

# Living in a World of Our Own: The Experience of Parents Who Have a Child With Autism

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In this article, we discuss findings of a hermeneutic phenomenological study that sought to describe the experiences of parents who have a child with autism. Qualitative interviews were conducted with parents from 16 families of children with autism residing in a western Canadian province. "Living in a world of our own" emerged as the essence of the parents' experiences. In "living in a world of our own," parents described a world of isolation. Three themes representing the essential challenging elements of the parents' experiences included vigilant parenting, sustaining the self and family, and fighting all the way. Although much is known about the fundamental importance of support to parents of children with chronic conditions and/or disabilities, findings from this study indicate that knowledge has not been adequately transferred to the care of children with autism.

**Keywords:** *autism; children; families, caregiving; parenting; phenomenology*

Autism is a complex developmental disorder characterized by a triad of impairments in reciprocal social interaction; communication; and restricted, repetitive, and stereotypic patterns of behaviors, interests, and activities (Committee on Children With Disabilities, 2001). Compared to other developmental deviations such as developmental intellectual impairment, autism manifests itself not in developmental delays but rather in striking deviations in development (Beauchesne & Kelley, 2004). Although the onset of symptoms for most children with autism occurs during late infancy, some children may not display any symptoms until 2 years of age after a period of relatively typical development (Committee on Children With Disabilities, 2001).

Understandably, few disorders can pose a greater threat to the well-being of families than autism (Seltzer, Krauss, Orsmond, & Vestal, 2001). Parents of children with autism are faced with many challenges. Adding to the challenges experienced by parents is that in spite of an early onset, autism often remains undiagnosed until or after late preschool years (Beauchesne & Kelley, 2004). Equally challenging is the intense treatment that requires a combination of strategies (Committee on Children With Disabilities, 2001). Although there is no proven cure for autism, the goal of treatment is to improve the overall functional status of the child by promoting the development of communication, social, adaptive, behavioral, and academic skills as well as lessening maladaptive and repetitive behaviors (Committee on Children With Disabilities, 2001).

In achieving treatment goals, there is growing evidence that treatment should be started before the age of 5. One of the primary components of treatment involves intensive behavioral training based on the applied behavioral analysis (ABA) approach. The aim of training is to reinforce desirable behaviors and

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**Authors' Note:** This research was funded by a Sister Bertha Baumann Research Award from St. Amant Centre in Winnipeg, Manitoba, Canada. Dr. Woodgate is supported by a Dorothy J. Lamont Scientist Award, funded by the National Cancer Institute of Canada and the Canadian Institutes of Health Research's (CIHR) Institute of Cancer Research. We would like to thank the families who participated in this study.

decrease undesirable behaviors (Committee on Children With Disabilities, 2001; Pelios & Lund, 2001). Undertaking ABA programming is highly detailed and structured, requiring up to 40 hours per week of one-to-one behavioral training. Despite the professional expertise and guidance provided to parents, a great deal of parental input and commitment is required. In fact, parents have been described as “co-therapists” (Pakenham, Samios, & Sofronoff, 2005). Increasingly, parental and professional (therapeutic and educational) collaboration is being deemed essential, especially in countries (Canada, United States) that are integrating children with autism into regular (full- and part-time) school classes (Bryson, Rogers, & Fombonne, 2003; Committee on Children With Disabilities, 2001).

Research directed at understanding what it is like to be a parent of a child with autism is in its early stages. Primarily, the existing research explores the degree of stress and level of functioning in parents in relation to a variety of factors including coping behaviors (e.g., Hastings et al., 2005; Higgins, Bailey, & Pearce, 2005; Sivberg, 2002), depression (e.g., Dale, Jahoda, & Knott, 2006), and personality and demographic factors (e.g., Duarte, Bordin, Yazigi, & Mooney, 2005). Although this work points to parents experiencing increased stress and the potential for adjustment problems, it is not considered within the context of the family’s evolving life experience of children with autism (King et al., 2006). King and colleagues (2006) reinforced that the research tends to adopt a narrow perspective of the child with autism where the child is viewed as a “stressor” testing parents’ ability to cope and negatively influencing their psychological well-being.

