



Promoting Professional Involvement in the Development and Maintenance of Support Groups for Persons with Autism

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Introduction

Autism is one of the most common of the severe developmental disorders. An autistic person is identified as a person who has problems with communication, exhibits repetitive, stereotyped patterns of behavior and engages in imaginative play (American Psychiatric Association, 2000). The autistic spectrum is comprised of persons with high-functioning autism (IQ of 85 or above), medium functioning autism (IQ of 55-84), and low functioning autism (IQ of 54 or below; Baron-Cohen, 2006). Persons with autism fall within a continuum of mild to severe, and in 70% of cases they also have concurrent mental retardation (Fombonne, 2003). They often also have anxiety and depressive symptoms (Sterling, Dawson, Estes, & Greenson, 2008). Current estimates of autism suggest that autism has a prevalence rate of 60/10,000 individuals (Chakrabarti & Fombonne, 2005). In Ontario there are approximately 70,000 people with autism, with over 50,000 of them being aged 20 and over (Autism and Developmental Disabilities Monitoring Network Surveillance [ADDMNS], 2002).

Despite the prevalence of autism, both persons with autism and parents of individuals with autism agree that isolation is one of their greatest challenges and that acceptance by others is a primary solution (Muller, Schuler, & Yates, 2008). Interventions often operate out of a medical model which aims to make persons with disability as 'typical' as possible. Operating out of a social model which emphasizes acceptance and social support may be more beneficial (Carter, 2009). Social support groups, particularly those designed by those participating and which focus on acceptance, may provide the opportunity for em-

powerment and social interaction (Saleeby, 2009), both of which are fundamental in reducing isolation.

This study examines the responses of ten individuals with autism and their families who responded to a request for an interview, particularly around their present needs for group activity, as well as their past experiences with social support and support groups for autism. Participants claimed they experienced greater levels of social support in groups that included activities which provided social and life skills training, promoted confidence, and developed inclusion and professional assistance. The findings provide insight into the needs of participants in support groups for autism. They are discussed in light of the literature and in terms of implication for professional practice.

Literature Review

Identified Challenges for Persons with Autism

Identified challenges for persons with autism include difficulty with social interactions and isolation. According to a study by Orsmond, Krauss, and Seltzer (2004), 74.5% of adults with autism had weekly routines of either exercise or walking, 38.5% participated in weekly recreational activities, 22.6% participated in weekly socializing activities with relatives, and 20.9% spent time with friends on a weekly basis. Only 8% of adults with autism had social friendships with same-aged peers. These rates are significantly lower in comparison to the general population. Life skills and daily functioning are often impacted by difficulty integrating information and applying meaning to stimuli. Persons with autism

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often find it challenging to adjust to varying circumstances (Berger, Aerts, Van Spanendonck, Cools, & Teunisse, 2007). Adolescents and young adults with autism disorders (ASD) often experience vocational failure (Hillier, Fish, Cloppert, & Beversdorf, 2007). Even for adults with autism who have good cognitive and communication skills, and who have the ability to live independently, marry, and find employment, outcomes are varied (Howlin, 2000).

The support group consists of “a structured ongoing series of meetings among people who share a common problem and who will give advice, encouragement, information and emotional sustenance” (Barker, 2003, p. 121). The support group addresses the challenges faced by the participants by increasing a sense of community as well as members’ social competence and by providing members opportunities to help, share and support others (Howlin & Yates, 1999; Mishna & Muskat, 2004). This can result in positive changes in attitudes, self-esteem and behavior for members (Kessel, Merrick, Kedem, Borovsky, & Carmeli (2002). Support groups are different from self-help groups in that self-help groups aim to affect change by engaging in changing social policies, while support groups are usually sponsored by a larger organization and offer emotional support and education with professional assistance (Schopler & Galinsky, 1995).

Defining Nature of Social Support

Depending on the nature of their disability, people with autism need varying amounts of social support, the assistance an individual receives from others (Findler, 2000). Social support is defined as “formal and informal activities and relationships that provide for the needs of humans in their efforts to live in society” (Barker, 2003, p. 407). Two broad categories of social support include 1) formal versus informal and 2) structural/support networks and functions (Findler, 2000; Glidden & Schoolcraft, 2007). Formal support comes from professionals such as teachers, social workers, physicians, or agencies (Findler, Glidden, & Schoolcraft), and is provided through an array of public and private agencies. Support

from immediate or extended family, relatives, friends, neighbors, other parents of children with disabilities, religious organizations, or social clubs are all considered mechanisms for informal support (Dunst, Trivette, & Cross, 1988).

Existing and perceived formal and informal support. Families report low perceived social support; they worry about acceptance, access to interventions, social and life skills, and social isolation (Carter, 2009). Families seeking support for individuals with autism find that the support individuals with autism received as children is not as available to them as adults. In Ontario, formal supports are often limited to individuals with IQs below 70, thus excluding many individuals with autism who do not display an intellectual disability (Autism Ontario, 2008). Limited access to services has resulted in families believing that service delivery is too crisis-driven, and that service agencies provide inadequate levels of service (Hastings & Johnson, 2001). Most people with autism live either with family or in assisted living arrangements, and informal support is largely provided by family members.

