

The Quality of Life in Families of Children with Autism:
A Comparison with Families of Children who do
Not Have Autism

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Abstract

Using a mixed-method, this study examined the quality of life in families of children with autism in comparison with families of children who do not have autism. Participants consisted of parents of 17 children with Autism aged 6 to 12 years old and parents of 17 children who did not have Autism. The former group was recruited through intervention programs for children with Autism and their families in British Columbia, as well as Ontario. Among the families of children with autism, the incidence ratio of male to female children (4:1 to 5:1, based on DSM-IV, APA, 2000) is reflected by the number of families had male versus female children with autism. The latter were recruited through letters sent home with children from their schools and local after-school care programs in Victoria, B.C.

Participants completed a survey package consisting of: the *Quality of Life Inventory (QoLI)*, *Family Environment Scale (FES)*, *Family Support Scale (FSS)*, *Child Behavior Checklist* and a demographics questionnaire. Parents of children with autism also completed a questionnaire detailing the interventions their child has received and their degree of satisfaction with these interventions. Qualitative open-ended responses were also completed by all participants. The quantitative results reflected few significant group differences. Families of children who do not have Autism reported statistically significant greater satisfaction with their neighbourhoods and communities and annual household income than did families of children with Autism. Within families of children with Autism, those with higher annual household incomes had access to more interventions and of longer durations. They also reported shorter waiting periods to access such programs than did those with lower household incomes.

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Acknowledgments

There are a number of people without whose assistance, completion of this study and thesis would not have been possible. With the encouragement, guidance and wisdom of Dr Lily Dyson, I was able to conceive of and pull together this project. I would also like to extend appreciation to Dr Jim Tanaka and Dr Margie Mayfield for their feedback, support and assistance in bringing this project together.

The families who participated are many and I would like to extend a heartfelt thank you to each and every one of them for revealing details, at times, quite personal about themselves, their children and their lives. Without their generous contribution, this study and thesis never would have come to fruition.

The many centres, schools and parents' groups who allowed me to recruit through them have also been particularly helpful, from meeting with me, distributing information to their clients, to inviting me to participate in their meetings and including me in their mailing lists. While I am incredibly grateful to these centres and their staff for all their assistance, I have chosen not to acknowledge them by name. This is in order to honour my guarantee of confidentiality to the participants.

On a more personal note, I wish to say "thank you" to my parents, Linda and Gardner Church for their ongoing love and support (especially the encouragement, problem solving, reality checks and pep talks). And of course, my personal cheering section, Meghann Fior, Linnea Hagens, Kara Josephson and Aimie Shaw.

Dedication

This study is dedicated to all families. I am constantly amazed at the strength and love demonstrated by families in all kinds of situations.

This study is also dedicated to children with autism. These children struggle to learn and cope with so much in such a short period of time and yet, they maintain the sense of wonder and joy that makes childhood so special. I remain inspired by their persistence and exploration of the world.

Most especially, I want to dedicate this work to my own family, my inspiration for studying families: Mom, Dad, Anthony, Katharine, Emma and Charlotte. My grandparents are also to be mentioned, especially Pappy, who guided me to autism intervention. I have been blessed with such a wonderful and loving family and hope to ensure the same for all the children I may reach throughout my career.

WELCOME TO HOLLAND

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Chapter 1

Introduction

Autism is a pervasive disorder impacting every aspect of the child's life. For the purposes of this study, autism will refer to the diagnosis of autism, according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* (APA, 2000). Thus, references to children with autism indicate that the children meet the diagnostic criteria for autism, such as; (a) impaired social interaction, (b) lack or deviancy of social reciprocity, (c) delayed or deviant verbal language, with no independent attempt to compensate using other forms of communication, (d) inability or deviant play, (e) repetitive and stereotyped (sometimes aggressive or maladaptive) behaviour, (f) delayed or deviant functioning in one of three areas: "1) social interaction, 2) communicative language (e.g., child does not use language to convey information), and 3) symbolic or imaginative play" (APA, 2000, p. 70-71).

The features of autism present several difficulties to the individual with the disorder, as well as those who interact with him/her. Problems presented in autism can include (but are not limited to): (a) tantrums when there is a change in their daily routine or environment or when they cannot immediately gain access to desired items, (b) they may also engage in aggression or self-injurious behaviour, thereby threatening their own safety, as well as the safety of those around them, (c) they also often experience communication impairments, rendering it difficult to discern what they are communicating and/or their communicative intent, (d) inability to engage in imaginative play, and (e) inability or difficulty generalizing and maintaining skills (e.g., self-care skills, social skills and academic skills).

The transactional nature of family relationships results in each family member being impacted differently by the presence of a child with a developmental disorder (Dyson, 1996). Parents often report becoming overly involved in their child's disorder, thereby losing a sense of self (Cashin, 2004). Parents also often report high rates of anxiety and stress due to their child's autism. The presence of a child with autism may impact the family in many aspects and includes: (a) quality of life (QofL), (b) family functioning, and (c) social support.

Effect of Autism on Family Quality of Life

Quality of Life (QofL) refers to general feelings of: (a) well-being, (b) positive social involvement, as well as (c) opportunities to achieve personal potential (Schalock et. al., 2002). This research examined each of these factors within families of children with autism. Specifically, it considered the ability of family members to experience satisfaction across domains of QofL, family cohesiveness, and access to social support.

For the purpose of this paper, family functioning will refer to those criteria set out by Dyson (1996; 1997). These include: (a) family cohesion, (b) expressiveness, (c) conflict and (d) pursuit of personal interests. The family environment, as well as the activities the family is able to engage in, are affected by the behaviour and needs of the child with autism. Caregivers and family members of children with autism can often experience social isolation, financial expenses and health problems which compromise their QofL more so than those living with typically developing children (Cashin, 2004; Dyson, 1996).

In a phenomenological study examining the experience of parenting a child with autism, Cashin (2004) reports four domains of family functioning which decrease in the presence of autism. Similar to Schalock's (1996) measures of QoFL, these domains include: (a) development and activity, (b) stress and emotional well-being, (c) financial considerations, and (d) physical health, indicating the importance of examining how these domains are impacted by the presence of a child with autism. In addition to studying quality of life, it is important to examine the context within which QoFL is occurring. For the purpose of this study, the context is the family.

Effect of Autism on Family Functioning

In their study analyzing the psychological well being of mothers of children with autism, Rodrigue, Morgan, and Geffken (1990) measured the mother's sense of family adaptability and cohesion, social support and the impact of autism on the family. These mothers reported not only less marital satisfaction and high family cohesion, but less family adaptability. These findings reflect Cashin's (2004) finding that parents of children with autism become absorbed by the disorder, limiting their activities to those which the child with autism can or will participate in.

In a study examining the psychosocial adaptation of fathers of children with autism and Down Syndrome in comparison with fathers of typically developing children, Rodrigue and associates (1992) found that fathers of both children with autism and Down Syndrome reported more financial impact and inability to engage in family-oriented activities than fathers of typically developing children. While fathers tend to report higher levels of social support and higher levels of satisfaction raising their child with special needs than mothers typically do, this may be due to gender-

typed roles. Boyd (2002) reports that mothers tend to report lower levels of parenting satisfaction and social support when raising a child with special needs, while reporting higher levels of stress and anxiety. The author argues that this is due to mothers' higher rates of involvement in the daily activities and needs of their child with special needs. Nevertheless, Boyd (2002) found that it is apparent that both mothers and fathers of children with autism report higher rates of stress and lower levels of social support than do parents of children with Down's Syndrome, as well as parents of typically developing children.

Effect of Autism on Social Support

According to Dyson (1997), social support refers to the emotional and physical comfort provided by family members, friends, and others within our social network. This definition of social support also incorporates the community of individuals who provide services, such as teachers, doctors and other care-providers. In families with typically developing children, relatives, friends and parents of their children's peers tend to become parents' main sources of social support. Families of children with autism require services and supports which differ from those families whose children do not have autism. Consequently, the opportunities to encounter and interact with others are also different.

Because families with a child with autism must accommodate the needs of their child, they have less free time to associate with others or engage in activities where they would develop social contacts. Due to the behaviours associated with autism, families often must limit the places and events to which they can go as a family. These behaviours are often not understood or tolerated by parents' family

members and peers. Consequently, parents of children with autism often report feeling rejected by their friends and families (Cashin, 2004). Families of children who have autism reported that they have fewer social contacts than do families of children who do not have autism.

Families with a child with autism tend to lose valuable sources of social informal support. However, they may gain more formal support, such as that from service providers. For instance, in a study examining the relationships available to parents of children with developmental disabilities, Chopra and French (2004) report that parents tend to report the service providers and professionals who assist them with their child's needs as being their main source of social support. These findings are supported by findings in a study examining parental stress, family functioning and social support as reported by mothers and fathers of school-age children with developmental disabilities (Dyson, 1997).

According to Boyd (2002), social support is extremely important to parents, not only for their own psychological well-being, but also for that of their child. Apparently, parents of children with autism who have access to strong sources of social support tend to be more effective parents in terms of developing skills to cope with their child's needs. Consequently, these parents also tend to report lower rates of problem behaviours. Thus, it is possible that those parents who report loss of social contacts and opportunities to pursue interests beyond their child will also be those who tend to report lower satisfaction and senses of self-efficacy in their parenting a child with autism.

Despite several findings of the negative effects a child with autism present to the family, other studies indicate that the presence of a child with special needs is beneficial to families (Scorgie & Sobsey, 2000; Todd & Jones, 2005; Yau & Li-Tsang, 1999). Children with developmental disorders, as well as their families, tend to be studied under a medical model (Yau & Li-Tsang, 1999), resulting in data which reflects only the negative aspects of having a disorder and/or raising a child who has one (Hassall, Rose, & McDonald, 2005; Li-Tsang, Yau, & Yuen, 2001; Scorgie & Sobsey, 2000; Todd & Jones, 2005; Yau & Li-Tsang, 1999). In fact, when given the opportunity to reflect upon how having a child with a developmental disorder has changed them, many parents will state that their child's disorder forced them to reassess their lives, as well as their values and that the child's disorder has had a positive impact on their family (Scorgie & Sobsey, 2000). Such findings have been explained by applying Dabrowski's model of positive disintegration (Dabrowski, 1976).

Positive Disintegration

According to Dabrowski's (1976) model of positive disintegration, two processes take place during the reaction to trauma or stressful events. The first process is the replacement of prior attitudes with new ones by achieving or experiencing sequential learning or development. The second process which must take place is the incorporation of these processes into one's personality. In order to pass through these processes, the individual must go through five levels of disintegration: (a) primitive integration, (b) uni-level disintegration, (c) multi-level spontaneous disintegration, (d) organized, systematize spontaneous disintegration,

and (e) secondary integration, which occur through experiencing external and internal conflicts (e.g., societal pressures and emotions). Thus, in the present case, one would replace negative attitudes toward raising a child with a developmental disorder with positive attitudes through the experience of parenting such a child and accessing support services.

The replacement of negative attitudes would then be reflected in one's personality and approach to life and situations on a day-to-day basis. In order for this model to occur according to Dabrowski's (1976) postulation, disequilibrium, such as a crisis or major challenge, is necessary for such a transformation to occur. In the present example, the disequilibrium may be the presence or diagnosis of a child with a developmental disorder or a diagnosis of a developmental disorder. Equilibrium can then be achieved through coping, acceptance and adjustment, reflected by a transformation in terms of attitudes and behaviours toward the situation.