Although minimal, there is research that seeks to understand the meanings parents assign to having a child with autism. This includes work by Gray who through an ongoing study produced a series of articles about the social experiences of Australian parents of children with autism. Gray focused on describing how parents experienced “normal family life” (1997) and stigma (1993, 2002). “Normal family life” for these parents was not associated with the outward signs of domesticity (e.g., owning a house or holding a job) but was instead linked to factors such as their ability to socialize, the emotional quality of their interactions among family members, and the routines and rituals that comprised their perceptions of what “normal” families do (Gray, 1997). Although most parents with a child with autism felt stigmatized, parents of aggressive

children were more likely to experience stigma more acutely than parents of passive children (Gray, 1993, 2002). As a consequence, many parents isolated themselves and their families from social contacts, finding communal encounters burdensome because of the combination of their child’s disruptive, antisocial behaviors coupled with a normal appearance (Gray, 1993).

Findings from another Australian study revealed that the lived experience of parenting a child with autism is best characterized as a shrinking nature of the parent’s self (less spontaneity, social contact, and having fewer things), where parents felt pulled into a vortex of a restricted and repetitive way of being-in-the world (Cashin, 2004). On the other hand, King et al. (2006) found through qualitative inquiry that the belief systems of families of children with autism or Down’s syndrome changed. Specifically, shifting familial beliefs reinforced that raising a child with a disability can be a life-changing experience that spurs families to examine their belief systems (King et al., 2006). Seemingly a burdensome experience, some parents of children with autism experience positive adaptations in the form of changed worldviews concerning life and disability with the recognition of positive contributions made by their child to themselves, their family, and to society in general.

Despite this increasing understanding of what it is like to be a parent of a child with autism, more research needs to be undertaken that strives to understand, make sense of, and elicit the meaning of childhood autism from the perspectives of parents. The overall purpose of this study was to describe the lived experience of parents who have a child with autism.

## Method

### Design

The methodology of hermeneutic phenomenology, as described by van Manen (1990), was used to address the study’s purpose. Hermeneutic phenomenology seeks to “uncover the structure, the internal meaning structures, of lived experience” (van Manen, 1990, p. 10). Foundationally, hermeneutic phenomenology explores the individual’s context to capture the essence or the underlying meaning of lived experiences as they are brought to light through the experiences of individuals. The experience needs to be described as well as interpreted to fully understand the meaning of the lived experience.

## Setting and Participants

The study was conducted in a city in a province of western Canada. The only legitimate informants in phenomenological research are those who have lived the reality (Baker, Wuest, & Todd, 1992). Therefore, recruitment strategies were directed at selecting individuals who had lived the experience of being a parent of a child with autism. Participants were recruited through a support group whose purpose is advocacy, support, and the facilitation of accessibility to effective treatment.

Twenty-one parents from 16 families of children with autism participated. Sixteen of the 21 parents were mothers, and 5 were fathers, with a total of five couples participating in the study. The parents ranged in age from early 30s to late 40s. Nineteen parents were Caucasian, and 2 were Asian. All parents were married except for one mother who was separated at the time of the interview. Except for 2 parents, all parents had at least one other child in addition to their child with autism.

The children with autism ranged in age from 3 to 9 years, with the children's age of initial diagnosis ranging from 2.5 to 3.5 years. The children with autism were all boys except for one child, which supports current incidence of autism being four times more common in boys than girls (Committee on Children With Disabilities, 2001). The children, as described by the parents, varied in the severity with respect to the degree of impairment in communication, social relations, and repetitive and stereotyped behavior. All the children except for two were involved in ABA training (the number of years and hours per day devoted to the training, structure, and content varied for each child). During the time of the study, funding for families had just been made available from the government to support preschool children in the ABA program. However, only six families qualified for the funding. For the other families, the children were too old or already enrolled in the ABA program with cost incurred by the parents. Additional treatment services for the children included speech therapy, occupational therapy, physical therapy, psychiatric services, respite services, and a child care or teacher's assistant. Funds for these services were also provided by the government but only if parents accessed them through the public health care system. The extent of treatment that the children received was dependent both on what services were available to them and what parents could afford. Parents often sought out private treatment

services because of the unavailability of services in the publically funded health care system.