Examples of Support Group Strategies and Outcomes

Support groups can mitigate the apparent gap between needed support and received support. Mishna and Muskat (2004) created a group which met for about two and a half hours a month for a year to problem-solve real difficulties faced by the group’s members. Interventions concentrated on developing specific skills and reducing inappropriate behaviors. They used role-plays, the teaching of skills, and teaching strategies for what to do in an emergency situation, such as a fire. To help teach social rules, they used social stories (Gray, 2000) as well as conversational strategies. Social rules have also been taught through peer-mediated approaches and the teaching of rules within a social context (Moore, 2005; Weidle, Bolme, & Hoeyland, 2006). Jerome, Frantino, and Sturmey (2007) encouraged the teaching of “age-appropriate leisure skills” such as accessing games and music on the Internet, requiring facili-

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tators to have an understanding of specialized interventions such as Treatment and Education of Autistic and Related Communications Handicapped Children [TEACCH] (Van Bourgondien & Schopler, 1996).

Eskow and Fisher (2004) proposed that interaction between students with disabilities and students without disabilities fostered social acceptance. They described an arrangement where a group of individuals with severe disabilities who sought opportunities for social inclusion were paired with undergraduate and graduate students to work together on on-campus activities. This matching promoted problem-based learning experiences and resulted in positive outcomes.

In their study of 44 adults with autism, Garcia-Villamizar and Hughes (2007) found that accommodation in the work environment through vocational rehabilitation programs impacted positively on the self-esteem and cognitive performance of persons with autism. Supported employment is “a supportive approach to hiring and retaining people with developmental disabilities” (Garcia-Villamizar & Hughes, p.143). Job coaches who provide training and support, along with simulation training, can be employed to create a successful work environment for both the employee with autism and for their employer (Lattimore, 2006).

Challenges to Creating Effective Support Groups

In the implementation of these strategies and the creation of effective support groups in general, common challenges which arise include anxiety and communication. A study by Gillott and Standen (2007) compared 34 adults with autism with 20 adults with intellectual disabilities, utilizing informant-based measures of anxiety and stress. They reported that adults with autism were almost three times more anxious than the comparison group and gained significantly higher scores on the anxiety subscales of panic and agoraphobia, separation anxiety, obsessive-compulsive disorder, and generalized anxiety disorder. Anxiety may impact the level of safety felt by members

in the group.

Difficulty in communication patterns, particularly the interpretation of social cues and norms, can be exacerbated by anxiety (Jordon, 2010). Implementing a specific teaching program such as the Treatment and Education of Autistic and Related Communications Handicapped Children (TEACCH) may be beneficial in promoting communication efforts (Schopler & Reichler, 1978). TEACCH is particularly valuable because of its focus on structured teaching, communication training, leisure and social skill development, and stress reduction programs (Van Bourgondien & Schopler, 1996). TEACCH provides training on functional skills and is adaptable to low and high functioning individuals. By emphasizing visual skills and creating predictability in the world, the environment is structured to align with the autistic individual’s strengths and challenges, in the process reducing anxiety. Employing TEACCH is often challenging due to the lack of training group facilitators may have.

Another major challenge in the development of support groups is lack of clarity about the needs of individuals with autism separate from their families (Howlin & Yates, 1999; Jerome, Frantino, & Sturmey, 2007; Shaw, 2001). Given that the needs for support are complex and varied, but that support groups are beneficial, there is need for service from the perspective of those with autism. This study attempts to address these gaps by posing the following question: “What support group functions do adults with autism and their families find most useful?” It aims to gain a better understanding of the factors which motivate persons with autism to participate in support groups, and the role that support groups can play in their lives. In understanding specific needs, the roles of professional facilitators may become more solidified.

Methods

The main research question to be examined is “What self-help group functions do adults with autism and their families find most useful?” The researcher aims to find out what caused partici-

pants to engage in self-help group participation and what roles of self-help participants think the most important. Thus, this qualitative study explores the benefits and challenges of self-help group participation as identified by the participants. The researcher also seeks to gain suggestions from participants on what factors contributed negatively, as well as positively, to the degree of their participation in self-help groups. The researchers used the accepted procedures and techniques found in qualitative research (Bryman, 2004), aiming to understand the participants' experience from their perspective (Holosko, 2010). Thus, the design of the study is qualitative, and the focus is to gain an emic perspective of the lived experiences of persons with autism in support groups. The research was approved by the University of Windsor Research Ethics Board.