Taking into consideration such findings as those made by Boyd (2002), Cashin (2004) and Dyson (1997), it is apparent that families of children with autism will report a significant amount of difficulty in their day-to-day functioning. However, in light of Dabrowski's (1976) theory of positive disintegration, as well as such findings as those made by Scorgie and Sobsey (2000), Todd and Jones (2005), and Yau and Li-Tsang (1999), it may well be that families of children with autism do adapt and function following a period of adjustment to the symptoms and needs posed by the disorder. By measuring QoL, family functioning and social support, it may be possible to examine the day-to-day functioning of families of school-aged children with autism in order to determine whether they adjust to the needs and symptoms

associated with autism in order to achieve a QoFL comparable to those families in which the children do not have autism. Additional qualitative analyses may be conducted within the families of children with autism in order to determine what formal and informal supports have been sought and/or enacted in order to address difficulties the child or family are having and assist with the process of adaptation and achieving equilibrium.

Statement of the Problem

It is, thus, unclear whether the presence of a child with autism negatively influences the family in terms of QoFL, family functioning and social support. The research demonstrates that there are several consequences to the presence of a child with autism in the family. Some of these are negative or disruptive (Boyd, 2002; Cashin, 2004; Dyson, 1997), while others appear to be positive (Scorgie & Sobsey, 2000). Further research suggests families adapt to accommodate the needs and changes that result from autism (Perry, 2004; Scorgie & Sobsey, 2000). The discrepancies reflected in the research regarding families of children with autism and their experiences raise several questions. Specifically, this mixed-methods study attempted to answer the following questions: (a) Is there a significant difference between the quality of life of family members when a child between the age of 6 to 12 years old has autism and the quality of life in families of children of similar ages who do not have autism? And (b) If differences do exist, what are they? In order to guide policy and practice effectively, it is necessary to determine whether a difference between their experiences and those living with children who do not have autism, in terms of QoFL, family functioning and social support exists.

Purpose of the Study

In the study of autism, a gap in knowledge exists concerning QofL, family functioning and family social support in families of school age children. A further quandary is how these aspects of family life in families of children with autism compare with families of school-age children who do not have autism. Specifically, the objectives of this study are to apply quantitative measures and qualitative analyses in order to explore aspects of family life within families of children with autism in comparison to those whose children do not have autism in terms of: (a) QofL, (b) family functioning and (c) social support. Further analysis among the families of children with autism identified whether receipt of intervention reduces problems for these families.

According to Nastasi and Schensul (2005), qualitative and quantitative methods of research are required in order to provide balanced, evidence-based intervention programming to individuals with autism. In their study examining the contribution of qualitative research to autism intervention, the authors concluded that valuable findings regarding the experiences of the individual, as well as of his/her family members and service providers has historically not been used to benefit the person with autism or those he/she interacts. The information gleaned by qualitative study is valuable in exploratory research as it can help the researcher to identify the needs of the family and to inform program design when addressing these needs. As will be demonstrated, the findings made using quantitative data are often quite different from the reports participants provide within qualitative measures.

This study is important because there is: (a) a discrepancy between findings among various research studies regarding the experiences of families of children with developmental disorders, (b) little information regarding the QoFL of families of children with autism, and (c) little comparative information between the QoFL of families of school-age children with autism and those of children who do not have autism.

Hypotheses

In order to narrow and guide this research, several hypotheses have been formulated. These include:

1. There are differences in terms of Quality of Life and family functioning between families of children with autism when compared with families of children who do not have autism. Specifically, families of children with autism tend to report lower levels of Quality of Life and family functioning than do families of children who do not have autism.
2. Families of children who have autism will report statistically significantly greater dissatisfaction with and significantly less social support than do families of children who do not have autism.

These hypotheses are based on findings in previous research, which examined similar variables in families of children with other developmental disorders (Andersson, 1988; Cashin, 2004; Dyson, 1996; 1997).

Summary of Chapter One

This chapter introduced the diagnostic criteria and features associated with Autism and indicated the potential influences the presence of autism may have on

various aspects of family functioning. The importance of conducting this exploratory, mixed-methods study in order to establish the possible influences was also highlighted.

Glossary

Autism Spectrum Disorder: Listed in the DSM-IV (APA, 2000), Autism Spectrum Disorder (ASD) is a pervasive developmental disorder, meaning that it is characterized by varied impairment across several areas of development and functioning. These areas include: social reciprocity, communication, stereotypic behaviour, interests and activities. Characteristics common to ASD are reflected either as delays in functioning or deviant functioning. (APA, 2000)

Autism: This disorder lies on the spectrum referred to in ASD. The diagnostic criteria for autism, such as; (a) impaired social interaction, (b) lack or deviancy of social reciprocity, (c) delayed or deviant verbal language, with no independent attempt to compensate using other forms of communication, (d) inability or deviant play, (e) repetitive and stereotyped (sometimes aggressive or maladaptive) behaviour, (f) delayed or deviant functioning in one of three areas: “1) social interaction, 2) communicative language (e.g., child does not use language to convey information), and 3) symbolic or imaginative play” (APA, 2000, p. 70-71).

Chapter 2

Review of Literature

The presence of a child with autism can have a profound impact upon family members in several areas of their lives. In this chapter, the effect of the presence of a child with autism in a family will be examined from the existing research. This chapter will review literature pertaining to the quality of life (QoL), family functioning, and social support in the presence of a child with autism in the family. It will also consider studies which have been conducted with regards to these variables in families of children with autism and/or developmental disorders. The purpose of this evaluation is to establish what data, pertaining to the experience of raising and/or living with a child with autism, are currently available. It will also provide a context for the current study. The concept of QoL, as well as its measurement will be discussed.

While the literature, as will be discussed in later sections of this chapter, reveals several examples of the difficulties associated with the presence of a child with autism within the family, such an experience need not be solely negative. Though Cashin (2004) states that parents of children with autism face a period of crisis upon initial diagnosis of their child's disorder, there is literature which suggests this period may be only temporary. It may be that although the presence of a child with autism poses difficulties on a day-to-day basis, families adapt to the needs of their child with autism.

Stress

A popular model of family stress was performed by Hill (1949, as cited by McCubbin, et al., 1980). This model, known as the ABC-X model, postulates that an event or hardship arises (A), interacting with the family's ability to cope with or address the crisis, which is based upon the resources available to them (B), which in turn interacts with how the family defines the event (C). The combination of these three factors results in the crisis, as perceived and/or experienced by the family (X). Hill's model of stress also allows for consideration of how the family adjusts to the stressor. This involves a preliminary stage of disorganization, an angle of recovery (which is very much based upon family definition of the crisis, as well as resources available for coping) and a new level of organization.

The ABCX model of stress has subsequently been added to and modified by others in an attempt to better define stress and the variables which contribute to or are impacted by stress. For instance, the Double ABCX model allows for consideration of several stressors (e.g., the initial crisis, followed by work related problems), new, as well as existing resources available to the family, and a modified definition of the stressor over time. However, Perry (2004) argues that this model of stress is limited when applied to research on families of children with developmental disorders because: (a) the stressor (e.g., the diagnosis or presence of a developmental disorder) is conceptualized as a crisis and (b) the model assumes adaptation to the crisis or stressor. As children with developmental disorders continue to develop across the life span, there will always be new experiences and transitions required of all family members (McCubbin, et al, 1980; Perry, 2004; Scorgie & Sobsey, 2000; Todd &

Jones, 2005). Thus, a model of stress which acknowledges that the presence of a child with a developmental disorder is not a static crisis, but an adaptation which is present over the life course, is necessary.

In her model of stress in parents of a child who has a developmental disorder, Perry (2004) has identified the characteristics of the child (e.g., propensity toward aggression, degree of dependency) and stress encountered as a result of daily living (e.g., employment, illness in a family member) which contribute to parental outcomes (e.g., parent's satisfaction with parenting the child, family environment, interventions) in terms of stress. According to this model, the factors which mediate whether the parent(s) achieve(s) positive or negative outcomes are: (a) the resources available to the individual (e.g., personality variables, coping strategies, beliefs), (b) family system resources (e.g., demographic variables, marital satisfaction), as well as (c) informal social supports (e.g., emotional support, child care assistance) and (d) formal supports and/or services (e.g., intervention programs, clinical services).

Negative outcomes can be achieved when: informal or formal supports and/or services are lacking in quantity or quality, when there is a lack of resources available to the family and when parents tend to have a negative perspective regarding the child's disorder (Perry, 2004). In fact, Perry (p.12) identifies "professional run-around" (e.g., when parents are referred to various professionals in order to learn about various aspects of the disorder and/or treatment options) as a predictor of negative outcomes. Conversely, when parents have positive outlooks and expectations for their child, they tend to report lower levels of stress. According to

Perry, it is difficult to determine whether these outcomes are a result of the quality or quantity of supports available to them.

In Perry's (2004) model of stress, major stressors are identified as falling into seven domains: (a) child characteristics, (b) other life stressors, (c) individual personal stressors, (d) family systems resources, (e) informal social support, (f) formal supports and services and (g) parental outcomes (e.g., those stressors or characteristics, such as personality, emotional states, cognitive appraisals, and attributions about those emotional states, which are not accounted for by considering the first six domains). The advantages of this model are that it provides a comprehensive approach to examining the influences of stress on QoFL within the context of the family, based upon literature and research across several areas (e.g., family systems and stress, coping, social support, developmental psychology, ecology theory).

Identification of sources of stress helps to determine which issues within the context of the family are most in need of addressing and improving upon in order to alleviate the stress experienced by families of children with developmental disorders in order to improve the individual family members' (as well as the collective family's) QoFL. However, this model does not account for changes over time or across developmental stages. In order to address this limitation, Perry (2004) suggests conducting either longitudinal studies or those which have a focus such as the present study. That is, to study families of children with developmental disorders at a specific life stage in order to compare them to those families whose children do not have a developmental disorder.

Positive Adaptation

There is expansive literature linking parents' attitudes and expectations with the outcomes of children with developmental disorders (Field & Hoffman, 1999; Turnbull & Turnbull, 1996). Despite the negative outcomes of parenting a child with a developmental disorder, some parents have reported positive aspects to parenting a child with a developmental disorder (Li-Tsang, Yau, & Yuen, 2001; Rose & McDonald, 2005; Scorgie & Sobsey, 2000; Todd & Jones, 2005; Yau & Li-Tsang, 1999). In a qualitative review of mothers of adolescents with developmental disorders, mothers reported that during their child's early childhood, they had placed a lot of importance upon seeming to be an "ordinary family" (e.g., being a family whose children did not have exceptional needs) (Todd & Jones, 2005). However, as the mothers adjusted to their child's needs, they tended to legitimate their own family as being worthwhile. These mothers also tended to question their parenting abilities less as they became more comfortable with their abilities to parent a child with a developmental disorder.

Other positive effects can occur with the presence and resulting duties of a child with a developmental disorder. In a study examining transformations in parents of children with various developmental disorders, Scorgie and Sobsey (2000) found that parents of such children reported that their self-esteem and self-confidence had increased as a result of advocating for their child. Parents of children with developmental disorders also reported developing a good sense of humour about themselves, as well as their child's disorder. In fact, many parents reported that they

found themselves smiling and laughing more often than they had prior to the birth of their child.