## Data Collection

Data collection took place over a 16-month period. All parents participated in audiotaped, open-ended, in-depth qualitative interviews conducted by the first author. Parents were given the option to be interviewed either individually or with their spouse. The open-ended interview method helped to elicit detailed responses deemed significant to the study's purpose (Morse & Field, 1995) but also afforded parents the opportunity to use their own words and talk about what really mattered to them. A minimal number of broad, data-generating questions were asked as recommended in phenomenology (Munhall, 1994; Streubert & Carpenter, 1999; van Manen, 1990). For this study, parents were asked to describe what life was like for them before, during, and after their child was diagnosed with autism. Open-ended probes ("Tell me what happened next?" or "How did that make you feel?") were used as necessary to facilitate parents' telling their stories. In asking the questions, care was taken not to introduce concepts that would have biased parents' responses. Field notes describing the interview context were made. Parents also completed a brief demographic form prior to being interviewed.

Five joint interviews (i.e., involving both parents) and 14 individual interviews were conducted for a total of 19 interviews. The individual interviews all involved mothers, with three of the mothers requiring a second interview. Interview sessions for all parents lasted from 1.5 to 3 hours.

## Data Analysis

Data analysis was concurrent with data collection. All interviews and field notes were transcribed using the Microsoft Word word processing program. The transcripts were reviewed repeatedly for significant statements in an attempt to find meaning and understanding through themes. Thematic statements were isolated using van Manen's (1990) selective highlighting approach. In this approach, the search for themes or structures of the experience involved selecting and highlighting sentences or sentence clusters that stood out as thematic of the experience. Notes were made to capture the thematic statements. All phrases, sentence clusters, notes, and textual data were then reduced until essential themes emerged. Essential themes are

unique to the phenomenon of parents who have a child with autism and are fundamental to the overall shared description of living the experience. Critical to interpretation was a movement from an understanding of the whole text to more specific parts within the text and then back again to the whole (Benner, 1985). In an effort to be as true to the meanings as possible, descriptions were written and rewritten to include the meaningful themes and to ensure that they were presented as disclosed (van Manen, 1990). Saturation occurred when there was ongoing replication of data concerning the emerging essential thematic elements of the phenomenon under study. Measures to enhance the methodological rigor of the research process were undertaken to include prolonged engagement with participants and data, careful line-by-line analysis of the transcripts, and detailed memo writing (Lincoln & Guba, 1985). Preliminary interpretations were also discussed with participants during and following each interview, which helped to uncover and lend support for the emerging essential themes.

## Ethical Issues

Ethical standards were maintained throughout the course of the project by careful attention to issues of recruitment, written consent, confidentiality, anonymity, potential vulnerability, and sensitivity. Ethical approval from a university-based ethical review committee was sought and obtained. The one transcriptionist hired for the project signed a confidentiality agreement.

## Findings

This section describes the essence, themes, and subthemes that emerged from the analysis of the experiences of parents who have a child with autism.

### The Essence of the Parents' Experiences: Living in a World of Our Own

The essence, "living in a world of our own," ultimately defined what it was like to be a parent with a child with autism. Just as parents described children with autism as "being in their own world," so too did parents experience similar feelings. Parents basically felt that they were now having to "go it alone" in all aspects of their daily lives but especially with respect to dealing with the challenges of parenting and caring for a child. In "living in a world of our own," parents described a world that left them at times feeling

isolated. Parents' sense of isolation is described as arising from four main sources.