Recruitment

All ten participants lived in metropolitan Windsor, Ontario, Canada and were recruited using purposive sampling by advertising the research in a letter to the membership of a support group that serves persons with autism with a year-long, eight-week summer day program. A letter of information about consent accompanied the letter. The letter advised interested readers to contact the researcher directly to arrange an interview. Snowball sampling was utilized as a secondary strategy and involved asking each subject to share the recruitment letter with anyone they thought might be interested in taking part in the research. Thus, contacts made initially through purposive sampling led to other participants through snowball sampling. The participants received a small honorarium of \$20.00 to help to compensate for the time spent in the interview.

Participants

The sample includes 10 persons with autism and their parents in the metropolitan Windsor and Essex County, Ontario, who are enrolled in support groups. Windsor is south of the city of Detroit and across the Detroit River from Detroit, Michigan, and has a population of 210, 891

(Statistics Canada, 2011). The population of Windsor Census Metropolitan Area (CMA), which includes the towns of Tecumseh and LaSalle, as well as parts of Lakeshore, Essex, and Amherstburg, is 319, 246 (Statistics Canada, 2011).

Participants with autism reported their ages as 17, 18, 19, 21, 29, 30, 39, and 50. Three participants stated their age as being 18. Six participants had a diagnosis of high-functioning autism while four individuals needed significant levels of support. Five individuals currently attended high school, one participant attended middle school, one participant had attended high school in the past, and one participant had never attended school outside an institution. One participant had completed high school and entered college, but dropped out due to the level of stress he experienced, and one participant was attending university. Eight were male and two were female. One individual had immigrated to Canada from Asia and all other participants were Canadian Caucasians. Two participants lived alone, four lived in two-parent households and four lived with their mothers. Five of the participants had their mothers present during the interview, three participants had their mother and father present, one participant had his mother, father, and siblings present, and one participant chose to have their support worker present during the interview.

All participants had an income of \$20,000 or less. Two participants worked part time, while one worked full-time. One individual who was employed full time and living with his mother received no formal support. Two participants who lived alone received formal supports to help with the activities of daily living. All participants or their parents had participated in support and self-help groups.

Data Collection and Analysis Procedures

Data collection procedures included a 90 minute semi-structured interview centered on the following research question "What self-help group functions do adults with autism and their families find most useful?" Other questions included in the Interview Guide which branch from

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the main research question are the following:

- How has autism affected you?
- Why did you become involved with a support group?
- What experiences have you had as a participant in support groups?
- What are the positive effects for individuals involved in support groups?
- What are the negative effects for individuals involved in support groups?
- What experiences do you think contribute to positive effects in support groups?
- What experiences do you think contribute to negative effects in support groups?

In this study, “persons with autism” refers to adolescents or adults who have historically received support from support groups, and who have been diagnosed with autism. “Parents” in this study refers to those who speak on behalf of, or support, persons with autism. “Support groups” refer to groups that address particular challenges associated with the need for support and education and which usually have access to professional assistance.

Nine interviews took place at the participants’ residences. One participant requested that the interview take place in the researcher’s office. Six of the participants spoke on their own behalf and were able to understand and answer the interview questions independently. Although parents and other family members were present during most of the interviews, these individuals with autism responded to the questions independently. Four of the participants were unable to comprehend the interview process or to speak on their own behalf. In each of these cases, parents spoke on their behalf. The implication of having some parents speak on behalf of persons with autism is discussed later in the analysis of the findings.

All interviews were audio-taped. Atlas-ti software was used during the coding process. Several participants who responded to a distribution of the findings helped to support the trustworthiness of the study. Further, independent coding of the first interview, by both the researcher and an as-

sistant researcher, produced similar perspectives and so improved the credibility of the research. Interviews were transcribed after completion. Codes and categories created through the process of coding provided insight into the shaping and development of themes and sub-themes. The research was approved by the Research Ethics Board, University of Windsor.

Findings

An analysis of the responses to the research questions produced twenty-three categories of codes and six main themes. As a framework of results the following main themes and categories were generated:

Theme 1: Experiences with Autism

- C1: Diagnosis
- C2: Experiences with Professionals
- C3: Negative Social Experiences

Theme 2: Experiences with Social Support

- C4: History of Institutionalization
- C5: Public School Experiences
- C6: Aging Out
- C7: Formal Supports
- C8: Activities with Support Worker
- C9: Activities with Family
- C10: Parental Concerns

Theme 3: Support Group Activity

- C11: Support Group Involvement
- C12: Recreational Support Groups
- C13: Structured Workshop
- C14: Experiences with Work-Related Group Activity

Theme 4: Parent-Related Support Group Activity

- C15: Initial Parental Self-Help Groups
- C16: Reinventing Parental Self-Help Groups
- C17: Parent Groups and Persons with Autism

Theme 5: Support Groups Based on Skill Acquisition

- C18: Needing Additional Life and Social Skills
- C19: Recommending Professional Skills

Theme 6: Using Support Groups to Enhance Relationships with Others

- C20: Communication Needs
- C21: Enjoyable Social Activities
- C22: Aiming for Friendships
- C23: Seeking Greater Involvement

In Theme 1: Experiences with Autism, participants recalled their previous experiences with autism. Many participants and parents expressed frustration at the process of arriving at a diagnosis. They complained that professionals often appeared unaware of the symptoms associated with autism with comments such as, “We went to the doctor and the doctor just kind of said, well he’s a boy, he is ok.” Some participants described childhood incidences of bigotry that had affected their self-esteem. As one participant remarked, “My life was kind of cruel or something, I was being picked on at school a lot... well, being called retarded and threatened to be beaten up.” Bullying in school was a common problem for most participants, and many parents reacted by focusing on the need to protect their children with autism. Both parents and individuals with autism considered bullying events resulted from the lack of opportunities for public education to make public aware of the symptoms of autism.

