainable.

Holosko, Leslie, and Cassano (2001) suggest that another way of avoiding disempowerment is to provide regular feedback to service users at all levels of the organization. They stressed that success depended on knowledge and skills in developing partnerships and collaboration between service users and human service organizations. Others suggested creating community initiatives by having professionals join with vulnerable populations in mutual aid organizations with the intent of developing community initiatives (Wharf & McKenzie, 2004). Upholding empowerment while influencing social policy requires that all collaborative parties maintain a common and clear understanding of collaboration (Claiborne & Lawson, 2005).

Developing Relationships with Professionals

In identifying the need for professional help, many participants in this study reflected the desire for flexible and complementary relationships with professionals (Ben-Ari, 2002). The creation of flexible and mutually beneficial relationships between professionals and self-help group members would provide opportunities for integrating knowledge and experience. Putting this vision into practice would allow professionals to move in and out when needed (Sherraden, Slosar, & Sherraden, 2002). Wituk, Tiemeyer, Commer, Warren, and Meissen (2003) recommended that self-help groups continue to be managed by members, but that they should be able to access the support that professionals can provide. Adams (2003) has suggested the role of facilitator as being the most appropriate role for professionals to take on when working collectively with clients. As consultants, professionals can work collaboratively with self-help groups in forming strategic alliances without assuming a directive role (Cossom, 2005). In addition to the necessity of creating community initiatives, participants identified professional involvement as being essential in policy advocacy training (Jansson, 2003).

Encouraging Advocacy

Adams (2003) viewed both the self-help group itself and self-help group advocacy as forms of empowerment. Self-help groups need to focus on advocacy in helping members become knowledgeable about social policies and skillful at policy advocacy. Advocacy, as a strategy, helps clients gain needed interventions and it also helps them change social policies that negatively affect them. In the process, the advocate promotes fair and equitable practices.

Research shows that self-advocacy skills are essential to improving the quality of life for people with disabilities and their families. As well as protecting clients against abuse and violations of their rights, advocacy groups are important in gaining access to healthcare. Jurkowski, Jovanovic, and Rowitz (2002) found that family advocates who took part in self-help groups were nearly 11 times more likely to receive the interventions they need.

Without support from self-help groups and professionals, families managing children with disabilities may continue to experience marginalization. Advocacy is also essential to preventing continuing abuse or re-institutionalization of those who have been classified with disabilities. Existing programs such as Partners in Policy Making (2008) train people with disabilities and their families to self-advocate. This training includes learning to collaborate with service providers as well as educating themselves about disability issues and personal difficulties. On a collective level, applying advocacy to problems is consistent with conflict theory. It connects self-help groups and professionals with socioeconomic and political environments that promote and cause oppression (Mullaly, 2002). For example, in this study, promoting recommendations that Revenue Canada adjust its controls on advocacy for self-help groups (Wharf & McKenzie, 2004) would help avoid further loss of self-help group members to groups that encourage advocacy.

IMPLICATIONS FOR PROFESSIONALS

Self-help group members looked to professionals to help them navigate the social welfare system. In addition to the self-help group's therapeutic role, participants need support in learning how to speak for change, both individually and collectively. To be effective, professionals need greater knowledge of developmental disabilities, empowerment and disempowerment processes, organizational and leadership skills, and policy advocacy. In addition, professionals must be familiar with social policies and policy advocacy in order to incorporate findings from research (Jansson, 2003). Preparation allows the professional worker to identify and document the need for policy changes, to aid parents in gaining services, and to promote new policies and legislation. In conclusion, to help empower others, professionals need to encourage practice based on values, leadership, and policy advocacy.

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