*Society's lack of understanding.* Parents expressed feeling isolated because of what they perceived was a lack of understanding by society of what autism was and what was involved in caring for a child with autism. Despite the challenging nature of autism, parents felt that their suffering was not recognized by others around them but instead was invisible. Parents felt that society placed less value on the lives of the children with autism and felt stigmatized, thereby adding to the feelings of isolation:

The school is stigmatizing my son. The resource person said I should not expect other kids in Grade 1 to buddy with him. They are saying, "Why would another kid want to play with your kid?"

*Missing a "normal" way of life.* Parents expressed feeling isolated from a "normal" way of life. Many aspects of the parents' life were affected by their child's autism because of the intensive care that their child with autism required. One parent reinforced the impact autism had on his life by stating, "We have no life, we only have a program [referring to the ABA program]!"

*Feeling disconnected from the family.* Although parents reinforced that they garnered their major source of support and strength from their family, parents were not immune from experiencing isolation within the family. Most notably was the sense of isolation parents experienced in not always feeling like they were a part of the world that their child with autism lived in. They first experienced this isolation when their child's behavior started to change and during those times when they tried to connect to their child only to have the child resist the parent's getting close to them. Parents on occasion also felt disconnected from their spouses when both experienced different feelings that resulted in their not "always being on the same wavelength" or stage of the autism trajectory. Parents also experienced feeling isolated from those extended family members who seemed to lack an essential understanding of what they were going through and/or failed to be present to provide practical support and assistance.

*The unsupportive "system."* The most concerning factor contributing to parents' sense of isolation was the "system." The "system" was defined by parents as a conglomerate of all child-related agencies and

institutions (e.g., health care facilities, educational settings) existing to protect and advance the development of the child with autism. Parents described a system that was inaccessible in many ways. The inaccessible system is manifested by having to deal with unsupportive professionals in the system who appeared to lack training in, and knowledge of, autism, along with limited, inadequate, and inappropriate resources deemed necessary in providing support to raising a child with autism. "There are not enough people, there is not enough funding, and so on" were words consistently voiced by parents.

Parents also had experiences of the "system" itself isolating them from their child:

Maybe my husband would not like me using this word, but really the total brutality of how parents are treated. You are really made to feel like an outsider in your child's life.

Overall, the product of the sense of isolation left parents with a diminished sense of hope.

Parents expressed feeling completely defeated and on their own when they felt that family members, friends, professionals within the system, and others in their lives were not there to support their sense of hope that things would get better for their child.

### Themes Supporting the Essence

Three themes supported the essence: (a) vigilant parenting, (b) sustaining the self and family, and (c) fighting all the way. These themes speak to how parents struggled and fought to remove the isolation that they and their children experienced.

#### *Theme 1: Vigilant Parenting*

To be able to protect their child with autism from a world that was not always there to support them, parents became superparents completely focused on every aspect of their child's world.

Parents described having to develop sense of heightened watchfulness and preparation for action or, as one parent referred to it, "mental monitoring." The intensive nature of parenting is exemplified by the following:

Well, it is almost like a home with an alcoholic. You walk around on eggshells because you do not want to possibly upset them in anyway. It is just that you are walking on eggshells 24 hours a day. You are continually trying to teach a child who does not want to

learn. During the bad parts it was, we were just drowning in autism.

Although it was not uncommon for the mothers to assume the primary responsibility of the direct treatment for their child, fathers were also involved in some aspect of the direct care in addition to assuming traditional responsibilities. Parents viewed parenting as a team effort and, when sharing their thoughts on parenting during the interviews, often responded in the voice of "we" as opposed to "I." They recognized the importance of standing by and supporting each other even during those times when they had differing perspectives.

In becoming "vigilant," parents adopted three strategies that helped them to protect their children: (a) acting sooner rather than later, (b) doing all you can, and (c) staying close to your gut feelings.