In Theme 2: Experiences with Social Support, participants expressed both positive and negative experiences with regard to institutions and public schools. One participant who lived in an institution until he reached adulthood, and another participant who lived in an institution for a few months during his adolescence, related their discontent with institutional living. However, the former missed the social activities offered in an institution, expressing appreciation for the skills

learned and the friends acquired in an institutional setting. One participant remarked on their public school experience by explaining, “I felt so stress... like I felt so sick all the time. I was so stressed that my heart felt like it was going to crush itself and explode at the same time.” Despite their misgivings with regard to school, most participants enjoyed the social activities high school had offered them and which were no longer available to them once they left high school. Both persons with autism and their parents expressed concerns regarding the “aging out” of programs as children graduated from secondary schools.

Seven persons with autism received respite services provided by support workers, expressing that respite “gives us a break.” Parents spoke favorably of respite services made possible by government funding. Generally, participants received approximately 10 hours a week of respite which involved the services of a support worker, although two of the participants received considerably more respite due to extenuating circumstances. Several persons with autism enjoyed the activities they engaged in with the support worker. These included such things as shopping, walking, eating out, swimming, singing and dancing, and other recreational activities. However, although grateful for the much needed service, some parents expressed disappointment that support workers lacked the ability to provide skills training while engaging the participant in social activities. As one parent expressed, “They can take him out to the mall, but that’s not really teaching him social skills.” Persons with autism also appreciated parents, siblings, and extended family members who provided social support in the form of activities such as eating out, going for a coffee, attending church, shopping, fishing, golfing, playing computer games, watching television, playing music, and horseback riding. Most parents expressed that their children had a variety of needs for social support and suggested that their children’s needs were based on their level of functioning and particular interests.

Most parents viewed themselves as the greatest support for the participant with autism. Alt-

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though grateful for respite services and social activities made possible by support workers and family, parents especially expressed concern regarding their autistic children's options once they grew older and they were no longer able to provide the required support their son or daughter with autism needed. As one parent anxiously expressed, "What happens when we get old and when we die, and our children are not self-sufficient...what options are out there?"

In Theme 3: Support Group Activity, participants noted their experiences with groups that provided support. Support groups offered one of the most important forms of social support for persons with autism and their families. Most of the participants and their parents benefited from a yearly day program, offered for eight weeks each summer. Once admitted to the support program, children were entitled to remain within it until their 21st birthday. This summer support group for children with autism was highly appreciated by parents who placed particular value on the social and skill training their children received through professional involvement. One parent described the program as providing a "wonderful [option], because for the simple fact is, they [professionals] appear more educated, more understanding, more loving." Participants over the age of twenty-one who had formerly attended an eight week support program during the months of July and August were no longer eligible to participate in the group due to their age.

Several of the higher functioning participants with autism also joined recreational support groups where they engaged in such social activities such as physical fitness, swimming, walking, rock climbing, music, and bowling. These support groups were made up of members with various disabilities and their aim was to increase social activity and friendships in an inclusive environment within the context of a 10 to 16 week program. Participants had a group leader and were encouraged to try new activities; however, some of the higher functioning individuals were also critical of these groups. As one participant observed, "It was a lot of repetition with kind of the same thing over and over."

Two of the participants took part in structured support group workshop environments after high school. In both cases, the participants dropped out. As one participant stated, "I did not like it there. Quit the job. I was not happy there." One of these individuals subsequently secured several positions working in restaurants and grocery stores. He expressed satisfaction about working with colleagues who included him in social activities such as birthday parties and other celebrations or socializing opportunities, such as going for a coffee. Two persons with autism secured part time volunteer work experience by exposure to helpful members of their parents' support group.

In Theme 4: Parent-Related Support Group Activity, parents spoke about their initial experiences in self-help groups where they managed without professional leaders. They indicated that 20 to 30 years ago "back then the professionals didn't know any more than we did because they were just learning too...the literature that did exist at that time suggested it was caused by refrigerator mothers." At the time they believed that professionals knew no more than they did regarding autism. Reinventing the role played by their self-help group, parents formed other support groups that focused on the needs of their children. In one instance, several of the participants' parents split from their original self-help group to form another group that specifically explored the challenges faced by persons with high-functioning autism. In another exceptional case, several of the participants' parents joined another group of parents in creating a second parental self-help group. This group concentrated on fundraising and establishing support programs for their children. They created an eight week summer-based support group for their children which engaged professionals and trained students from a disability-related college program. While this group originated as a self-help group for parents, it also became a support group for their autistic children.

