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Irene Carter and Andrew Wilson

Introduction

In this paper, the experiences of parents of children with autism are explored by considering how parents conceptualize autism. Participants focused on addressing autism from a medical perspective with language that centers on causes, cures, modifications, prevention, and treatments. Parental experiences reflect cultural influences, providing insight into why parents are motivated to consider particular interventions for their autistic children. The authors consider how social workers may help parents to consider different perspectives in understanding autism and supporting their autistic children.

Literature Review

Autism is often diagnosed between the ages of eighteen months and three years with characteristics that exhibit a delay or absence in speech development and stereotypical and repetitive movements, with prevalence rates of 60 to 70/10,000 (Chakrabarti & Fombonne, 2005; Mesibov, Fuentes, Joaquin, Prior, & Wing, 2006). Current studies indicate genetics play a significant role; however, the etiology of autism remains fully unknown (Rapin, 2002), with more males than females affected, at a ratio of 4 to 1 (Fombonne, 2003). Autism affects individuals at varying levels of severity who often display symptoms of anxiety and depression (Sterling, Dawson, Estes, & Greenson, 2008). Behaviors are often purposeful, self-soothing, or communicative and may increase when the person with autism is stressed. Assessing intellectual levels, as well as symptoms, in persons with autism, particularly those who are non-verbal, is difficult and subject to interpretation. As one of the most severe developmental disorders, autism has staggering effects on public agencies as well as families (Bryson, Rogers, & Fombonne, 2003; Tidmarsh & Volkmar, 2003).

There is a burden of care for parents of children with autism, as the challenge of raising a child with a disability brings added economic, psychological, and social costs (Bryson, Rogers, & Fombonne, 2003). The literature indicates that parents of children with autism are more likely to have symptoms of psychological distress than parents of children with other developmental disabilities, due to higher levels of challenging behavior associated with the autistic child and lower levels of family help (Bromley, Hare, Davison, & Emerson, 2004; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Parents of children with autism are regarded as more susceptible to the likelihood of negative health outcomes like depression and marital dissatisfaction. Negative outcomes are related to the severity of the child's symptoms and the maintenance of social support, both informal and formal.

Informal support involves support from immediate or extended family, relatives, friends, neighbors, other parents of children with disabilities, religious organizations, self-help groups, or social clubs (Boyd, 2002). Informal supports provide support with daily living routines and often offer emotional aid, encouragement, and someone to talk to about problems and personal issues. Internal family support is often the first-line of help for parents and children with autism. Additionally, mutual aid groups provide opportunities to share experiences with other parents and to offer emotional help and encouragement (Carter & Wilson, 2011). Questions that involve how to obtain services, cope with the present, and plan for the future are addressed through others with similar experiences (Cash, 2006). Parental groups that focus on children with autism play a leading

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role in advocating for change and developing supportive services, providing a parental link between formal and informal services.

Formal support networks include both professionals, such as physicians, infant specialists, social workers, and therapists, and agencies, such as hospitals, early intervention programs, and government departments, that are formally organized to provide assistance to persons with specific and defined needs (Findler, 2000; Glidden & Schoolcraft, 2007), including support with daily tasks, financial support, and professional guidance. When parents seek formal social support they often confront social policies that typically limit the provision for chronic conditions such as developmental disabilities. Historically, as governments withdrew institutional placement of persons with developmental disabilities, deinstitutionalization happened without sufficient community help (Community Living Ontario, 2011). To access services, families often must access formal support for their children with autism through a number of different provincial ministries, making it necessary for families to navigate their way through a fragmented array of welfare and mental health programs (Heinonen & Spearman, 2010). As the welfare state became incrementally retrenched, the government became increasingly dependent on care provided by women (Graham, Swift, & Delaney, 2009), that is, female family members of family members who require care, helping to explain the hardships many parents of children with autism experience.