*Acting sooner rather than later.* This strategy referred to parents' keeping abreast of all aspects of their child's care. Parents described always having to anticipate the next course of action to ensure that their child received the most appropriate and timely treatment. It was important, as one parent expressed, "not to let the window of opportunity pass them by." Parents shared many stories of the great lengths that they went to in order to get the help for their child in a timely fashion:

They said it would be 6 months to a year to get into speech therapy. And I said, "That is not acceptable." I said, "Get us in as soon as possible, and what is your earliest you can get us in?" And he told me that they occasionally phone parents if someone is sick or does not show up for an appointment. I said, "Okay, you give me a 30-minute notice, 5-minute notice, I will be there." And we got in, in 3 weeks.

*Doing all you can.* This strategy referred to parents trying anything and everything to help their child develop to his or her full potential, whatever that potential might be. It was important, as one mother reinforced, "to adopt a try-anything-that-works attitude." "Doing all you can" involved a range of activities for parents from seeking out specialized services for their child, to changing their home environment to enhance the safety and comfort features for their child.

Associated with the do-all-that-you-can approach was the belief that their child had the ability to learn and grow. Parents needed to be committed to advancing their child's potential. Parents also needed to be

both flexible and reasonable when considering multiple options and acknowledged that professionals who were also flexible and willing to consider new solutions helped parents to be able to do all that is possible for their child.

*Staying close to your gut feelings.* This strategy referred to parents' acknowledging and acting on the innermost feelings that they held about their child with autism. Parents reinforced that it was important to trust their "gut feelings" and to persevere in doing what they thought was the best thing for their child and not to be concerned about what others think. The "gut feelings" served as a special source of information for parents that helped them to make decisions about their child's care.

### *Theme 2: Sustaining the Self and Family*

Just as important as it was for parents to protect the child with autism, so too was protecting their own sense of self as well as the family's sense of self. The challenges posed by autism placed parents on guard to the possibility of permanently losing pieces of their self and their family. Parents felt it was important not to let autism get the better of them or their family, or else this would only lead to further isolation. Sustaining the self and family was important to parents in and of itself, but also because parents viewed that a strong sense of self and family would enhance protective measures for the child with autism:

Everything changes when you find out your child has autism, and you know that you have to be and do this for your children, absolutely that comes first. But you also have to put your own self in perspective because if you are not up to par, then you are not going to help him anyway.

In keeping things together as a person and a family, parents reinforced it was important to (a) work toward a healthy balance, (b) cherish different milestones, and (c) learn to let go.

*Working toward a healthy balance.* "Working toward a healthy balance" referred to parents' recognition of the importance of having a life that is not solely focused on helping their child with autism develop to his or her full potential. Parents needed to create a balance between their focus on parenting a child with autism and all the other aspects in life if they hoped to arrive at a healthy sense of well-being for themselves and their family. In striving for a

healthy balance, it was important for parents to step back and acknowledge that they and their children without autism had needs of their own that needed to be met. Although the child with autism required additional parental attention, parents spoke of the need to take time away from all the work that went into parenting a child with autism.

In working toward a healthy balance, parents stressed that it was important to set priorities and concentrate on issues defined as important. As one father noted, it was important "not to sweat the small stuff anymore."

*Cherishing different milestones.* In sustaining the self and family, parents expressed the importance of accepting that their child with autism would experience milestones in his or her development differently compared with other same-aged, normally developing children. Despite the differences, parents stressed that these milestones were just as important as the "normal" milestones and that each milestone needed to be celebrated. Cherishing different milestones helped to preserve parents' sense of hope. One mother, in reference to the loss of her son's normal development, expressed,

I was grieving the loss of my son and looking at this new challenge. I was going to have to deal with this for the rest of my life, and I had no hope, and it is only with minor little accomplishments that my son with autism made that I was able to regain the hope bit by bit.

The minor accomplishments often came about from parent and child working on some aspect of the child's therapy in which a connection was made between the two.