The parents reported that it was not the experience of parenting a child with developmental disorders that elicited increased happiness, but the cultivation of a sense of humour which allowed them to maintain a sense of balance in their lives (Scorgie & Sobsey, 2000). Interestingly, parents also reported that their marital relationships and social networks improved. While many parents reported that the presence of a disorder in their family had increased tension within a marriage, it also forced parents to work together in order to ensure positive outcomes for their child, as well as the rest of the family. Another source of support they had received from other parents in similar situations was crucial to their parenting success. Finally, parents also reported changes in their attitudes toward other people in general and to their perspectives toward life. Parents suggested that they had become more understanding of and patient with others, as well as more willing to help. The parents also reported that they had changed their perceptions about what is important and valuable in life.

Characteristics for Successful Adaptation

Using qualitative data, Li-Tsang et al. (2001) attempted to identify characteristics of successful parents of children with developmental disorders. The determining features for success fell under the following categories: personal resources, family and marital relationships, parent-child relationships, and attitudes and values, reflecting characteristics present in both Schalock's (1996) QoL model and Perry's (2004) model of stress. Successful parents tended to be: self-confident, pro-active, positive, sociable and outgoing. They accepted their children and

advocated for them. They actively sought resources and information related to their child's disorder, advocating for empowerment opportunities for their child. This group of parents also tended to have higher educational backgrounds than did families with less successful adaptation.

While several participants reported that one or the other parent had left their professional careers to care for the child, the participants in their study tended to be pro-active and highly motivated (Li-Tsang et al., 2001). They also tended to make their family their first priority in life, reporting high rates of spousal support. All parents reported that they would accept their child, regardless of the challenges and criticism they would face across the lifespan. Many parents, though not all, suggested that they emphasized family relationships over material benefits, as well as viewing their lives positively. Few parents engaged in intrinsic or extrinsic blaming for their child's difficulties, while most parents reported that they would readily seek assistance from family members and support groups. Several parents also reported that professional support and advice had been extremely helpful in the early stages of their child's development. Literature thus suggests that the presence of a child with autism induces stress for families which may affect various aspects of family life in a negative manner. However, family may also develop adaptation strategies. It becomes important to examine these negative and positive effects on the family life that centers on QoL, family functioning and social support.

Moreover, the contradictory evidence that the presence of a child with a developmental disorder may be detrimental or beneficial to the family, it is necessary to determine those factors which will lead to successful adaptation in parenting a

child with a developmental disorder. In addition to the contradiction in the literature regarding the presence of a child with autism, Perry's model of stress and the phenomenon of positive adaptation must also be considered. There are several criteria which influence positive adaptation. However, it is unclear whether stress and/or positive adaptation among these families may be reflected in terms of these criteria. For instance, it is unknown whether QofL, family environment and social supports available to the family differ as a result of the presence of a school-aged child with autism.

Quality of Life

Schalock's (1996) model of QofL takes into consideration various aspects of the lives of those with disabilities and developmental disorders. He argues that such consideration will help to assess whether individuals with special needs are able to participate in the mainstream, enjoying access to the emotional and physical well-being, material aspects and self-actualization that their typically developing counterparts have access to on a regular basis. As Schalock (1996) has suggested, QofL is a multidimensional construct, taking into consideration cultural values and attitudes, as well as individuals' ability to understand and respond.

There are varying uses of measures of QofL, and measures of QofL can focus on the individual or on a group. Thus, Schalock (1996) proposes a conceptual model of QofL, employing a "five-way categorization of life domains" (p. 126). This model considers: (a) physical well-being (e.g., health, fitness, mobility, and personal safety), (b) material well-being (e.g., finance and income, environmental aspects, transport, security, and job security), (c) social well-being (e.g., quality and breadth of

interpersonal relationships, and community involvement), (d) development and activity (e.g., acquisition and use of skills and productivity and contribution, and (e) emotional well-being (e.g., affect, fulfilment, stress and mental state, self-esteem, status and respect, religious faith, and sexuality). These five categories reflect aspects which can be impacted by life challenges and which in turn impact reported experiences of stress within Perry's (2004) model of stress.

Quality of Life: Importance

It is important to consider the QoFL of those with special needs within the context in which the individual lives (Poston, Turnbull, Park, Mannan, Marquis, and Wang, 2003). For the purpose of this study, QoFL will be defined according to Schalock's conception of QoFL. This definition refers to one's feelings of well-being across a number of domains. The context considered in the current study is the family. Children with autism tend to live with their families, who are required to consider their needs and behaviours on a daily basis. As has been demonstrated, this can create stress and anxiety within families. This in turn has been associated with frequent reports of health related problems, difficulty of the parents to attain their career goals and financial needs (Poston et al., 2003).

According to Poston et al. (2003), research into individual Quality of Life (QoFL) has been carried out far more extensively than family QoFL. The authors argue that while individual QoFL is necessary, studies of family QoFL become an extension of QoFL measures, because individuals tend to participate within the context of a family. Thus, determining how the family functions and what supports are available to them allows service provision to take these into consideration when

designing and/or coordinating services for the individual and the family such that they are appropriate to their needs. These measures are particularly pertinent in a climate which emphasizes family-centred services, which the authors suggest has become the trend in service provision to individuals with disabilities or disorders, as well as to their family members.

According to Schalock (1996), QofL has become a major principle, affecting “social, political, technological and economic trends” (p. 123). Furthermore, he argues that current practices surrounding programming and caring for individuals with developmental disorders emphasize “self-determination, inclusion, equity, empowerment, community-based supports and quality outcomes” (p. 123). Shifts toward relying less upon public, standardized support (e.g., deinstitutionalization) result in requiring the individual and family to independently meet the needs previously met by these institutions. Thus, it is necessary to ensure that these individuals continue to maintain a reasonable standard of living, comparable to that enjoyed by the general population.

Contrary to Schalock’s (1996) contention, Wolfensberger (1994/1996) argues that, in fact, measuring QofL among individuals with disabilities and disorders, as well as their families, is a harmful practice. He suggests that by doing so, notions of QofL become confused with valuation of life. Furthermore, he suggests that measuring QofL in comparison with the general population is harmful, as it fails to consider individual differences. However, Schalock (1996) has proposed a model of QofL which takes into consideration, not only objective measures of an individual’s QofL, but also considers the individual’s subjective interpretation of his/her QofL.

Furthermore, he argues that consideration of an individual's QoFL must take into consideration his/her personal circumstances, allowing for as much self-determination as possible.

Family Quality of Life: Effect

There has been extensive research conducted regarding quality of life in families of children with various developmental disorders (Andersson, 1988; Bagenholm & Gillberg, 1991; Cuskelly & Gunn, 1993; Duvdevany & Abboud, 2003; Dyson, 1996; 1997), but few of them take into consideration families of school-aged children with autism. Research, however, suggests that the QoFL of families of school-aged children with autism would also be affected, likely, negatively.

Due to the transactional nature of family relationships, when a child has a disorder, it impacts each member of the family in various ways (Becker-Cottrill, McFarland, & Anderson, 2003; Cashin, 2004; Dyson, 1996; Greenberg, 2004; Poston, et. al., 2003; Poston & Turnbull, 2004). While much of the research regarding QoFL, well-being and parent-child relationships with children with autism tends to focus on the mother-child transaction, the entire family and individual members of the family are impacted by the presence of this disorder. As a result of the symptomatology and needs of an individual with autism, caregivers and family members often report experiences and issues which compromise their ability to realize a satisfactory QoFL (Cashin, 2004).

According to Gray (2002), the years immediately following diagnosis of autism for a child tend to be extremely stressful to families. Families encounter for the first time the behaviours, needs, educational policies and treatment issues and

must learn to negotiate and adapt their expectations accordingly. In a ten-year, qualitative, longitudinal study, Gray (2002) found that during this period, parents reported physical health problems (often stress related), career problems, anxiety, and depression. Many reported seeking psychotherapy and/or using medication to help them cope. Parents reported that they had altered their lifestyles such that they no longer resembled the lives they had envisioned for themselves or their children. The areas most altered fell into areas as follows: (a) development and activity, (b) unreinforcing parenting experiences, (c) the impact of attitudes family members encounter, and (d) anxiety over the adjustment of typically developing siblings.

In a phenomenological study examining the experience of parenting a child with autism, four domains of family functioning decrease in the presence of autism (Cashin, 2004). Similar to Schalock's (1996) measures of QoFL, these domains are: (a) development and activity, (b) stress and emotional well-being, (c) financial considerations, and (d) physical health, indicating the importance of examining how these domains are impacted by the presence of a child with autism.

It is imperative that parents and other family members of a child with a developmental disorder are able to maintain interests and activities which allow them to realize their own self-actualization (e.g., their ability to participate in activities and achieve the goals they have set for themselves), as this is something that is valued by those not caring for an individual with special needs (Schalock, 1996). In Gray's (2002) study, it was found that mothers, more often than fathers, reported not being able to follow their desired careers as a result of their child's needs. Furthermore, both fathers and mothers reported reduced pay, increased absences and fewer

promotion opportunities as a result of their child's needs. Such consequences can impact not only a parent's ability to realize self-actualization, but also his/her sense of well-being.

When a child has autism, parents report a variety of impacts to their QoFL, such as limited access to social supports, financial impacts and concerns for the child's future, less time for oneself and a need for respite, experiences of guilt and resentment toward the child and stress related to caring for the child with autism (Cashin, 2004; Greenberg, 2004; Järbrink, Fombonne, & Knapp, 2003; Miles, Takahashi, Haber, & Hadden, 2003; Paquette, 2004; Rodrigue, Morgan, & Geffken, 1990, 1992). Families who are having difficulty meeting their own needs will not be as helpful to their child or sibling who has autism as those who are experiencing greater degrees of satisfaction with their QoFL.

According to Cashin (2004), parents report high levels of stress when considering the options available to their child with autism for when they are no longer able to care for him/her. Parents must ensure that their child's financial needs will be provided for. This extends not only to once the parents have retired and are earning a set income, but also to when they have died and the child has no or a limited source of income. Given the various financial considerations faced by families with a child with autism, it is apparent that they often face many challenges which inhibit their ability to maintain a QoFL comparable to those raising typically developing children.

In an interview with Bryson (2003), she states that the failure to expand the focus from early intervention to including research about interventions and services

required by families of children with autism across the lifespan, as well as those currently available to these people with autism during early childhood, has resulted in poor service provision to this population. For most families, the intensive intervention programming is prohibitively expensive and results in parents not seeking the interventions they require or spending less in other areas of their lives. For instance, according to Marin (2005), many families will have several mortgages on their homes, will sell their houses or may not be able to afford houses as a result of the costs related to providing interventions and care to their children. Furthermore, Cashin (2004) also states that parents report costs associated with damages incurred by their child's behaviour as another source of financial strain. Among the domains of QoFL proposed in Schalock's model of QoFL, access to financial resources plays a significant role in attaining and maintaining a desirable quality of life. When additional strain is placed upon one's financial resources, it threatens a domain of QoFL which can then impact upon one's ability to achieve and maintain satisfaction within other domains of QoFL. For instance, in the above case, families may opt for less suitable or safe accommodations for their families in order to ease the financial strain they are experiencing. It may also impact one's ability to pursue and fulfill one's own interests and goals, another domain within Schalock's (1996) model of QoFL.