The categories in Theme 5: Support Groups Based on Skill Acquisition, outlines the services perceived by parents to be needed by persons

with autism. These include additional life and social skills, and the help of professionals who are expert in implementing behavior-changing interventions. Parents indicated that their children needed to learn “how to interact, and to take criticism, and how to share and how to be tactful, and courteous, and dependable.” Additionally, for high functioning participants, parents suggested “social skills are needed in employment.”

In Theme 6, *Using Support Groups to Enhance Relationships with Others*, a few participants with autism agreed with their parents regarding the benefits of social skills training when it enabled them to enhance their communication with others. However, in other cases, the focus of participants with autism clearly differed from that of their parents. Although persons with autism agreed that training in social skills acquisition would provide enhanced abilities with regard to communication, they aimed for something deeper than activities by hoping support group activity would primarily provide them opportunities to make friends. Participants stated that they found it difficult to meet prospects or to join group activities where they would be most likely to meet potential friends. One participant spoke of the difficulty in “finding somebody who’s like you but not too different from you.” With regard to the development of helpful and constructive support groups, both participants and parents suggested that account should be taken to ensure that social support provided by trained staff be meaningful.

Experiences with Social Support

Participants’ experiences with social support focused on the varying influences of the family, institutionalization, school and work experiences, and isolation. Participants indicated the need for greater levels of social support through the development of support groups that promote friendships, confidence, and acceptance as well as provide social and life skills training.

Influence of family. Eight participants experienced a significant level of family involvement in their daily support. Even for those living inde-

pendently, support from family members was important even if they received significant support from a public agency. In addition to providing support, families also played an important role in advocating for services. Most families and individuals expressed concerns about “aging out.” This phrase refers to the age of ineligibility, where at age 21 individuals with autism no longer qualified for funding for school and supportive community programs. For example, at the age of 21, most participants experienced exclusion from school and summer programs, their only sources of socialization other than through the receipt of formal services. As they aged, parents worried about their children’s futures and expressed concern about the availability of formal supports and the absence of informal supports and friendships.

Effects of institutionalization, school and work experiences. One participant had previously lived in an institution from age 7 to 19, and another had stayed in an institution for a few months during adolescence. Although they mentioned missing friends - both among staff and residents - that they had made there, the bulk of their memories consisted of negative experiences with institutional living, and they eventually returned to live with their parents. With the recent closure of residential institutions, daily support for individuals with autism rests largely with the family from birth to death. Today, most family members anticipate that their autistic offspring will remain in the family home indefinitely, but concerns arise regarding their adult offspring’s care when the parents are no longer be able to provide it themselves.

All participants, with the exception of the participant who was institutionalized at age seven, had attended public school. Most participants relayed negative stories about school, focusing on the lack of professional programs and staff. Participants recalled negative school experiences of bullying and exclusion by other children and sometimes staff. Following graduation from school, three of the participants attended sheltered workshops. None of the three participants worked in sheltered workshops presently, expressing a

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dislike of workshops. One individual had found satisfactory employment at a grocery store, two found employment cleaning offices with voluntary agencies and working in the entertainment industry, while one experienced university as being a positive and interesting experience. Despite some satisfaction with school and employment experiences, most participants expressed the continuing need to address issues surrounding stigmatization in the school and work environment.

Distinguishing Self-Help Groups from Support Groups

Most of the participants' parents joined self-help groups when their children were first diagnosed. They sought an explanation for autism, indicating that they soon realized that available professionals knew no more than they did. They were also drawn to self-help groups when their interest extended to political action. In particular, self-help groups offered information, support, and solutions to identified problems, empowering their membership in the process. Often, both parents and children benefited from parental membership in self-help groups, as family-orientated social events were structured to accommodate autistic children.

Most persons with autism in this study participated in the support group created by their parents for eight weeks each summer for several years until the cut-off age of 21. The group offered respite to parents and structured activities of a recreational and social nature for their autistic children. As reported by the participants with autism and their parents, the eight week summer support groups provided one-on-one assistance. The one-on-one assistants were largely students from a nearby university and college who were trained and supervised by full time professionals. As the children aged, many of them branched out to participation in other social support group activity with varying levels of structure.

Differences and Similarities Between Needs Stated by Participants and Parents

Participants with autism and their parents often differed on their thoughts regarding the benefits of support groups for persons with autism. The benefits of social skills training were particularly stressed by parents when they spoke on behalf of their children with autism. Parents commonly recommended support groups provide competent facilitator-led training in social and life skills, accommodation, assessment, and evaluation. In contrast, persons with autism who spoke on their own behalf stressed the importance of creating opportunities to make friends and becoming socially involved at a greater level as the primary benefits of support groups.