*Learning to let go.* "Learning to let go" referred to the parents acknowledging that there were certain situations associated with their child's autism that they could not always change and that in those situations it was important to step back and let things transpire as they naturally would. It was important to recognize that as a parent, one cannot be responsible for everything and to avoid the "what ifs":

But also we had to realize one of the last two years that our son cannot go past his potential. We ran his program as best as we could, we made sure he had the right staff and supplies, and maybe we did not spend as much time on some things, but we cannot change the past. We did as best as we could. We had to learn to let go.

### *Theme 3: Fighting all the Way*

“Fighting all the way” referred to how parents fought to make the system work for them and their child.

Parents fought to improve the system not only for their own child with autism but for all families who have a child with autism. Parents’ altruistic motives were sharpened by their need to prevent other families from experiencing a similar fate of intrusive feelings of isolation. Parents realized that for their voices to be heard, they needed to function as advocates:

We do not have the strength in numbers, so what we have to do is we have to stay in there advocating for all special needs kids and in our case particularly those with autism. We cannot let the system rip them off.

Parents stressed that in fighting to make the system work, they needed to (a) become more direct, (b) learn all they could, and (c) educate others.

*Becoming more direct.* To fight all the battles, parents had to change their behavior. Specifically, parents had to precipitously pull themselves together emotionally (to prevent controversy and confrontations) and become more direct in how and what they asked for in relation to support and treatment options for their child with autism:

I have become more and more straightforward to the point that, I think they are all afraid of me. But it is not my nature, like to be really challenging. I see myself as kind of a shy person, a soft-spoken person.

*Learning all you can.* Ensuring the effective functioning of the system, parents stressed the importance of learning about every dimension of raising a child with autism. Especially useful sources of information included conversations with other parents of children with autism about a range of issues such as learning how to navigate the system. Another important source was what parents learned from the interactions they had with professionals who were involved in the care of their child. With each professional–parent encounter, parents learned more about how best to respond to the professional so that the professional would listen to them. However, the most important source of learning was the knowledge they gleaned directly from their child with autism. Parents consistently indicated that they had learned so much from their child, which helped them to become more

discerning, understanding, and patient. The intense nature of caring for a child with autism heightened their sensitivity to the behaviors of others and helped them become expert teachers.

*Educating others.* In making the system work, parents found it was important to educate others about the importance of respecting the child with autism and his or her parents. Parents fought to ensure that friends, professionals, and society in general knew about the unique characteristics of and contributions made to the world by children with autism.

Parents wanted others to realize that parents of children with autism try their best in raising their child and as such should not be judged or blamed for their child’s behavior. Parents expressed that professionals needed to be more receptive to both the child and the parent and, more important, advocate with the parent in ensuring that the needs of children with autism are met.

## **Discussion and Conclusion**

The ultimate aim of our study was to gain a better understanding of the lived experience of parents who have a child with autism. In order not to delimit the parents’ account of their experiences, we avoided using the word *parenting* in the description of the overall purpose. In doing so, parents shared with us not only aspects of their parenting role but also other aspects of their lives that were central to the autism experience. Findings in our study revealed both similarities to and differences from previous research conducted in the area.

For the Canadian parents in our study, having a child with autism not only affected their parenting role but more to the point defined how they lived in their world. The parents experienced feelings of being in their own world and going it alone to the point that it became the essence of their experience. Gray (1993, 1997) also found a sense of isolation to be a dominant condition in the lives of Australian parents who had a child with autism. However, what was unique in our study was that from the perspectives of the parents, their sense of isolation was found to be mainly the result of external sources (e.g., society’s lack of understanding). In contrast, the isolation reported by Gray was more self-imposed in that parents tended to isolate themselves from social contact with the outside world because of the awkward encounters with outsiders.