Bailey (2008) explains that parents can become isolated in the community as well as the family. When driven by anxiety about the need for early intervention and guilt about not being more proactive, parents seek a cure to their child's disability, reflective of the medical model of disability. The medical model of disability carries an attitude of benevolence and aims to cure and prevent disability. Professionals function as gatekeepers who often adopt the goal of curing the disability or trying to train the person who is different to be functional. Closely related to the medical model, reactions to disability include perspectives that view people with non-

rehabilitative disabilities as tragic, injured, and helpless victims (May & Raske, 2005). The medical model translates into social policies that try to compensate victims for their tragedies and views the individual with a disability as limited, forcing them into a social role that is stigmatizing and inappropriate.

Alternatively, the social model of disability pictures persons with disabilities as an oppressed, marginalized minority, kept from taking part in society by negative environmental and societal factors (Oliver, 1990). Negative social factors are viewed as presenting obstacles to social participation for persons with disabilities in addition to any limitations experienced due to a disability. The social model of disability provides support for parents of children with developmental disabilities, allowing them the opportunity to take action based on a theory of oppression at both personal and collective levels (Linhorst, 2006; Mullaly, 2010). The social model of disability is a useful approach to understanding how social policy, and the social attitudes that influence it, preserves the lack of acceptance and accessibility for children with autism. Kliewer, Biklen, and Kasa-Hendrickson (2006) challenge us to overcome "deeply ensconced professional and cultural responses to significant disability" (p. 169) by employing a social model of disability perspective. They describe the study of disability as a scholarly convergence of autobiography, political advocacy, social critique, the humanities and social sciences, and modes of qualitative inquiry, displacing "traditional, reductionistic, psychological and medical orientations with their emphases on defect, impairment, and abnormality" (p. 188). Biklen (2005) indicates that autism is best understood as a social and cultural construction from an insider perspective, where persons with autism are viewed as seeing the world differently. Stuart (2008) suggests autism is more about the culture that creates the idea of autism than about autism, reflecting how celebrities, journalists, parents of people with autism, and experts view autism (Biklen, 2009). Biklen allows us to view autism from other than a medical model, reframing the negative understanding of disability as a worri-

some, family tragedy to one of accepting human variation.

While their parents may be seeking a medical solution, persons with autism have begun to prioritize acceptance for who they are, evident by the movement in self-advocacy for acceptance of a model of neuro-diversity (Broderick, 2009; Canadian Broadcasting Corporation, 2010). Persons with autism appreciate the construct of neuro-diversity as positioning autism within social, cultural, and political discourse (Broderick & Ne'eman, 2008), viewing autism as not a disorder, but a neurological difference that is to be tolerated and respected. Broderick and Ne'eman point out that an unnecessary conflict has arisen between parents, who depend on the disease model to raise funds for autism, and self-advocates and persons with autism who object to interventions to change who they are. Broderick and Ne'eman argue that autism as neuro-diversity better mitigates ignorance and discrimination and better reflects the needs of the autistic individual educationally, economically, and politically.

Cultural influences affect how disability is understood, impacting on people's reactions and attitudes towards disabilities. For example, fearful of how their autistic children will be accepted by society, parental self-help groups sought Applied Behavior Analysis [ABA] (Lovaas, 1987; Rapin, 2002) to eradicate or lessen symptoms of autism, based on suggestions that such help would make their children indistinguishable from typical children. Proponents of ABA focus on reinforcement and discrimination learning to transform autistic symptoms through the application of up to 40 hours of instruction weekly. Based on the hope their children will improve through the intervention of ABA, parents employ advocacy to access ABA for their children (Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004).

Barnbaum (2008) recognizes that there are competing notions of disability and questions whether disability is always socially constructed. The notion of a "cure" to persons with autism, as reflected in the medical model of disability, rais-

es ethical questions. Barnbaum (2008) writes that the social construction of disability proposes that the social limitations experienced by persons with disabilities cause persons with disabilities to be viewed as disabled, and if the social limitations were lifted they might not be viewed as disabled. With respect to autism, Barnbaum argues that persons with autism often miss fundamental aspects of human interaction, limiting their ability to enter into reciprocal relationships. Thus, he suggests that the limitations that accrue from being autistic are not merely the result of barriers constructed by society. Barnbaum stresses that individuals with autism can learn to compensate for their deficits, learning to recognize and engage with others. Thus, Barnbaum supports parents in their actions to improve their children's behavior in seeking a better quality of life for their children. Although Barnbaum extends this support to persons with autism who are cut off from others in hope that once they have the opportunity to engage in reciprocal relationships, they will be motivated to continue to do so, he recognizes parental autonomy about decision making for those with autism is coming into question.