Both parents who spoke on behalf of their children and participants who responded independently hoped that support group activity would provide opportunities for social interaction, thereby easing the social isolation experienced by persons with autism. Most participants and their families worried about the effects of isolation on the lives of people with autism and their family members. As participants often lacked opportunities for social support, such intervention allowed for a positive alternative, providing acceptance and possibilities for sharing with and helping others. Although support group intervention may not be suitable for all individuals, for those who struggle with socialization, self-esteem, or a sense of competence, support groups present a useful intervention.

The findings of this study outline the past and present experiences of social support for youth and adults with autism, including their experiences with support groups. The participants described the challenges they faced and obstacles they encountered in seeking support, indicating that support groups presented an opportunity to ease their isolation and make friends. The implications regarding the variety of needs which were expressed by the participants and their parents, including the need for experienced staff to develop meaningful social involvement, is explored further in the following discussion.

Limitations and Future Direction

Limitations of this study include the small geographic area and the small sample size and the variation in the functioning capacity of the individuals with autism who participated. Moreover, as a qualitative study to gain specific information, it did not represent either the views of all participants in self-help groups or those of professionals who provide interventions and services for autism. Another limitation of the study is the lack of diversity in participants' cultural and educational backgrounds and the limited number of years of experiences with support groups that participants had.

Future studies on the benefits of support groups for persons with autism need to include larger populations of persons with autism, and concentrate on the experiences of specific groups, as well as increase representativeness by employing a variety of different recruitment strategies. A quantitative approach using a survey or structured interviews with a few open questions for specific populations would be appropriate. Future studies on the differences between low and high functioning ASD in support groups would be beneficial to integrate into research designs to provide further insight regarding professional training for group social workers.

Professional Implications

This study was based on the underlying theoretical assumption that persons that do not have support group experience have difficulty steering through the social world, but with group experience their situations may improve (Lang, 2004). The study implies that there is a need for professional training of group workers in working with persons with autism, with respect to providing a more meaningful social involvement. Part of this training would involve the development of assessment skills in differentiating the needs of persons with autism at varying levels of functioning from needs determined by parents on behalf of their autistic children. Although some research indicates that family members should have sub-

stantial input regarding the needs of persons with autism (Howlin & Yates, 1999), individuals with autism who depend on their parents to communicate for them may have their independent thinking processes stifled if there is incongruence between what they wanted to say and what was stated by their parents (Carter & Wilson, 2011). A skilled group worker would apply the core value of "respect for persons and their autonomy" listed in the Association for the Advancement of Social Work with Groups (AASWG) Standards (2006, p. 2).

The movement from structured environments into more flexible ones not only may provide meaningful social interaction but also provide opportunities for the practice of autonomy. The tendency to be in structured environments (Buys & Tedman-Jones, 2004) and prevailing family and societal attitudes significantly impact the availability of options for autonomy for persons with disabilities (Kelm, 2009). Low expectations in regard to achieving social goals such as getting married or working can have a disempowering effect (Kelm, 2009). Therefore, group workers must always be conscious of how the group and interventions may be influencing sense of autonomy of individual members as well as the comfort level or desires of members to express their autonomy. Social workers must be conscious of the ethical element "maximizing member choice and minimizing coercive processes by members or worker to the extent possible" (AASWG Standards, 2006, p. 17). This is particularly relevant in light of the concern that as persons with autism age, the amount of formal support decreases, a concern stated by participants of the study. When parents are unable to provide support, persons with autism may not have the developed skills needed to enter different living circumstances (Buys & Tedman-Jones, 2004). The common tension between promoting autonomy and ensuring safety and protection for persons with disabilities (Malin & Wilmot, 2000) must be navigated carefully by social workers.

In using group approaches in the community it would be important to consider the effect of stigma, which participants in the study identified. Consciousness-raising may be effective to use in

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the group to buffer against stigmatization in the real world. It may also be helpful to consider where each autistic individual exists on the spectrum and gear support group intervention in an individualized manner (Renty & Roeyers, 2006) while still remaining conscious of the overall group goal. The heterogeneity and the levels of anxiety group members experience in relation to differences or in general (Gillot & Standen, 2007) are important to factor in as they may influence safety in expressing autonomy.

Social workers should also identify the need for opportunities for persons with varying degrees of autism to intermingle socially with non-autistic peers in order to improve their social functioning (Moore, 2005; Weidle, Bolme, & Hoeyland, 2006). Most participants expressed hope that support groups would provide both segregated and inclusive peer-related activities, depending on the members' needs. Participants felt that coming together with individuals who had similar needs served as an opportunity to address common needs. However, participants also appreciated the importance of providing individuals with autism opportunities for engaging in activities with non-autistic peers. Effective group social workers should be skilled in generating cohesion, which includes the ability to use discussion and activities to encourage interaction, full participation and reward of members, the ability to guide members in developing a sense of pride of the group and sense of identity in members, and the ability to create bonds (Toseland & Rivas, 2009).