As the child becomes physically larger, behaviours and/or aggression can become unmanageable and/or dangerous to caregivers, requiring the services of ongoing, professional care. However, the cost to house, care for and meet the needs of such an individual range from \$400 to \$600 CDN per day (Marin, 2005). In the

province of Ontario, this situation has resulted in parents unable to afford to provide adequate and appropriate care to their child, relinquish custody rights to children's aid services in order to ensure their child receives the care he/she requires. In such circumstances, parents are required to testify in court that they are unable or unwilling to care and provide for their child.

Family Functioning: Importance

The transactional nature of family relationships results in each family member being impacted differently by the presence of a child with a developmental disorder (Dyson, 1996). The emotions associated with the presence of a child with autism within a family are varied and can influence family cohesion. For instance, attachment between the child with autism and each family member may be quite different from attachments observed between a typically developing child with each of his/her family members. There are varying theories and conceptions about the causes and consequences of autism (Sigman & Mundy, 1989). For instance, there is some evidence that the primary deficit of autism is a global impairment of social and emotional functioning, precluding attachment and bonds between infants with autism and their caregivers (Buitelaar, 1995; Rogers, Ozonoff, & Maslin-Cole, 1993). Conversely, another theory suggests that autism is the deficit of a specific set of social skills (i.e., the inability to empathize and to interpret cues conveyed expressing other people's internal states). There are also some who postulate that autism is primarily biological in nature, interfering with attention and arousal systems. In this case, attachment would be possible, yet unreinforcing and at times, punishing for the child (Rogers et al., 1993).

The response of a child with autism to attempts to bond with him/her can have a profound impact on the family members' satisfaction with their relationship with him/her. For example, while cuddling with a young child can be reinforcing for both the caregiver and the child, children with autism often have sensory excesses (e.g., perceiving sensory stimuli more intensely than would the average person) which make this experience quite frightening. Therefore, they respond by using self-protective measures (e.g., protesting, physical aggression) which would be punishing to the caregiver.

Another theory of autism, originally proposed by Bettelheim (as cited by Zimmerman, 1993), is one which attempts to blame the parents, namely the mother, for being cold and insensitive to the child. According to this field of thought, the primary caregiver creates a disordered environment by conveying rejection to the child, resulting in the child's pathology (Zimmerman, 1993). If this theory were supported, research would reflect this by reporting a lack of attachment between the child with autism and his/her caregiver, which it does not. Rather than reflecting a failure to attach, the child with autism will tend to display attachment in untraditional manners (e.g., pinching or sniffing the caregiver, throwing tantrums when the caregiver leaves). Furthermore, this theory would have to demonstrate that the parent-child attachment or lack thereof, is due to poor, negligent or insufficient care-giving.

Mother-blaming is a common experience among mothers of children with various disorders and disabilities (Zeanah & Larrieu, 2000). The impacts on the mother-child relationship, as well as on the mother's perception of her self-efficacy in caring for her child with special needs are often insurmountable. They can result in

hesitation to seek professional assistance and isolation from social supports (Zeannah & Larrieu, 2000), both areas which a parent of a child with a disorder or disability requires access to on a regular basis.

The stress associated with planning for the care of a child with autism across all stages of development can be daunting to families. As has been mentioned, parents of children with autism must often alter their career goals in order to accommodate the needs of their child. While doing so, they are also faced with excessive financial needs resulting from costs associated with interventions and problem behaviours (Cashin, 2004). The pursuit and attainment of one's career and personal goals is a domain in Schalock's (1996) model of QoFL. Not only would the inability to pursue one's career goals, but it would also impact another domain within the model of QoFL. In addition to impacting parents' ability to pursue their own career and personal goals, the presence of a child with autism also influences financial well-being.

A further consideration impacting the family's economic resources is planning for the care and long-term future of the child, once his/her parents are no longer able to care and/or provide for him/her. The costs associated with intervention, accommodating problem behaviours and saving for long-term care often results in strained financial resources and thus, accommodations made to the family's physical environment. The combination of the child's symptoms, parents' feelings regarding the disorder and/or its symptoms, as well as the impact of strained finances would presumably create a tense or unpleasant family environment.

Family Functioning: Effect

In a study analyzing the psychological well-being of mothers of children with autism, Rodrigue, Morgan, and Geffken (1990) measured the mother's sense of competence, coping, marital satisfaction, family adaptability and cohesion, social support and the impact of autism on the family. They also conducted observations of interactions between the mother and child with autism in comparison to those of mothers and their typically developing children or mothers of those with Down Syndrome. The mothers of children with autism reported less parenting knowledge and less value associated with parenting. This may be a reflection of their unfamiliarity with the characteristics, needs and behaviours associated with autism. These mothers not only reported less marital satisfaction and high family cohesion, but less family adaptability (Rodrigue, Morgan, & Geffken, 1990), reflecting Cashin's (2004) finding that parents of children with autism become absorbed by the disorder, limiting their activities to those which the child with autism can or will participate in.

Boyd (2002) reports that mothers tend to report lower levels of parenting satisfaction and social support when raising a child with special needs, while reporting higher levels of stress and anxiety. The author argues that this is due to mothers' higher rates of involvement in the daily activities and needs of their child with special needs. Nevertheless, it is apparent that both mothers and fathers of children with autism report higher rates of stress and lower levels of social support than do parents of children with Down's Syndrome, as well as parents of typically developing children.

Mothers of children with autism not only tend to report less satisfaction with their parenting experiences, marriages and family cohesion than mothers of children with Down Syndrome, but they also report greater levels of depression, anxiety and anger than do mothers of typically developing children (Gray & Holden, 1992). In fact, in their study examining the psycho-social well-being of parents of children with autism in Australia, it was found that both fathers and mothers reported high levels of depression and anxiety. Furthermore, no correlation was found between coping behaviours of parents (e.g., seeking help and information) and the degree of their psycho-social well-being, indicating that regardless of coping mechanism parents enacted, they continued to report lower levels of psycho-social well-being than did parents of typically developing children.

In a study examining the psychosocial adaptation of fathers of children with autism and Down Syndrome in comparison with father's of typically developing children, Rodrigue, Morgan, and Geffken (1992) found that fathers of both children with autism and Down Syndrome engaged in more wish-fulfilling fantasy and information seeking in order to cope. These fathers also reported more financial impact and inability to engage in family-oriented activities than fathers of typically developing children. While fathers tend to report higher levels of social support and higher levels of satisfaction raising their child with special needs than mothers typically do, this may be due to gender-typed roles.

In a study examining stress and adaptation of parents in families of children with and without handicaps, Dyson and Fewell (1986) found that families of children with handicaps reported stress levels almost twice as high as those of families of

children who did not have handicaps. Furthermore, the authors found that as the severity of the disorder increased, so too did the stress level reported by parents. According to this study, stressors included behavioural or attitudinal deficiencies demonstrated by the child, the severity of the disorder, physical incapacitation, and parental pessimism in terms of the child's disorder (Dyson & Fewell) suggest that family functioning is likely impacted by the presence of a child with autism.

Social Support: Importance and Effect

According to Dyson (1997), family stress resulting from a child's disability is influenced by the resources available to that family. Social support, personal perspective and life satisfaction of the other parent influences one's own satisfaction and adaptation to parenting a child with special needs (Perry, 2004). In a study examining the relationship between stress and social support on the well-being of Arab mothers of children with intellectual disabilities, Duvdevany and Abboud (2003) found that those who received greater amounts of informal social support (e.g., support from neighbours, friends, and family members rather than from clinical team members) reported lower stress levels and greater degrees of well-being than did mothers who relied primarily upon formal supports as their means of social support. Interestingly, education level of the mothers and their place of living were not related to the level of stress or well-being reported by mothers. This indicates that when they receive sufficient support, parents of children with developmental disorders are able to experience satisfaction with their lives and parenting experiences regardless of their socio-economic status. However, this study also found that educated mothers from urban areas tended to use government-funded support services less often than

did less-educated mothers from rural settings. Thus, it may well be that those who are educated have access to sources of support independent of government sponsored services. It is also likely that these sources of support are more numerous in more populous settings, such as urban areas and are, thus, easier to find independent of government organization.

In a meta-analytic review of literature regarding stress and the influence of social support on mothers of children with autism these results were replicated (Boyd, 2002). In fact, the author found that mothers of children with autism who received informal support repeatedly reported lower rates of stress than did those who relied upon formal social supports, such as clinical teams and government funded support programs. Furthermore, he suggested that lower levels of social support were significant predictors of depression and anxiety in mothers of children with autism.

Interestingly, Dyson and Fewell (1986) found that despite previous research which found that parents of children with special needs received significantly less social support than did parents of typically developing children, parents of children with disabilities tend to report perceiving higher levels of social support than do families of typically developing children. However, the sources of support they reported were more likely to be those related to public services associated with the disorder (e.g., professionals, agencies and parent support groups). It may well be that while families of children with disabilities do perceive greater degrees of social support they also require more professional assistance and support than do families of typically developing children. Thus, their sources of support are called upon more often than are those of families with non-handicapped children.

Summary of Chapter Two

Autism is a disorder which presents many challenges to the family. It does not preclude the individual with autism from interacting with his/her family members in a way which will be enjoyed by each other. It may well be that families with a child with autism face many challenges and threats to their QofL. However, the research discussed to date suggests that it is possible for these families to attain a QofL comparable to that of the mainstream. In order to do so, identification of the threats to their QofL is necessary. Also, because the characteristics of autism include aversive behaviours, families of children with autism must adapt their levels of expectation of reinforcing interactions with their child with autism. Parents of children with developmental disabilities tend to adapt successfully to the presence of a disorder in a child (Yau & Li-Tsang, 1999). According to the authors, these parents tend to reassess their goals and values for themselves, as well as for their child's so that they are more reflective of their situation.

This chapter also established the importance of examining QofL of families rather than individuals when considering the experience of those living with/raising a child with autism. Furthermore, this chapter ascertained the transactional nature of families and the influence that one person's disorder, in this case autism, has as a result. There are various theories regarding the nature of autism. Each of these theories suggests different consequences for the individual, as well as for those involved with him/her. Factors which enhanced parental adjustment and adaptation include: social support from extended family and friends, support from social services and formal interventions, and the family's interpretation of the disorder and its impact

upon the individual with the disorder, as well as upon other members of the family (Yau & Li-Tsang, 1999).

In light of the research reviewed in the current chapter, it is unclear what impact the presence of a child with autism has on the family. There are suggestions that families struggle as a result. However, other research suggests that the presence of a child with autism provides positive impacts. Thus, this chapter has revealed the need for further investigation in order to answer the following questions: (a) is there a difference between family members in terms of quality of life, family functioning and social support when a child between the age of 6 to 12 years old has autism and the quality of life in families of children of similar ages who do not have autism?

In light of the research presented in this chapter, it is hypothesized that:

1. Differences in terms of Quality of Life will exist between families of children with autism when compared with families of children who do not have autism. Families of children with autism will tend to report lower satisfaction with their Quality of Life and family functioning.
2. Families of children who have autism report statistically significantly greater dissatisfaction with and significantly less social support than do families of children who do not have autism.