Barnbaum (2008) agrees that to force a cure on persons with autism in trying to change who they are fundamentally is a violation of their autonomy. Rather than trying to change the autistic person by making him into someone he is not, Barnbaum suggests the focus should be on integrating as much as possible persons with autism into regular society. As an example, he calls for supplying social navigators for persons with autism as a way to navigate the food court or bus service. The navigators could assist persons with autism to engage with the world in the manner that Braille does for the blind and interpreters do for hard of hearing individuals. Thus, he does support therapy be made available to help autistic persons better care for themselves that will demand greater resources be applied by society in creating educational opportunities.

In summary, models of disability provide insight into how we view interventions for persons with disabilities (May & Raske, 2005). Parents

employ the medical model in aiming to make the child with a disability appear as typical as possible, even though some persons with autism indicate intense behavioural interventions are invasive (Canadian Broadcasting Corporation, 2010). The social model of disability presents disability as originating with beliefs and practices of the dominate culture and suggests persons with disabilities be accepted for who they are with access to appropriate social support. Distinguishing differences between what parents view as a need for children with autism and what children report they need requires that we better understand parental motivation and alternate theories of disability. Although society is endeavouring to move towards acceptance of persons with disabilities by adjusting society to accommodate their needs, parents remain fearful about how their children will manage socially. Parents are challenged to evaluate interventions with respect to appropriateness, effectiveness, accessibility, and cost, and often turn to professionals for help. Professionals need supportive training in disability when helping individuals with autism and their family members seek social supports.

Methodology

In this qualitative study, all participants in one-on-one interviews demonstrated intense interest in sharing their experiences. They willingly participated in a lengthy interview, and were able to articulate their conscious experiences. "Parents," in this study, represented those parents that lived with a child diagnosed with autism, including those from both two-parent and lone-parent families. Parents identified their "children with autism" individually, confirming their child's diagnosis and their child's medical, educational, and social needs.

Sampling

Purposive sampling, as well as advertising and snowball sampling, resulted in 22 participants who agreed to give in-depth interviews. Purposive sampling, the most common form of qualitative sampling, is "a type of nonrandom sample in which the researcher uses a wide range of methods to locate all possible cases of a highly specific and difficult-to-reach population" (Neuman & Kreuger, 2003, p. 563). This method is based on the assumption that the researcher wants to discover, understand, and gain insight, and therefore will select a sample from which the most can be learned. Snowball sampling is "a type of nonrandom sampling, in which the researcher begins with one case, then, based on information about interrelationships from that case, identifies other cases, and then repeats the process again and again" (Neuman & Kreuger, 2003, p. 565). This strategy involved asking each participant or group of participants for referrals from other potential participants. Other contacts resulted from placement of general information about the study and an attached recruitment letter on the Autism Ontario (2012) website. Advertising allowed potential participants to directly contact the researcher, who then determined which research participants met the criteria.

Sample specificity provided methods of locating people who matched the desired characteristics. Initial contacts resulted from the placement of general information about the study and an attached recruitment letter, on the Autism Ontario (2012) website. Eighteen of 22 participants came from the Greater Toronto Area (GTA). Four participants lived in southeastern Ontario, outside the GTA. Recruitment resulted in 19 person-to-person interviews and 3 telephone interviews. Interviews averaged two hours and the participants received a small honorarium of 50 dollars to assist with any attendant care responsibilities.

Data Analysis

Analyzing data involved reading transcribed descriptions and using Atlas.ti software (Scientific Software Development, 2003) to aid in a line-by-line coding process. Then, after extracting significant statements, the researcher clustered the meanings into themes and integrated the themes into a narrative. Initially, the coding phase involved identifying meaning units, assigning them to codes, allocating codes to categories, and documenting coding rules. Atlas.ti software aided the process of creating and merging codes by locating quotations and categories quickly and allowing changes to be made efficiently. The coding process produced 39 categories of codes that the researcher arranged into six main themes.