Group structures at school and work environments promote meaningful social interaction and increase self-esteem (Garcia-Villamizar & Hughes, 2007). As many participants had positive experiences with work, peer-mediated activities and simulation training in the group could be used to enhance supportive, inclusionary opportunities in school and work (Lattimore, Parsons, & Reid (2006). One challenge may be the stratification which starts happening in groups when those with hidden disabilities are reluctant to disclose the nature of their disability; groups may become closed and some members unwelcoming to others (Corrigan, Jones, & McWhirter, 2001). Given that

the primary needs of participants in the study are friendship and companionship, and Weidle, Bolme, & Hoeyland's (2006) suggestion of self-acceptance as a realistic single group goal, effective group social workers should carefully guide group members through the above dynamics in a way which is inclusive for all.

Conclusion

This particular study on the needs of adults with autism espoused setting up a generalized group support as the key to developing a sense of belonging. Participants longed for experiences of developing personal connections and friendships to help them cope with daily frustrations and counteract the negative effects of stigmatization. Both parents and participants hoped that support groups would lead to greater acceptance in social environments. As implied in this study autistic individuals may have complex needs; hence there are a number of areas to be further explored. This implies the need for more professional development training for group workers working with autistic individuals. Consistent with the literature, participants themselves suggested support groups engage facilitators who are informed about the needs of individuals with autism and the functions of support groups (Peckham, Howlett, & Corbett 2007). A knowledge base on the history of autism and symptoms associated with different spectrum ends is crucial for facilitating in a way which ensures promotion of autonomy and inclusion.

References

- Association for the Advancement of Social Work with Groups, Inc. (AASWG). (2006). *Standards for Social Work Practice with Groups* (2nd ed.). Retrieved from www.aaswg.org
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- Autism and Developmental Disabilities Monitoring Network Surveillance (ADDMNS), Principal Investigators. (2002). Prevalence of autism

- spectrum disorders—Autism and Developmental Disabilities Monitoring Network, fourteen sites, United States, 2002. *Centers for Disease Control Morbidity and Weekly Report 2007*, 56, 12-28.
- Autism Ontario. (2012). Retrieved from <http://www.autismontario.com/>
- Barker, R. L. (2003). *The social work dictionary* (5th ed.). Washington, DC: NASW Press.
- Baron-Cohen, S. (2006). The hyper-systemizing, assortative mating theory of autism. *Progress in Neuro-Psychopharmacology & Biological Psychiatry*, 30, 865-872.
- Berger, H. J., Aerts, F. H., Van Spanendonck, K. P., Cools, A. R., & Teunisse, J. P. (2007). Central coherence and cognitive shifting in relation to social improvement in high-functioning young adults with autism. *Journal of Clinical and Experimental Neuropsychology*, 25(4), 502-511.
- Bryman, A. (2004). Social work strategies. *Social research methods* (2nd ed., pp 13-19). New York: Oxford University Press Inc.
- Buyts, L., & Tedman-Jones, J. S. (2004). Barriers to Autonomy for Older Adults with Lifelong Intellectual Disability. In C. Bailey, D. Cabrera, & L. Buyts (Eds.), *Social Change in the 21st Century Conference, Centre for Social Change Research* (pp. 1-12). Brisbane: Queensland University of Technology.
- Carter, I. (2009). A consideration of ambivalence and advocacy in self-help: The case of autism. *The Journal of Self-Help and Self Care*, 4(3), 271-285.
- Carter, I., & Wilson, R. (2011). Reflections on face-to-face and online self-help group participation: Comparing the views of persons with autism with those of parents speaking for their autistic children. *International Journal of Self-Help and Self-Care*, 5(4) 353-369.
- Chakrabarti, S., & Fombonne, E. (2005). Pervasive developmental disorders in preschool children: Confirmation of high prevalence. *The American Journal of Psychiatry*, 162(6), 1133-1141.
- Corrigan, M. J., Jones, C. A., & McWhirter, J. J. (2001). College students with disabilities: An access employment group. *The Journal for Specialists in Group Work*, 26(4), 339-349.
- Dunst, C. J., Trivette, C. M., & Cross, A. H. (1988). *Enabling and empowering families*. Cambridge, MA: Brookline Books.
- Eskow, K. G. & Fisher, S. (2004). Getting together in college: An inclusion program for young adults with disabilities. *Teaching Exceptional Children*, 36(3), 26-32.
- Findler, L. S. (2000). The role of grandparents in the social support system of mothers of children with a physical disability. *Families in Society*, 8, 370-381.
- Fombonne, E. (2003). Epidemiology of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, 33, 365-381.
- Garcia-Villamizar, D. & Hughes, C. (2007). Supported employment improves cognitive performance in adults with autism. *Journal of Intellectual Disability Research*, 51(2), 142-150.
- Gillott, A. & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities*, 11(4), 359-370.
- Glidden, L. M., & Schoolcraft, S. A. (2007). Family assessment and social support. In J. W. Jacobson, J.A. Mulick, & J. Rojahn (Eds.). *Handbook of intellectual and developmental disabilities* (pp. 391-422). New York: Springer Publishin Co.
- Gray, C. (2000). *The new social story book*. Arlington, TX: Future Horizons.
- Hastings, R. P., & Johnson, E. (2001). Stress in UK families: Conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders*, 31(3) 327-336,
- Hillier, A., Fish, T. Cloppert, P., & Beversdorf, D. Q. (2007). Outcomes of a social and vocational skills support group for adolescents and young adults on the autism spectrum. *Focus on Autism and other Developmental Disabilities*, 22(2), 107-115.
- Holosko, J. J. (2010). Chapter 18. An overview of qualitative research methods. In B. A. Thyer (Ed.), *The handbook of social work research methods* (2nd ed., pp. 340-354). Thousand