The following chapter will include the methodology for investigating: family environment, family support, QoL, child behaviour and demographic information in families of children with and without autism.

Chapter 3

Methods

Overview

This chapter describes the methodology selected for this study. The purpose of this chapter is to discuss the participants of this study and their demographics, and procedure, as well as instrumentation and implementation of this study. This will serve to provide a framework for the findings of the study. Mixed methodology within research provides a comprehensive description about the subject at hand through the integration of research strategies (Cresswell, 2002).

While qualitative research is often dismissed by quantitative researchers as being 'subjective', it can provide valuable information about the actual experiences as reported by participants (Ercikan & Roth, 2006). Furthermore, it can provide objective data through the use of coding. Themes can be extracted from the responses provided by participants. These themes can then provide quantitative data about the number of participants who make the same responses. On the other hand, quantitative data has been criticized for only providing objective data, thereby limiting exploration into the actual experiences as reported by participants.

For the purposes of this study, *family* will refer to the unit in which the child with autism lives and interacts with on a daily basis. It will include parents or primary caregivers and, where applicable, siblings. Actual relationships of the primary caregiver will vary from biological parents, to step or foster parents, as well as any other form of primary caregiver, such as grandparents, where the biological parents are not present or providing care to the child. Schalock et al. (2002) argue that it is

important to measure QofL in populations which have been excluded from the mainstream as a result of disability because “every human being is entitled to live a good life within his or her environment” (p. 461). While the authors were referring to the QofL of individuals with disabilities or disorders, it is also necessary to measure the QofL of those who care for and live with these individuals.

The survey materials were piloted on four parents, two of whom being parents of children who had autism, while the other two being parents of children who did not have autism. The ages of the children with autism were 5 and 13 years old. The ages of the children who did not have autism were 9 and 5 years old. Parents of children with autism reported that their concerns with the study included: Ensuring confidentiality and informing parents that participation would be confidential, that parents have access to the results of the study upon completion, the studies need to reflect parents’ experiences with interventions, and that studies focus too much on measurement and empirical data while failing to consider qualitative data, making it less accessible to the general public. Parents of children who do not have autism reported that they wanted a guarantee of confidentiality and that the demographic questionnaire focused too much on autism. The issue of confidentiality was addressed in the letter of intent, indicating that participation would be confidential and voluntary. The focus of autism embedded in the questionnaire was deemed appropriate by the researcher, as the purpose of this study is to examine issues specific to family functioning in families of children who have autism.

Participants

Participants consisted of parents of 17 children with autism aged 6- to 12-years-old who were recruited through intervention programs specifically for children with autism, support groups, agencies and services designed specifically for children with autism and their families in Victoria, Sooke, and Saanich, British Columbia, as well as Toronto, Ontario. The comparison group consisted of parents of 17 children who did not have autism. These participants were recruited through letters sent home with children from their schools in British Columbia, as well as through local out-of-school care programs in Victoria, B.C.

Among the families of children with autism, the incidence ratio of males to females is between 4:1 and 5:1, based on *DSM-IV* (APA, 2000) in attendance at the programs, as there were more male children (and families thereof) than females requiring access to these services. While the study was open to all participants, regardless of social class, ethnic or racial group, almost all ($N = 34$) self-identified as being Caucasian, while one participant self-identified as part Caucasian and part Native. Parents completed survey materials. Among the parents of children who have autism, two (13%) were male, while one (6%) of parents of children who do not have autism was male. The remaining participants were females.

Confidentiality

Confidentiality was assured to the parents. The researcher sent the consent and information forms to the programs, centres, and support groups, where they were passed out to parents at the discretion of the administrators of the program. In the case of five programs from which participants were recruited, the research information was provided on the program's website and/or included in their newsletters, which

were distributed to families in paper and electronic form once monthly.

Questionnaires were mailed from the researcher to consenting participants. The researcher did not know the identity of participants unless participants chose to reveal it at their own discretion.

Instruments

The *Quality of Life Inventory (QoLI)* (Frisch, 2005) was administered as measure of quality of life among parents. Specifically, it measures 16 areas: (a) health, (b) self-esteem, (c) goals and values, (d) money, (e) work, (f) play, (g) learning, (h) creativity, (i) helping, (j) love, (k) friends, (l) children, (m) relatives, (n) home, (o) neighbourhood, and (p) community. This inventory also provides an overall score, which reflects one's mean QoL. The *QoLI* consists of 3-point Likert scales measuring the importance one places on each of the domains of Quality of Life. It also contains a 6-point Likert scale for the satisfaction one reports associated with each domain.

The original *QoLI* was norm-referenced across 12 states in the United States of America, in a sample consisting of 798 individuals. The sample consisted of racial and ethnic diversity reflective of the American census taken in 1990. The *QoLI* provides raw scores, weighted satisfaction ratings and conversion scores based upon a participant's opinion of the importance of a given aspect of his/her life in comparison to his/her satisfaction with that aspect. Reliability is high, with a retest coefficient of 0.73, $p < .001$, with an internal consistency of 0.79. Validity for this measure was measured against the *Satisfaction with Life Scale (SWLS)* and the *Quality of Life*

Index scores, achieving a significant and positive correlation with these measures ($r = .56, p < .001$ with the SWLS and $r = .75, p < .001$ with the Quality of Life Index).

The *Family Environment Scale (FES)* (Moos & Moos, 1994) was used to determine whether there are statistically significant differences between family environments of those families with and without children with autism. It is a reliable (ranging from $\alpha = .68$ to $.86$) and valid measure, which has been normed over a population of 2220 families. Among these families, 788 were identified as being in distress prior to taking completing the *FES*.

Participants indicate whether statements (e.g., "Family member really help and support one another, Moos & Moos, 1994) are true or false for their families. The *FES* is comprised of three domains: (a) relationship dimensions, (b) personal growth dimensions, and (c) system maintenance dimensions. These domains are further broken down into subscales which measure socio-environmental characteristics of families. These characteristics include: (a) cohesion, (b) expressiveness, (c) conflict, (d) commitment, (e) help, (f) support family members provide to one another, (g) ability family members perceive they have to act openly and to express themselves directly, (h) amount of openly expressed anger, aggression and conflict, (i) independence, (j) achievement orientation, (k) intellectual-cultural orientation, (l) active-recreational orientation and (m) moral-religious emphasis. The *FES* has several uses, among them the identification of differences between family environments of normal families and those which are under distress.

The *Family Support Scale* (Dunst, Trivette, & Jenkins, 1986), a five-point Likert scale, which indicates the extent to which external sources of social support are

available to the family, was used to determine whether there is a perceived difference in the types of social support available to both the experimental and control groups. It has a test-retest reliability of .77 and is considered a valid measure of family support (Dunst et al., 1986). Participants are asked to indicate whether each source of support has been unavailable, “not helpful”, “sometimes helpful”, “generally helpful”, “very helpful” or “extremely helpful”. Circling N/A indicated unavailability of a given source of support, while 1 indicated unhelpful and 5 indicated extremely helpful.

The items are based upon the belief that having connections with social networks and the social support they provide lessens stress, promotes well being and enhances the use of coping strategies (Dunst, Trivette, & Deal, 1988). Some of the items (specifically those referring to professional agencies, intervention programs and professionals providing care or intervention) were not relevant to the families of children who do not have autism. Thus, participants circled N/A or wrote “not applicable” beside the item.

The *Child Behavior Checklist (CBCL)* (Achenbach, 2004) was completed by parents to determine whether there are differences in the behaviour of children with autism and that with typical development and if so, to identify how their behaviour differed. The *CBCL* can also be used to compare the behaviour of those with autism who are receiving different interventions in order to determine whether there is a significant difference between the types and/or duration of intervention and the behaviours these individuals exhibit. The *CBCL* has a test-retest reliability of .84 and has been extensively measured for validity, with the finding that it is a statistically

significant valid measure (Achenbach, 2004). It was norm-referenced across 1300 children.

Participants circle “0” to indicate when a statement is untrue with regard to the child, “1” to indicate that it is “sometimes true” and “2” to indicate that it is “very true or often true”. Examples of statements found on the *CBCL* may include “Feels he/she has to be perfect” or “Acts too young for his/her age”. The *CBCL* is comprised of three scales: (a) the DSM-Oriented Scales (scores range between 0 and 26), (b) Competence Scales (scores range between 0 and 15) and (c) Syndrome Scales (scores range from 0 to 26 for the anxious/depressed subscale; 0 to 16 for the withdrawn/depressed subscale; 0 to 22 for the somatic complaints subscale; 0 to 22 for the social problems subscale; 0 to 30 for the thought problems subscale; 0 to 20 for the attention problems subscale; 0 to 34 for the rule breaking subscale; and 0 to 36 for the aggressive behaviour subscale).

The DSM-Oriented scales which measure behaviours/emotional states or traits against states/traits commonly found in disorders in the DSM-IV-TR. The behaviours it controls for include those that are common to: (a) affective problems, (b) anxiety problems, (c) somatic problems, (d) attention deficit/hyperactivity problems, (e) oppositional defiant problems, and (f) conduct problems.

A demographic questionnaire (e.g., age, gender, income, number of visits to health professionals regarding concerns other than autism in each family member, number of absences from work and reason, has the child with autism received intervention and if so, for how long and what kind was it, who lives in the household, race, ethnicity) was employed to determine whether there were differences in terms of

health and psychological well-being among the corresponding families. Parents were also given an opportunity to inform the researcher of any issues pertinent to their family or autism that they felt would assist in this study in the form of the question: “Do you feel there is anything else I should be aware of? If so, please provide an explanation in the space below. Please feel free to attach additional sheets of paper if necessary.”

Procedure

After receiving Ethical Approval from the Human Research Ethics Committee at the University of Victoria, I obtained approval from various centres, schools and organizations for both children with and without autism. These are all centres which provide interventions, education, and support services for children with autism and their families located in the Greater Toronto area of Ontario and in the Greater Victoria area of British Columbia. Introductory and consent forms (Appendix A) were then sent to local elementary schools to send them home with all students (regardless of whether or not they had autism) to be signed by self-selecting parents.

Parents were provided with two consent forms, one to retain and one to return to the school. Signed consent forms were mailed to the researcher by consenting participants. Parents were provided with questionnaires, by mail, to complete independently. Upon completion, they returned the completed packages to the researcher by mail in the envelope provided to them with the survey package.

Summary of Chapter Three

This chapter details the methods employed in this study. First, it introduces the findings of the pilot study, as well as how the issues raised by pilot study

participants were addressed in the formal study itself. This chapter then describes who the participants were and how they were recruited. Confidentiality and how it was achieved is then reported. The instruments used are then outlined. Details regarding their reliability and validity from their respective norm reference testing are provided. Finally, the procedure for recruitment and participation is outlined.

Chapter 4

Results

This chapter discusses the quantitative and qualitative results of the present study. Findings reflect that although there were no significant statistical differences between families of children with autism and those of children who do not have autism in terms of Quality of Life, qualitative analysis reveals differences in various domains of quality of life between these two groups.