To promote study credibility, the study concluded by using the procedure of verification to reduce misinterpretation. Distribution of the findings to participants as well as sharing of information about autism from published documents resulted in constructive feedback. Participants responded by confirming that the study's findings reflected their experiences and that their concerns about appropriate interventions for children with autism were increasing, especially within the public school environment.

Findings

The participants were composed of a largely homogeneous group of white Canadian-born individuals. Nineteen participants were white, 1 was Asian, and 2 were unknown. Three participants had immigrated from Asia, Eastern Europe, and England. The age of the participants ranged from 35 to 54 years of age. The interviews consisted of 17 mothers (5 single and 12 married), 3 mother and father dyads, 1 mother and grandmother dyad, and 1 divorced father. Three participants received income assistance from the state; however, most participants reported an income of over $50,000 dollars, earning a family annual income below the average income of $75,829 for the Greater Toronto Area (Canadian Broadcasting Corporation, 2008). Most of the parental advocates were approximately 40 years of age, and their children ranged from the age of 4 to 14 years. They also had the educational and financial means, resources, and support to advocate for improved services for children with autism, despite the stress and financial obligations associated with parenting a child with autism. Greater representation from parents with less means may have resulted in different stories, some that may have revealed different themes.

Themes and Categories

The six main themes and 39 categories are presented in Table 1: Main Themes and Categories of Parenting Children with Autism.

Table 1

Main Themes and Categories of Parenting Children with Autism

1. Thinking Positively
   C1: Strengthens Family

C2: Holidays
C3: Spirituality

2. Feeling Discouraged
   C4: Disability Experience
   C5: Feeling Mum is Blamed
   C6: Feeling Guilty
   C7: Feeling Loss of Hope
   C8: Single Parent
   C9: Feeling Alone
   C10: Time for Relationship and Self
   C11: No Family Holidays
   C12: Financial Strains
   C13: Feeling Angry
   C14: Feeling Stressed
   C15: Feeling Fearful of Future

3. Appreciating Formal Support
   C16: Help Me by Helping My Child
   C17: Professional Supports
   C18: Diagnosis
   C19: ABA Success
   C20: Integration
   C21: School Segregation
   C22: Respite
   C23: Work

4. Criticizing Formal Support
   C24: Professionals
   C25: Diagnosis
   C26: ABA Stresses
   C27: Treatment Waitlist
   C28: Uninsured Treatment
   C29: Move for Services
   C30: Day Care
   C31: Respite
   C32: Lack of Public Awareness

5. Acknowledging Informal Support as Positive
   C33: Informal Support
   C34: Grandparent Support
   C35: Self-Help Groups

6. Experiencing Informal Support as Negative
   C36: Informal Supports Limited
   C37: Spouse has Limited Involvement
   C38: Siblings
   C39: Self-Help Groups

In Theme One, Thinking Positively, many participants voiced positive experiences about

parenting a child with autism. As one parent remarked, "I wish he didn't have a disability. But, also you don't see disability as an omen, like a bad destiny or whatever… it's possible to still have a life with disability." Participants expressed that they discovered that they were stronger both mentally and emotionally than they had first believed possible. Spiritually, several parents related how their experience as a parent of a person with a disability changed them "into more caring people," from someone who focused on giving rather than receiving. This experience encouraged some parents to view having a child with a disability in a more positive way, supported by identifying that family relationships were more important than the acquisition of possessions.

Positive parental experiences were tempered with negative experiences in Theme Two, Feeling Discouraged, which revealed participants' feelings of guilt, especially by mothers, as noted in the following quotation:

> …any parent who has a special [child], [thinks] well, is it something I did, did I breast feed too long, did I take something when I was pregnant, did I do this, did I do that.

Many participants felt the public often misunderstood behaviors exhibited by children with autism and, as a result, judged the parenting abilities of people with autistic children as being deficient. Whether single or married, many parents, especially mothers, felt that autism isolated them, as voiced in the following quotation:

> …it's such an isolated thing for your child to have because often you can't take them out of the house, take them out to social events when there're, you know, out of control…

Participants feared the public's lack of understanding and often reacted by avoiding public activities, a factor that contributed to their sense of isolation.