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- Oaks, CA: Sage Publication, Inc.
- Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism, 4*(1), 63-83.
- Howlin, P. & Yates, P. (1999). The potential effectiveness of social skills groups for adults with autism. *Autism, 3*(3), 299-307.
- Jerome, J., Frantino, E. P., & Sturmey (2007). The effects of errorless learning and backward chaining on the acquisition of Internet skills in adults with developmental disabilities. *Journal of Applied Behavior Analysis, 40*(1), 185-189.
- Jordon, C. J. (2010). Evolution of autism support and understanding via the World Wide Web. *Intellectual and Developmental Disabilities, 48*(3) 220-227. doi: 10.1352/1934-9556-48.3.220
- Kelm, J. F. (2009). Intellectual disability and the interdependent expression of self-determination (Master's thesis). Available from ProQuest Dissertations & Theses (PQDT) database. (UMI No. MR63898)
- Kessel, S., Merrick, J., Kedem, A., Borovsky, L., & Carmeli, E. (2002). Use of group counseling to support aging-related losses in older adults with intellectual disabilities. *Journal of Gerontological Social Work, 38*(1/2), 241-251.
- Lang, N. C. (2004). Concurrent interventions in multiple domains: The essence of social work with groups. *Social Work with Groups, 27*(1), 35-51.
- Lattimore, L. P. & Parsons, M. & Reid, D. H. (2006). Enhancing job-site training of supported workers with autism: A reemphasis on simulation. *Journal of Applied Behavior Analysis, 39*(1), 91-102.
- Malin, N. and Wilmot, S. (2000). An ethical advisory group in a learning disability service: What they talk about. *Journal of Learning Disabilities, 4*(3), 217-226.
- Mishna, F. & Muskat, B. (2004). "I'm not the only one!" Group therapy with older children and adolescents who have learning disabilities. *International Journal of Group Psychotherapy, 54*(1), 453-476.
- Moore, T. (2005). Friendship formation in adults with learning disabilities: Peer-mediated approaches to social skills development. *British Journal of Learning Disabilities, 33*, 23-26.
- Muller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism, 12*(2), 173-190. doi:10.1177/1362361307086664.
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3), 245-256.
- Peckham, N. G., Howlett, S., & Corbett, A. (2007). Evaluating a survivors group pilot for women with significant intellectual disabilities who have been sexually abused. *Journal of Applied Research in Intellectual Disabilities, 20*, 308-322.
- Renty, J. O. & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism, 10*(5), 511-524.
- Saleeby, D. (2009). *The Strengths Perspective in Social Work Practice* (5th ed.). Boston: Allyn and Bacon.
- Schopler, J. H., & Galinsky, M. J. (1995). Expanding our view of support groups as open systems. *Social Work with Groups, 18*(1), 3-10.
- Schopler, J. H. & Reichler, R. J. (1978). *Individualized assessment and treatment for autistic and developmentally disabled children*. Baltimore: University Park Press.
- Shaw, D. (2001). Adults with dyslexia: Benefits of a community support group. *The NERA Journal, 37*(3), 10-13.
- Statistics Canada. (2011). Census metropolitan area of Windsor, Ontario. Retrieved from <http://www12.statcan.gc.ca/census-recensement/2011/as-sa/fogs-spg/Facts-cma-eng.cfm?LANG=Eng&GK=CMA&GC=559>
- Sterling, L., Dawson, G., Estes, A., and Greenson, J. (2008). Characteristics associated with presence of depressive symptoms in adults with autism spectrum disorder. *Journal of Autism Developmental Disorders, 38*(6), 1011-1018.
- Toseland, R. W., Rivas, R. F. (2009). *An introduction to group work practice*. Toronto, ON: Pearson Education, Inc.
- Van Bourgondien & Schopler, E. (1996). Inter-

- vention for adults with autism. *The Journal of Rehabilitation*, 62(1), 62-65.
- Weidle, B., Bolme, B., & Hoeyland, A. L. (2006). Are peer support groups for adolescents with Asperger's Syndrome helpful? *Clinical Child Psychology and Psychiatry*, 2(1), 45-62.