Quantitative Data

SPSS for Windows (Version 12.0) was used for analyses of quantitative data. Descriptive statistics such as the mean and standard deviation were calculated for each quantitative measure to determine the overall importance and relevance of items for participants. This was to determine whether any differences existed in terms of their overall quality of life, factors in their family environments, as well as the perceived social supports they received. Independent samples *t*-tests were also conducted between children with and without autism on the *CBCL* in order to determine whether any significant differences existed between behaviours as reported by parents.

Given the nature of autism and its prevalence, the possibility of obtaining large samples was not available. Thus, the issue of Type II error (failure to reject the null hypothesis when it is false) would be a concern. To address this concern and given the exploratory nature of the current study, an alpha-levels of .01 and .05 were selected. According to the results of this study, with regard to its small effect size across a variety of variables, this is a valuable study.

Demographics

Families of Children With and Without Autism

The average family size was 4.53 ($SD= 1.50$), though there were families in which there were as few as one parent and one child, as well as one family in which there were two parents and five children, including one with autism. Independent t-tests were conducted in order to determine whether there were any significant differences between families of children with autism and those of children without autism in terms of the gender of the respondent. There were no significant differences. In families of children with autism, 2 respondents were fathers, while in families of children without autism, 1 respondent was a father. The remaining 31 respondents were mothers. Table 1a illustrates mothers' occupations, while Table 1b illustrates fathers' occupations. Additionally, Table 1c illustrates annual household incomes, Table 1d illustrates marital status, Table 1e illustrates race/ethnicity, Table 1f illustrates child's age and gender, while Table 1g illustrates child's academic variables, Table 1h illustrates child's extra-curricular variables, and Table 1i illustrates child's household chores.

Child Characteristics

The mean age of diagnosis of children with autism in this study was $M= 5.27$ years old ($SD= 2.68$, Minimum= 2.50 years old, Maximum= 10.00 years old). There were no significant differences between the families of children with autism and those of children who do not have autism in terms of: family size, age of the children, or the presence of other developmental disorders.

One-tailed Pearson correlation coefficients were performed within the autism group in order to determine whether there were correlations between: family size, number of adults, number of children, age of the child who has autism, number of people who have autism, number of people who have developmental disorders, marital status, age of autism diagnosis, overall quality of life, number of hours of behaviour, occupational therapy, speech and language pathology, and best practice interventions a child receives, total number of hours of intervention a child receives, total duration of waiting period for interventions, and total number of years a child has received intervention.

Independent *t*-tests were conducted in order to determine whether there were differences between families of children with autism and those whose children do not have autism on various demographic variables. Specifically, race/ethnicity, family size, marital status, annual household income, and number of visits to health professionals were considered. In terms of marital status, the difference between families of children who have autism and those in which the child does not have autism is not significant ($t(32) = .374, p < .05$). Thus, parents of children without autism are not significantly more likely to be married than are parents of children with autism. In terms of annual household income, the difference between families of children who have autism and those whose children do not have autism is significant ($t(32) = 2.070, p < .05$). Thus, families of children with autism tended to have annual household incomes which were lower than those of families of children who do not have autism.

In terms of number of visits to health professionals, there is a significant difference ($t(32) = 2.682, p < .01$). Families of children with autism tended to report significantly more visits to health professionals than did families of children who did not have autism. Though the mean number of absences from work that parents of children with autism reported appeared to be higher than those of parents of children who do not have autism ($M = 15, M = 2$ respectively), the differences were not statistically significant ($t(32) = 1.719, p < .05$). Reasons parents of children with autism cited for work absences included attending meetings with their child's school for special programming meetings or problem-solving, to care for their child when he/she was ill and nobody capable of managing his/her behaviours was available, and in order to take their child to consultations or interventions with professionals or experts, such as psychologists and therapists.

Table 1a

Family Demographics: Mothers' Occupations

Occupation	Group			
	With Autism		Without Autism	
	<i>n</i>	%	<i>n</i>	%
Commercial	4	23.5	2	11.8
Administrative	2	11.8	2	11.8
Academic	3	17.6	5	35.3
Homemaker	7	41.2	3	17.6
Helper Profession	7	41.2	3	17.6

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)

Table 1b

Family Demographics: Fathers' Occupations

Occupation	Group			
	With Autism		Without Autism	
	<i>n</i>	%	<i>n</i>	%
Academic	1	5.9	2	11.8
Administrative	0	0	2	11.8
Technology	3	17.6	3	17.6
Defense/Law Enforcement	4	23.5	1	5.9
Entrepreneurial	2	11.8	3	17.6
Mechanics/Engineering	3	17.6	4	23.5
Not part of child's life/Unemployed	4	23.5	2	11.8

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)

Table 1c

Family Demographics: Annual Household Income

Income	Group			
	With Autism		Without Autism	
	<i>N</i>	%	<i>N</i>	%
\$0-20 000	1	5.9	0	0
20 000—34 999	4	23.5	0	0
\$35 000—44 999	3	17.6	1	5.9
\$45 000—59 999	2	11.8	4	23.5
\$60 000—79 999	2	11.8	1	5.9
\$80 00—99 999	1	5.9	2	11.8
\$100 000—119 999	3	17.6	6	35.3
\$120 000 +	1	5.9	0	0
No Response	0	0	3	17.6

Note: *N* = 34, With Autism (*n* = 17), Without Autism (*n* = 17)

Table 1d

Family Demographics: Marital Status

	Group			
	With Autism		Without Autism	
Marital Status	<i>N</i>	%	<i>n</i>	%
Married	13	76.5	14	82.4
Divorced/Separated	4	23.5	3	17.6

Note: *N* = 34, With Autism (*n* = 17), Without Autism (*n* = 17)

Table 1e

Family Demographics: Race/Ethnicity

	Group			
	With Autism		Without Autism	
Ethnicity	<i>N</i>	%	<i>n</i>	%
Caucasian	17	100	13	17.6
Native/First Nations	0	0	3	17.6
Other	0	0	1	5.9 (East African)

Note: *N* = 34, With Autism (*n* = 17), Without Autism (*n* = 17)

Table 1f

Family Demographics: Child's Age and Gender

Age	Group			
	With Autism		Without Autism	
	<i>n</i>	%	<i>n</i>	%
6	4	23.5	3	17.6
7	3	17.6	4	23.5
8	2	11.8	2	11.8
9	3	17.6	4	23.5
10	1	5.9	0	0
11	2	11.8	1	5.9
12	2	11.8	2	11.8
Female	4	23.5	6	35.3
Male	13	76.5	11	64.7

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)

Table 1g

Family Demographics: Child's Grade Level

Grade	Group			
	With Autism		Without Autism	
	<i>n</i>	%	<i>n</i>	%
Kindergarten	4	23.5	1	5.9
1	0	0	2	11.8
2	0	0	4	23.5
3	1	5.9	3	17.6
4	4	23.5	1	5.9
5	1	5.9	1	5.9
6	0	0	2	11.8
7	2	11.8	0	0
Ungraded Curriculum	3	17.6	0	0
Does not Attend School	2	11.8	0	0

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)

Table 1h

Family Demographics: Child's Extra-Curricular Variables

Activity	Group			
	With Autism		Without Autism	
	<i>n</i>	%	<i>n</i>	%
Music Lessons	2	11.8	5	35.3
Sports	15	88.5	17	100
Clubs	8	47.2	12	70.8

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)

Table 1i

Family Demographics: Child's Household Chores

Chores	Group			
	With Autism		Without Autism	
	<i>n</i>	%	<i>N</i>	%
Take Out Garbage	1	5.9	1	5.9
Tidy Room	8	47.2	12	70.8
Caring for Pet	2	11.8	5	35.3
Caring for Sibling	0	0	3	17.6
Setting/Clearing Table,	1	5.9	7	41.3
Wash/Put Away Dishes	3	17.6	4	23.5

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)

Quality of Life: Quantitative Results

Analyses of differences were examined using scores achieved on the *Quality of Life Inventory (QofLI)*. Subsequent statistical analyses were done using these scores. The *QofLI* provides both a standard score and an overall ranking of quality of life. Overall quality of life scores are ranked from very low, low, average and high, based upon the standard score. The mean of each ranking given is provided, as well as the standard deviation and range. The mean scores and standard deviations for each of the sub-scales on the *QofLI* are presented in Table 2. One of the *QofLI* forms was incomplete among the parents of children with autism, thus it could not be scored. Missing data included: information about importance and satisfaction with love, friends, relatives, and information about the importance of the home, as well as information about satisfaction with children. However, according to Levene's test of equality of variances, this did not create significant variance of the means of overall quality of life ($F= 4.802$).

In terms of overall quality of life, the difference between families of children with autism and those of children who do not have autism was not significant ($t(31)= .220, p<.05$). Thus, we accept the null hypothesis, suggesting that families of children who do not have autism tend to report overall quality of life similar to families of children with autism on the *QofLI*. This was surprising, as Table 2 shows the distribution of t -scores and percentile ranges within each of the four rankings of quality of life appeared quite different according to whether or not the family has a child with autism.

Referring to Table 2, it appears as though more families of children without autism report very low quality of life. However, the qualitative data reflects how these families differ from families of children with autism in terms of what is preventing them from achieving a higher quality of life. For instance, the two parents of children with autism whose scores fell within the “Very low” ranking cited problems such as relatives who criticize their parenting skills, blaming them for their child’s disorder, while one of the three parents of children without autism had recently divorced, a second worried about one of her children, who was a young offender and the third was dissatisfied with a recent relocation to a new city.

Thus, independent *t*-tests were conducted on each of the items of the *QofLI* in order to determine whether there existed areas in which families differed significantly enough to influence the outcome of overall quality of life scores. In terms of satisfaction within specific domains, families of children with autism achieved significantly lower scores from those of children without autism in terms of: satisfaction with learning ($t(32) = 2.162, p < .05$) and neighbourhood satisfaction ($t(31) = 2.052, p < .05$).

Only the importance upon which families of children with autism placed upon their homes showed a significant difference from families of children who do not have autism ($t(31) = 2.836, p < .01$). Parents of children with autism reported placing significantly more importance upon homes. Interestingly, satisfaction with their homes did not differ significantly. While no significant difference existed in terms of importance of or satisfaction with friendships and social relationships on the *QofLI*, the *FSS* reflected a significant difference in terms of those who provide support to

families who participated in this study. While no significant difference existed in terms of importance of or satisfaction with friendships and social relationships, the *FSS* reflected a significant difference in terms of those who provides support to families who participated in this study.

Table 2

Ranking, t-Score Range and Percentile Rank of Overall Quality of Life: With and Without Autism

	Group					
	<u>With Autism</u>			<u>Without Autism</u>		
Ranking	<i>t</i> -Score Range	Percentile Rank	<i>N</i>	<i>t</i> -Score Range	Percentile Rank	<i>n</i>
High	58-59	81-84	2	58-71	81-99	7
Average	43-56	21-71	10	43-57	21-80	5
Low	37	11	2	40	17	2
Very Low	19-32	1-5	2	25-32	2-5	3

Note: *N* = 33, With Autism (*n* = 16), Without Autism (*n* = 17).