Several parental participants indicated that stress permeated every aspect of their lives. Indicating one of the factors creating stress, one participant explained, "We don't have spare time. We don't have extra time. We don't have any of the planned time that the average family would have, I'm sorry, we just don't."

Many relationships with spouses and siblings were strained as the family focused on the needs of the child with autism. Many parents were left feeling angry about the financial strains that autism had placed on the family due to the additional costs encountered regarding the autistic child's care or learning needs. In all cases, parents worried what the future would bring for their autistic children.

In Theme Three, Appreciating Formal Supports, many of the participants repeatedly expressed, "You help me by helping my child." Their positive experiences with professionals and schooling is evident in the following quotation:

> So they specialized in little, beautiful, autistic children. Only eight kids [with autism] in the school allowed and two teachers [to work with children with autism], so they do all the [teaching] ABA [Applied Behavior Analysis] style, as much one on one as they can manage…they believe in integration.

Coupled with other help such as respite, from a social point of view, mothers of children with autism found that the ability to work provided respite and relief from the feeling of being isolated. This concept is revealed in the following quotation:

> …working's good because, for me, I'm doing something else, I'm not totally focused on my son when I'm at work. I'm thinking about something else, I have other goals, I have other people I meet and it helps me put things into perspective somewhat so I actually think, I think, definitely that going to work is good.

Regarding negative experiences, in the fourth theme, Criticizing Formal Support, parental participants described the experience of their child's diagnosis as "being thrown out of a plane without a parachute." Many participants indicated they knew little about autism prior to the diagnosis and that acquiring a diagnosis was often a lengthy and shocking process. Some participants reflected on how desperately they waited for a diagnosis, explaining that they needed a professional diagnosis to gain access to waiting lists for service. Additionally, participants experienced frustration

when working with varying professionals, as is evidenced in the following quotation:

> When we came out of there we were given to the social worker…She said there's disability forms there you need to fill out, there is an income tax credit you probably should fill out. Get the doctor to fill that out. There's this, there's that…you have to talk about IBI [intensive behavioral intervention] …and there's new things happening with the initiative [a Province of Ontario autism program]. I just totally couldn't follow anything she was saying…I never heard a word from her again.

Most of the parents described experiences with regard to initiating and maintaining Applied Behavior Analysis (ABA), an intensive behavioral program used in the treatment of children with autism, for their children extremely frustrating. In the following quotation, they listed costly behavioral interventions and a lack of trained professionals as primary problems:

> Well, for example, the first three months of his therapy costs we paid $14,000.00 to the behavior institute. Okay, that's not counting supplies and the room we had to build in the basement for it…Six or seven thousand a month…And the supplies, the supplies, believe it or not…another five thousand, easy…But, I couldn't see myself stopping. I think I would go begging everywhere for money to help him…

Parents expressed frustration that they could not claim ABA as an insurable medical treatment. Participants' beliefs about the promise of ABA stemmed from researchers and professionals to hold parental face-to-face and online group discussions. Parents learned from others about studies involving ABA that claimed their children would improve and, in some cases, become indistinguishable from typical children (Lovaas, 1987). ABA was described by researchers as helping children, minimally, to learn, and in some cases, advancing the ability of children to learn significantly (Rapin, 2002). In an environment where little else was being offered in the way of help, many parents viewed this information as miraculous. Unfortunately, some parents who

experienced financial hardship in utilizing ABA speaks to the exploitation of parents by the disability-industry of helpers who are likely to profit from ABA.

Participants became angry when they experienced ABA as costly with waitlists and limited availability. Additionally, participants reported that even when their children were eligible for government funding, those under the cut-off age of six often received less than the eligible two years of ABA or no ABA at all prior to being removed from a waiting list on their sixth birthday. The yearly cost of $50,000 to $80,000 for ABA treatment prohibited the average family from accessing such services. Participants often reacted to problems with access to ABA by moving to jurisdictions with greater access to ABA and directing their respite funds to privately-funded behavioral interventions. When these strategies failed, they focused on advocacy as a strategy to promote the perceived needs of their children.