Another difference noted between our study and Gray's work was how parents dealt with their isolation. Gray (1994) found that parents coped by using a variety of strategies, most notably the use of service agencies (e.g., treatment services, respite services), family support, and social withdrawal. In contrast, parents in our study received a lot of support by valuing any accomplishment that their child achieved. Parents in our study also coped by trying to make changes within the system. They were dissatisfied with the system and fought for their voices to be heard. One possible explanation for the different findings could be that parents in our study were recruited from a support group of families of children with autism, whereas in Gray's work parents were recruited from a treatment center. The parents in our study, although feeling isolated from many external sources, nonetheless had the support from other families of children with autism and might have been encouraged to be advocates for their child.

Similar to the Australian parents in Cashin's (2004) study, parents in our study also experienced a different way of life because of their child's autism. In both studies, the different way of life usually meant having to give up things associated with a "normal" life as well as experiencing changes to their sense of self. However, whereas parents in Cashin's study experienced it as a loss of self to autism, parents in our study experienced it as a struggle to preserve their sense of self. The parents in our study recognized the potential for a loss of self and family and identified numerous strategies to preserve the self and family. Similar to the families in Gray's (1997) study, parents achieved a sense of normalcy by focusing their energies on maintaining some type of routine family life.

Our study also lends support to the work done by others in the field of parenting experiences of families of children with varying chronic health conditions (Ray, 2002; Rempel & Harrison, 2007). Most notable is the need for parents to develop an increased sense of parenting that is intense in both quality and quantity of behaviors. The fear of "letting the window of opportunity pass them by" combined with an "unsupportive system" where expert professionals lacked knowledge and expertise in dealing with the needs of families greatly contributed to the parents in our study becoming "vigilant." "Vigilant parenting" is similar to Ray's (2002) "parenting plus" and Rempel and Harrison's (2007) "extraordinary parenting." Although these two studies involved parents of

children with a variety of chronic conditions (excluding children who had behavioral or developmental disabilities alone), the parents in these studies, similar to our parents, worked hard and did whatever they could to ensure their child's survival and optimal development. In addition, they tried to balance their intense parenting with the need to sustain the self and the family while at the same time deal with "system" problems (Ray, 2002). Recognizing that parents of children with chronic conditions and disabilities experience similar experiences and struggles lends reinforcement for applying similar standards of care specific to how best to support parents regardless of the idiosyncratic nature of the child's condition.

### Limitations and Recommendations

As in all studies, this research was not without limitations. The cross-sectional nature of the study's design precluded understanding how the perspectives of parents change over time. Other limitations include a sample that lacked cultural diversity and that was mainly composed of mothers. We also recognize that parents in our study worked together in protecting their child with autism and as such, the findings may not reflect the experiences of single parents who lack the support of the other parent in parenting their child with autism. Future work addressing these limitations may result in additional stories of parents of children with autism. Despite the limitations, our findings help to confirm what it is like to be a parent of a child with a chronic condition such as autism, which might help professionals to provide more comprehensive and sensitive care. This study is important in light of the growing number of children diagnosed with autism (Committee on Children With Disabilities, 2001). The meanings parents assigned to their experiences could be used to inform future policy and program development.

Although there has been a dramatically increased understanding within the past two decades of the etiology, diagnosis, and management of autism (Committee on Children With Disabilities, 2001), this study reinforces that there are still gaps between what is done in model autism programs across Canada and the United States and what is generally available for most young children (Bryson et al., 2003; Committee on Children With Disabilities, 2001). A seamless system that will help to foster more enduring relationships between parents and all professionals involved in the care of children with autism should be fostered (Sperry,

Whaley, Shaw, & Brame, 1999). Professionals, family, friends, and others in the system who lack an understanding of the impact that autism has on children and parents need to be educated. Professionals caring for families of children with autism should be made cognizant of the concerns and meanings parents assign to their experiences. Sperry and colleagues (1999) also recommended that professionals assist parents in their role of advocator by familiarizing parents with their rights and by helping them to negotiate the service delivery system. Future work may be directed to doing intervention studies that involve the “expert” parent’s teaching the professional how to respond to parents of children with chronic conditions and/or disabilities. Given the expertise of parents of children with autism, parents could become invaluable assets in helping professionals understand human relationships and responses.

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