Family Functioning Scale

The mean reflects the average score on each subscale in order to determine whether there were differences in terms of how families function. The standard deviation provides information as to how much individual scores deviated from the mean. The mean and standard deviation scores for each of the scales on the *FES* are presented in Table 3. Independent *t*-tests were conducted in order to determine whether any significant differences existed between families of children with autism and those of children who do not have autism in terms of various aspects of the

family environment. Significant differences were identified in terms of cohesion ($t(32)= 2.44, p<.05$), expressiveness ($t(32)= 3.80, p<.01$), conflict ($t(32)= 3.78, p<.01$), independence ($t(32)= 2.30, p<.05$) and active-recreational orientation ($t(32)= 2.24, p<.05$). These scores indicate that those families whose children have autism report less cohesion, less expressiveness, more conflict, and lower active-recreational orientation than do families of children without autism.

Family Support Scale

Independent *t*-tests were conducted for each item on the *FSS* in order to determine whether there were differences between families of children with autism and those whose children do not have autism, in terms of the availability of each social support. There were no significant differences in terms of support from the respondent's parents, spouse or partner's parents, from the respondent's relatives, spouse, spouse or partner's friends, participant's own children, co-workers, family or child's physician, or school or day care centres. However, there was a significant difference between the support participants reported receiving from friends ($t(32)= 3.644, p<.01$), other children's parents ($t(32)= 2.461, p<.01$), parent groups ($t(32)= 3.657, p<.01$), social clubs or organizations ($t(32)= 3.250, p<.01$), church members or ministers ($t(32)= 2.566, p=.05$), early childhood intervention programs ($t(32)= 3.698, p<.01$), professional helpers ($t(32)= 3.823, p<.01$), professional agencies ($t(32)= 5.980, p<.01$). Parents of children who do not have autism reported receiving more support from friends and other children's parents, while parents of children with autism reported receiving greater amounts of support from social clubs organizations, church members or ministers, early childhood intervention programs

and professional helpers. This is not surprising as families of children with autism would be more likely to require services and/or assistance.

Interestingly, 3 (20%) of participants indicated differing levels of support on individual items according to time frames. For instance, one parent circled one point on the likert scale with a date (e.g., 1997–2000) in parentheses, circling another point on the likert scale and providing another date. Only those dates which reflected current time frames were considered, as the focus of this study is current QoL and family experiences.

Table 3

Mean (M) and Standard Deviation Subscale Scores (SD)—FES

	Group		<i>M</i>	<i>SD</i>	<i>t score</i>
	With Autism	Without Autism			
Cohesion	48.29	12.16	56.41	6.34	2.44*
Expressiveness	48.29	10.48	59.41	8.61	3.80**
Conflict	54.06	9.86	43.71	5.50	3.78**
Independence	32.06	13.00	27.00	12.22	2.30*
Achievement Orientation	36.41	8.56	38.35	9.05	-0.043
Intellectual/Cultural Orientation	46.41	10.58	48.76	7.28	-0.554
Active/Recreational Orientation	42.00	8.03	47.65	6.59	2.24**
Moral/Religious Emphasis	54.88	10.43	50.18	11.01	1.88
Organized	55.86	7.61	49.67	9.77	0.001
Control	51.76	8.66	51.41	8.28	0.604

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)* $p < .05$, ** $p < .01$ *Child Behaviour Checklist*

The *CBCL* was administered in order to determine whether there were differences between parents of children with autism and those of children without autism in terms of how they perceived their children's behaviour. Independent *t*-tests were conducted to analyze the scores on each of the subscales.

Significant differences were found between children with autism and those who do not have autism on the following subscales of the *CBCL*: withdrawn/depressed ($t(32)= 3.31, p<.01$), social problems ($t(32)= 5.06, p<.01$), thought problems ($t(32)= 5.010, p<.01$), attention problems ($t(32)= 6.06, p<.01$), aggressive behaviour ($t(32)= 3.17, p<.01$), and other problems ($t(32)= 3.07, p<.01$).

Children with autism also participated in significantly fewer extra-curricular activities ($t(32)= 3.96, p<.01$), had significantly lower scores on social interaction (e.g., number of friends, frequency of contact with friends and behaviour with others and by him/herself) ($t(32)= 7.39, p<.01$), and more problems at school ($t(32)= 4.27, p<.01$). Finally, they were also significantly more likely to have affective problems ($t(32)= 3.08, p<.01$), anxiety problems ($t(32)= 3.05, p<.01$), attention deficit/hyperactivity problems ($t(32)= 7.01, p<.01$) and oppositional-defiant problems ($t(32)= 3.09, p<.01$). Tables 4a, 4b, and 4c present means of scores attained by children with and without autism on the syndrome scales, competency scales and DSM oriented scales of the *CBCL*, respectively.

Table 4a

Mean Scores (M) and Standard Deviations (SD) Attained on the Syndrome Scales of the CBCL

Syndrome Scales	Group				<i>t</i>
	<u>With Autism</u>		<u>Without Autism</u>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Anxious/Depressed	5.65	3.26	3.64	3.96	3.05*
Withdrawn/Depressed	3.41	2.21	1.29	1.54	3.31*
Somatic Complaints	3.18	3.91	2.12	2.80	0.536
Social Problems	7.58	2.90	2.29	3.16	5.06**
Thought Problems	9.47	5.48	2.24	2.80	5.01**
Attention Problems	11.35	4.11	3.24	3.44	6.06**
Rule-Breaking Behaviour	2.77	3.02	1.76	2.98	0.548
Aggressive Behaviour	10.24	6.67	3.77	5.84	3.17**
Other Problems	6.12	3.01	2.94	3.15	3.07**

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$), * $p < .05$, ** $p < .01$

Table 4b

Mean Scores (M) and Standard Deviations (SD) Attained on the Competency Scales of the CBCL

Syndrome Scales	Group				<i>t</i>
	<u>With Autism</u>		<u>Without Autism</u>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Activities	10.07	2.93	13.80	2.37	3.832**
Social	5.73	4.23	13.13	1.60	6.33**
School	2.73	1.33	4.47	1.30	3.60*

Note: $N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$), * $p < .001$, ** $p < .0001$

Table 4c

Mean Scores (M) and Standard Deviations (SD) Attained on the DSM-Oriented Scales of the CBCL

DSM-Oriented Scales	Group				<i>t</i>
	With Autism		Without Autism		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Affective Problems	5.40	3.56	2.53	3.16	3.08*
Anxiety Problems	4.27	2.69	2.07	2.87	2.17*
Somatic Problems	2.00	2.80	1.87	2.24	0.14
Attention Deficit/Hyperactivity Problems	8.80	2.26	2.47	2.20	6.24**
Oppositional-Defiant Problems	4.07	2.55	1.87	2.33	3.19*
Conduct Problems	3.33	4.61	1.87	4.07	0.924

Note: *N* = 34, With Autism (*n* = 17), Without Autism (*n* = 17), **p* < .05, ***p* < .01

Additional Statistical Analyses

The age of the child with autism also had a significant negative correlation between number of hours of speech and language pathology intervention ($r = -.483$, $p < .05$). Annual household income was significantly, positively correlated with total number of hours of intervention children with autism received ($r = .553$, $p < .01$), as well as the length of time a child receives intervention ($r = .729$, $p < .01$). As funding for interventions and services to children with autism, in Canada, tends to decrease when a child reaches the age of 6 years old, this is not surprising. The children in this study no longer qualified for higher rates of funding, thus parents would be expected to subsidize funding according to what is financially feasible to their families. Only those parents who could afford to pay for interventions and services independent of external funding programs would have access to these programs once children reach the age of 6 years old.

Not surprisingly, as annual household income increased, so too did the number of hours of behavioural intervention ($r = .627$, $p < .01$) and speech and language pathology intervention ($r = .672$, $p < .01$). As their household incomes increased, families also tended to receive significantly more total hours of intervention ($r = .485$, $p < .05$), as well as significantly greater numbers of years of receipt of intervention ($r = .483$, $p < .05$). This suggests that those whose annual household incomes are greater have greater access to interventions. Despite these differences, there were no significant correlation between general quality of life and any of the specific QoL variables considered.

Long waiting periods for access to intervention were most common among behavioural intervention ($r = .482, p < .05$), occupational therapy ($r = .457, p < .05$) and best practice interventions ($r = .610, p < .01$). The duration with which children participated in occupational therapy was also significantly correlated with the duration they waited to receive such therapy ($r = .644, p < .01$), indicating that need for such therapy increased as waiting for access to these programs increased.

Parents of children with autism cited bullying and victimization by others occurring at school and in other locations as a main concern for their child with autism ($n = 9, M = 60\%$). Thus, independent t -tests were performed to see whether there was a difference between the types and amounts of interventions children received and the frequency of parental concerns of bullying. There were no statistically significant differences between any of the types of interventions available and the frequency with which bullying was cited as a concern. This indicates that the skills children with autism acquire or learn through intervention programs do not seem to influence whether or not others will bully them.

Qualitative Data

Participants were provided with opportunities to respond to open-ended questions on the *QofLI*, *CBCL*, and the demographic questionnaire. These questions pertained to: issues within specified domains which prevented the respondent from achieving satisfaction with that domain, child's school performance, concerns about child/children, best things about the child, as well as anything the participant felt the researcher should know. The themes that emerged indicated that parents differed in

terms of their experiences based upon characteristics of their children, situations and concerns.

Reliability

For the qualitative data, it was necessary to code themes according to the comments parents made on various survey materials in response to open-ended questions. The researcher coded the responses according to the recurring themes cited in parents' comments. To ensure reliability in terms of the theme coding, an undergraduate psychology student was recruited to code the data for comments written by parents. Once themes were established, inter-rater reliability was conducted to ensure accurate coding of the themes identified in parents' responses. This was achieved by determining the mean agreement between the investigator of the present study and a third year undergraduate student who has completed the course requirements for a minor in psychology, as well as a second year educational psychology Master's student, for each statement made by parents for each domain. Inter-rater reliability was 92 %, indicating a high degree of reliability in terms of the identification of themes. When disagreement occurred, the investigator and other raters discussed their theme choices to resolve how to code the theme. A resolution was achieved when all three raters agreed upon the rationale for providing a theme with a specific code.

Quality of Life

In the open-ended section, the *QofLI* allows the respondent to indicate one's subjective experiences regarding anything which may be preventing him/her from being satisfied with their experience of each of the following domains: health, self-

esteem, goals and values, money, work, play, learning, creativity, helping, love, friends, children, relatives, home, neighbourhood, and community. In some cases, the open-ended sections were left blank. The themes identified from this information include: time constraints, tension/stress (e.g., “I suffer muscle, shoulder, neck tension, and headaches but actively work with therapists and exercise to make it better”), money/financial concerns, inability to pursue interests/attain desired goal/outcome, dissatisfaction with current situation, and poor communication/lack of understanding. Examples of time constraints included: “Difficult to maintain balance for attention when extra care is required for one of the children,” “Concerned that if I stop helping the program [special needs support group] I coordinate at our church will cease,” and “Never have time to care for my personal health.”

Parents also indicated concerns related to money and financial well-being. Examples of these comments include: “There is never enough money to provide technology to help child’s development and communication needs or to help with physical problems,” “Not working right now contributes to money issues,” and “We have taken such a pay cut due to our special needs child—always short on money.”

Parents reported that they were often unable to pursue their own interests and/or achieve their personal or professional goals. For instance: “I learn on my own, not enough time, always caring for the children, want to do my M.Ed, but don’t know when,” and “My previous career as a technical writer is too demanding time-wise—difficult to do part-time.”