In Theme Five, Acknowledging Informal Supports as Beneficial, positive experiences with informal support from families and friends made a great deal of difference for some parents of children with autism, as noted in the following quotation:

> Everyone's been able to pitch in because they know how challenging it has been. And my aunt is a trooper. She's just one of these people that strengthened tremendously through the experiences she's had…offering any respite, whenever we want it.

Most mothers and some fathers sought informal support from self-help groups. Parents appreciated the ability of groups to bring together people who understood each other's situations. Several of these participants considered other parents as the best sources for learning about autism. Many participants commented that they could not have sustained their sense of self-esteem, empowerment, and motivation over the long term if it had not been for the help of other parents. These participants attributed an improved sense of self-esteem to self-help group participation, as noted in the comment: "I probably have a higher self-regard for myself now, self-esteem wise, than I

did six years ago." Several participants also experienced Internet-based self-help groups as a valuable communication tool, allowing them the opportunity for improved time management and activism.

Main Theme Six, Experiencing Informal Support as Inadequate, illustrates the lack of family support in the following quotation:

> …we have absolutely no family support. Like any supports that we get are supports we have to write a cheque for, unfortunately…I've seen those families with grandparent involvement and it's great. But we don't have that luxury. Unfortunately I wish we did.

Mothers remained the primary caregivers while fathers mostly assumed the role of the financial provider. As one mother explained:

> He's as supportive as he can be… He is doing what he thinks is best…I can't be angry at him all the time. He plays hockey Monday nights and I'm here alone. Is it fair? I don't have the answer.

Mothers refrained from involving siblings in caring responsibilities for the child with autism, although they realized that sometimes involvement would be necessary. In most cases, informal support from immediate family was often limited or non-existent, leaving mothers to assume most of the responsibility for the care of children with autism. Parents described informal help provided by other family members and friends a struggle to secure, largely because family helpers did not understand or know how to manage the behaviors typical to children with autism.

The findings in this study indicate parenting children with autism is significantly stressful, attributed to the limited availability of formal and informal support. Many participants experienced the diagnosis of their children as autistic as shocking and devastating when they learned that there was no cure and only limited interventions. Parents of autistic children found their lives to be to be highly compromised, viewing autism as dramatically impacting their lives by heightening risks to isolation, depression, anxiety, grief, guilt, blaming, and self-sacrifice. Disappointed with

available formal and informal social support, parents turned to other parents for information and help. As a strong voice for their children, parents found working with other parents useful in creating a therapeutic dialogue, public awareness, and access to information and help. The following discussion considers the implications of how parents perceive and experience the diagnosis of autism and what they might find helpful to meet the challenges of parenting a child with autism.

Discussion

Similar to the literature, mothers in this study reported experiencing parenting stress, describing themselves as experiencing guilt about their child's diagnosis (Hastings, Kovshoff, Brown, Ward, Epinosa, & Remington, 2005). For example, one participant had erroneously thought she had caused her son's diagnosis by being "a refrigerator Mom." This is a residual effect of the long-discredited parental causation theory of autism where parents emotionally absorbed blame for the autism, negatively affecting their social identity. Participants who refrained from taking their child out socially were responding to the experience of critical, disapproving looks from others observing their child's behavior. All mothers in this study bore unrecognized economic, social, and psychological costs. Mothering limited their capacity to work, resulting in restricted incomes, short- or long-term disability leaves, working part-time, or living on social assistance. Mothers assumed primary responsibility for the care of their autistic children, encouraged by current social policy that depends on women to care for vulnerable populations (Graham, Swift, & Delaney, 2009), often disguised and unrecognized through the use of seemingly neutral terms, such as "caregiver" (Home, 2002).

Participants in this study sought normalcy for their children by relying on the suggestions of researchers such as Lovaas (1987), who produced a study that reported significantly positive results of behavior modification treatment with children with autism. The result was often disappointing due to government restrictions on the availability of Applied Behavior Analysis (ABA), an intensive behavioral program that applied 40 hours of therapy per week to children under the age of

five. Lovaas claimed 47% of the experimental group achieved normal range in intellectual and educational functioning, in contrast to only 2% of the control group subjects. Parents in this study hoped that their child's functioning ability could significantly improve through ABA, adding to their frustration when they faced barriers in securing ABA.

As voiced by the participants, legal attempts by parents in Canada to have the government cover behavioral interventions for children with autism have generally met with resistance. Autism Society Canada (2009) reported a history of 1,600 Canadian legal cases about autism that included a few well publicized legal cases (C.R. v. Alberta; Auton (Guardian ad litem of) v. British Columbia (Attorney General); Wynberg v. Ontario). In the 2005 Wynberg v. Ontario case, some participants won a lawsuit case in Toronto that resulted in coverage for ABA for children beyond the age of six. The Ontario government successfully appealed this decision, but did subsequently introduce ABA. However, as indicated by the participants in this study, parents continued to be critical about the availability and quality of ABA services (Autism Ontario, 2009). Pubic demand resulted in waiting lists, parental complaints about the lack of accessibility, and an increase in funding for ABA with significant restrictions to access.

As evident in this study, ABA prevailed as the most sought after educational strategy by parents as it was thought to be more likely to have the desired outcome, which is children indistinguishable from their peers (Broderick, 2009). Concerns have been raised about the effectiveness, access, and cost of ABA (Schopler, Short, & Mesibov, 1989). Alternatives such as Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) were recommended as educational strategies. TEACCH adapts the learning environment to the child's characteristics by making use of visual cues and functional communication.

Parents continue to seek access to intense behavioral interventions based on hope that autism is not permanent, efforts that reflect a medical model of disability (Broderick, 2009). Broderick argues that the construct of recovery feeds the

hope associated with ABA for a return to normalcy. However, the medical model of disability limited parents' perspectives of disability with limited opportunities to understand disability by reframing and re-conceptualizing autism through perspectives based on the social model of disability.

Many participants found solace through their encounters with other parents via face-to-face and Internet-based self-help groups. Most participants recognized their challenges as stemming from limited access to various formal and informal social supports. As participants became empowered, personally and collectively (Boehm & Staples, 2004; Mandell & Salzer, 2007), they felt less alone and less distressed (Bloch, Weinstein, & Seitz, 2005). They understood the limitations placed on their child and worked to promote greater understanding of autism and accessibility for their children. As mainly mothers, they noted exclusionary practices affecting their children that primarily included social attitudes, a reflection of some aspects of the social model of disability. Offering a framework to rethink how society can improve the psychological well-being of persons with disabilities and their family members, a greater understanding of the social model of disability has the potential to assist parents in adjusting to the diagnosis of autism and addressing the needs of their children.

Implications for Social Work Professionals

Twoy, Connolly, and Novak (2008) found eighty percent of parents seek information from professionals in addition to family support and support from friends. Positive experiences expressed by many of the participants in this study reflected the literature that indicates the more resilient have committed and supportive marital and family relationships, understanding and helpful extended family and friends, and knowledge about autism (Bailey, 2008), circumstances that social work can help to maintain and promote. In the US, social work was impacted by the shift toward rights and community organizing and working with disenfranchised populations, such as people with disabilities, providing, for a short time, increased funding and opportunities for social workers in the disability field of disability

(Jurkowski & Welch, 2000). However, Oliver, Sapey, and Thomas (2012) write that although "social work appeared to be the occupational group that was best positioned within the disability industry to change its practice to the principles of the social model of disability," it has generally failed to take up the challenge. Yet, social workers, as indicated by Tom Shakespeare (2012), contributor to the World Report on Disability (2012), in his address to the 2012 Joint World Conference on Social Work and Social Development: Action and Impact July 8-12, 2012, Stockholm, Sweden, are the professionals in a position to make a significant difference in the lives of persons with disabilities.

Based on their professional education, social workers are apt to use a thorough assessment guide when helping parents assess the intervention needs of their children that includes key problems, goals and desired outcomes, specific objectives to achieve the goals, intervention approaches, and assessment and evaluation procedures to track progress (O'Hare, 2011). Social workers can focus on the reactions of families to the diagnosis and assist in initiating and maintaining post-diagnosis parent support groups that offer the potential to help families adapt to the diagnosis, reduce related stress, and navigate service systems. Banach, Iudice, Conway, & Couse (2010) did a pilot study that measured the effects of a six-session, co-facilitated, support group on the advocacy skills and self-efficacy of parents coping with a child's diagnosis. Statistically significant increases in the average mean scores for the three subscales of the Family Empowerment Scale were found, indicating positive implications for practice. Short-term support groups for parents that incorporate information about autism, community resources, and self-advocacy were found to be an effective way to meet the needs of families after diagnosis. Parental empowerment with regard to approaching service systems increased. Parents believed they could effect change in services for their child such as communicating effectively the rights of their child to agency administrators. Families with a recent diagnosis benefited from being aware of the best ways to secure services for their child. They found it helpful having

a social worker with knowledge of group work and group dynamics, paired with a professional knowledge of disability and school systems.

Social workers must also be aware of, and prepared to discuss, the cultural implications of how disability is viewed by the parent. Barnbaum (2008) stresses interventions for children with autism raises enormous ethical issues that social workers should be aware of when making suggestions to parents. Without awareness about the ethical implications of interventions for children with autism, social workers run the risk of perpetuating past injustices, such as the concept of refrigerator mothers or the role that society plays in insisting that persons with autism change instead of social attitudes and practices. For example, social workers need to be cognizant that the approach to disability and relevant interventions may differ between children with disabilities and the parents who speak on behalf of their children (Carter & Wilson, 2011). Future studies need to examine how the views of parents who speak on behalf of their children with autism are consistent with, or vary from, the views of autistic children. Social workers must take into account the degree and intensity of the interventions and the impact on the child as well as the family.

A common social work vision with respect to social justice and disability rights is an interest in making professional postsecondary education more responsive to the needs of persons with disabilities. In recent years, social work faculty has written about the need to develop courses specializing in disability content, and the development of opportunities for disability research (Carter, Hanes, & MacDonald, 2012). Research is required on the experience of persons with disabilities and the parents of children with disabilities with social work and their satisfaction and concern about service delivery. From a professional development perspective, social workers need to work collectively and effectively in continuing education to promote a positive image of autism, as well as other disabilities, by working to provide programs on disability that encourage social support for individuals with autism and their families. The social model of disability is seen as offering social workers and parents an alternative way to think

about their autistic child by reframing the negative understandings of disability. As life changes from one of exclusion to one of increasing community inclusion for persons with disabilities and their families (Accessibility for Ontarians with Disabilities Act, 2005), the study of disability and social work can help us move beyond present challenges by recognizing injustices and removing social barriers to full participation. Integrating the study of disability into schools of social work and continuing education programs through combined degree, minor, and certificate programs is one way to ensure social work as a profession is able to serve persons with disabilities adequately. Including a social work critique of disability, similar to their study of gender, race, and class, will add to social work's constructionist approaches and enable social work, professionally, to play a leading role in ongoing work with persons with disabilities.

Limitations

There are a number of limitations to this study. First, the researcher restricted the site to southeastern Ontario and the Greater Toronto Area, with most of the participants coming from the Greater Toronto Area. Second, participants largely represented middle-class parents. Third, although consistent with qualitative research, the study sample, at 22, was too small to generalize the findings to a larger population of parents of children with autism, and excluded a potentially larger representation from non-Canadian born residents. Fourth, participants' experiences varied in type and number of years of experience. Fifth, using a prepared semi-structured interview guide with set questions may have limited participant responses. Sixth, conducting three 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 work with children with autism or the views of autistic children who experience different forms of social accessibility and assistance.

Conclusion

As life changes from one of exclusion to one of increasing community inclusion for persons with disabilities and their families (*Accessibility*

for Ontarians with Disabilities Act, 2005), social work can help us move beyond present challenges by recognizing injustices and removing social barriers to full participation by employing options to the medical model of disability. Moreover, when considering what help to seek for autism, future studies need to examine how the views of parents who speak on behalf of their children with autism are consistent with, or vary from, the views of autistic children who may be focused on acceptance of autistic persons as they are (Carter & Wilson, 2011). The study of disability, at all levels of schooling, from middle school (Canadian Centre on Disability Studies, 2011) to university, that focus on persons with disabilities will help to ensure greater understanding and support for persons with disabilities. Minimally, there is a need to offer persons with autism and their parents opportunities to reframe and reconceptualize autism through the perspectives offered by the social model of disability.

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