The final two themes observed in the comments made by parents pertained to dissatisfaction with their current situations: “Self-esteem as a mother is good, as an

individual, as a woman, not as good;” “Extended family sometimes does not understand or respect our wishes in terms of adapting relationship and lifestyle due to the children’s diagnosis;” “I live and breathe autism 24/7. Mentally, would like to pursue learning and work in other areas;” and “ As I write this, I realize how many frustrations with my life have to do with care of our child that leaves me with no sleep, little spare time, little peace and calm, not enough money due to her care.” Parents also indicated poor communication and a lack of understanding among their families and friends. Examples of this final theme include:

Lack of awareness and understanding or compassion or tolerance has led them to all go away. Total loss of all family supports. Have even been challenged (not successfully) on keeping custody by my own mother because they are so overwhelmed by the number of symptoms and accommodations needed for us.

Developmental delays are profound. Children are non-verbal. Have to accept a radically different relationship and future.

It can become a very lonely place to raise a child with autism, as we have to update people around us all the time as they hardly seem able to follow along the different path of development.

Relatives do not really understand the disorder nor accept that it is lifelong.

Autism is associated with movie *Rainman*.

Children have difficulty with integration—Not enough public awareness.

The community needs to understand more the children’s disabilities.

The majority of our neighbours are not comfortable with our family's situation and remain distant.

Table 5 reflects the frequency with which the themes occurred in both families of children with autism and those of children without autism.

Interestingly, the comments made by both sets of parents are similar in terms of theme, as well as the causes of the problems which are preventing them from realizing satisfaction within each domain of QoFL. Examples of time constraints among families of children who do not have autism include:

Lack of time to maintain exercise, increases weight and decreases self-esteem.

Love the kids—time is an issue—balancing kids and work is so hard. Would like to spend more time here, would like to get some things done. While I don't have a lot of time to participate in volunteering, etc, I appreciate those that can. My contributions are solely financial.

In terms of tension and stress, parents of children who do not have autism made comments such as:

Often tired, too much activity and not enough time to rest; no time to relax.

Have a difficult child who doesn't seem to respond to parenting approaches; makes it difficult to remain positive with him; he is exhausting and I often get resentful of the energy he demands.

Money and financial concerns cited by parents of children who did not have autism tended to focus on not having enough for specific items and concern centred around finances: "not having enough for a house," and "Always a worry."

In terms of their inability to pursue their interests and attain desired outcomes,

parents of children who do not have autism cited such things as: “Need to believe in myself a little more, be less negative,” and “Love to work, but worried about the future”

When referring to dissatisfaction with their current situation, parents made comments; for instance: “Have a very difficult boss, he is demanding, high maintenance and draining.” Finally, in terms of poor communication and lack of understanding, comments included: “I feel I am a poor role model; feel need to be perfect parent; worried will raise them poorly.”

Qualitative differences were also discovered in considering importance and satisfaction with housing among the two groups. Specifically, parents of children with autism also cited concerns with their current housing situations. This data included: safety issues (e.g., “Not a safe neighbourhood,” “there is a great deal of petty crimes,” “Not in a good/safe position”), the inability to own their own housing as a result of one parent choosing to care for the child with autism over working (e.g., “We live in a co-op, but would prefer to own our own home in the suburbs”), and the need for more space so that interventions involving home programming can take place (e.g., “need private space, one or two rooms for space buffering for programming needs”). Conversely, parents of children who do not have autism reported dissatisfaction with housing in terms of the physical state of their housing (e.g., “Brand new house that isn’t completed: inside or landscaping,” “restricting because no sidewalks,” “Too small; no in-suite laundry, no pets, no yard/play area for children on-site”).

One major difference is reflected by the needs of the children with autism. Parents of these children reported not being able to work or pursue interests as a

direct result of their child's needs, which they reported were difficult for others to cope with. Also, parents of children with autism reported a concern with either themselves or their child not being accepted within their communities and neighbours, as well as among individual relatives and peers due to the child's disorder, whereas only one parent of a child who does not have autism reported concerns focused on poor communication and lack of understanding.

Finally, the QofLI provides respondents with the opportunity to cite additional problems or concerns. Only four parents used this space to comment further. Two parents of children with autism commented, as follows:

As I write this, I realize how many frustrations with my life have to do with care of our child that leaves me with no sleep, little spare time, little peace and calm, not enough money due to her care.

It can become a very lonely place to raise a child with autism, as we have to update people around us all the time as they hardly seem to be able to follow along with the different path of development.

Conversely, parents of children who do not have autism used this space to comment on their satisfaction with their situations, as demonstrated in the following quotes: "I feel very fortunate to be somewhat satisfied with my life. Listing problems that get in the way of my satisfaction in each area of life is hard to do," and "Guilt affects me—feeling beholden to do things or be a certain way."

Table 5

Themes With Frequencies and Percentages of the Comments Parents Made on the Quality of Life Inventory

Theme	Group			
	With Autism		Without Autism	
	Number	%	Number	%
Time Constraints	12	70.8	10	59
Tension/Stress	7	41.3	4	23.5
Money/Financial Concerns	10	59	6	35.3
Inability to Pursue Interests/Attain Desired Goal/Outcome	12	70.8	9	53.1
Dissatisfaction with Current Situation	12	70.8	8	47.2
Poor Communication/Lack of Understanding	11	64.9	5	29.5

$N = 34$, With Autism ($n = 17$), Without Autism ($n = 17$)

Child Behaviour Checklist

The *CBCL* allows respondents the opportunity to identify areas within the child's education which are problematic, as well as reasons for repeating a grade, defining special education being implemented. It also allows the respondent to indicate what concerns him/her the most about the child, as well as what the best things about the child are using open-ended questions. Themes identified among the families of children with autism as concerns included:

1. bullying or that the child is easily taken advantage of/does not understand people's intentions (e.g., "Victimized at school on the playground. He thinks everyone is his friend, he doesn't realize he's different"),
2. acceptance by others,
3. child's future (e.g., "What will happen to him as an adult?"),
4. ability to care for child,
5. learning/academic performance (e.g., "the overwhelming number of interacting issues and difficulty to treat and support him"),
6. food sensitivities/diet, (e.g., "Food sensitivities/allergies. It's a struggle to keep off these things so that [child's name] can have the health and energy"),
7. tantrums/aggressive behaviour (e.g., "Her tantrums..."),
8. child's inability to care for self (e.g., "inability to care for herself, lack sleep and self-care, lack of understanding"),
9. inability to attend (e.g., "inability to stay focused/attend for more complex/lengthy instructions/lectures, social awareness and functioning),
10. sensory issues (e.g., "sensory issues (esp. noise) and what these mean for his future happiness and independence"),
11. physical limitations (e.g., "lacks depth perception and often hurts herself as a result"),
12. sleeping difficulty (e.g., "he often does not sleep through the night," "lack, of sleep"), and
13. child's self-esteem (e.g., "Maintaining his self-esteem," "Helping him to function in a classroom without abuse from teachers or peers").

Not all themes identified among the parents of children with autism were reported by parents of children who do not have autism. These differences include: child's future/inability to care for self, ability to care for the child, food sensitivities/diet, tantrums/aggressive behaviour, difficulty sleeping, and sensory issues. Only one parent of a child who does not have autism reported concerns with bullying. In contrast to the parents of children with autism, who reported concerns of victimization of their child, this parent reported concerns that her child did not exercise sufficient regard for others (e.g., "at times, seems to have no regard for others' feelings if it means getting what he wants"). Table 6a reflects these differences.

During recruitment, the researcher was invited to participate at a parent support group meeting. One of the parents asked for suggestions on how to deal with bullying, at which point, every parent in attendance confirmed that their child had also been/is currently being bullied by his/her peers. The parents discussed the topic further, at which point, two parents mentioned that their children (ages 6 and 9) are urinated on in the boys' washroom at school. In one extreme case, a parent indicated that her son had been bullied so aggressively that he ran away from school and hid under a bush until the end of the school day, when his mother arrived to pick him up. According to this parent, the teacher's response had been to tell the mother that she was being unreasonable for taking exception to the other children's behaviour and that all children get teased over the course of their education. This anecdote supports the finding of the present study that bullying by others is a problem for children in this study with autism.

In terms of inability to tell what other people's motives are, parents of children without autism made comments such as: "He is easily led"; "he will give up the farm to have friends and be liked."

When parents of children who do not have autism cited academic or learning concerns, they tended to indicate concerns which reflected a lack of interest or desire to excel in the children. For instance: "He is gifted and is not receiving teaching/being challenged at his level. Easily bored in school," "Getting his work done so he can play." Finally, only one parent cited a concern related to physical limitations (e.g., "was in a car accident and lost use of right arm").

Table 6a

Specific Concerns Reported on the Child Behaviour Checklist

Theme	Group			
	With Autism		Without Autism	
	Number	%	Number	%
Bullying/Easily Taken Advantage of	9	53.1	1	5.9
Not Accepted	5	29.5	0	0.0
What Will Become of Child as an Adult	5	29.5	0	0.0
Tantrums/Aggression	7	41.3	0	0.0
Learning/School	11	64.9	3	17.6
Food Sensitivities/Limited Diet	3	17.6	0	0.0
Inability to Care for Self	7	41.3	0	0.0
Ability to Attend	5	29.5	3	17.6
Sleeping Difficulty	3	17.6	0	0.0
Sensory Issues	2	11.8	0	0.0
Physical Limitations	5	29.5	1	5.9
Child's Self-Esteem	4	23.5	2	11.8

Out of 34, n families responded to the different questions. With Autism ($n = 17$), Without Autism ($n = 17$)

The *CBCL* also allows the opportunity to report on the best things about the target child in an open-ended question. The open-ended questions were responded to by some participants, but not all participants. While all participants were given the opportunity to comment, only some did so. Thus, the N varied for that section, as

reflected in Tables 6a and 6b, according to how the comments were coded. Coding was applied according to the themes conveyed in the comments supplied. The themes regarding the best thing about the child included: (a) temperament/joy/happy (e.g., people person, hard worker, enthusiastic, humourous), (b) creativity/imagination (e.g., creative, incredible imagination, divergent thinker), (c) sense of humour (e.g., great sense of humour, really funny), (d) adaptability/flexibility (e.g., incredibly resilient, adaptable, flexible), and (e) academic development. Interestingly, these themes were relatively similar among both sets of parents, though in some cases (e.g., adaptability/flexibility and academic development), the qualities observed by parents differed. Table 6b reflects examples of the statements made by parents regarding the best thing about their child. Only parents of children who did not have autism cited adaptability or flexibility as being a quality their child demonstrated. Parents of children with autism made statements such as: "He is now able to verbalize," "His development has been great." Parents of children who do not have autism tended to comment on academic development in terms of their child's academic and cognitive performance: "He is really smart, a quick thinker," "He learns things really quickly," and "He is doing great in school."

Table 6b

Best Things About Their Child, Reported by Parents on the Child Behaviour Checklist

Theme	Group		Group	
	<u>With Autism</u>		<u>Without Autism</u>	
	Number	%	Number	%
Temperament/joy/happy	14	82.6	13	76.7
Creativity/Imagination	3	17.6	5	29.5
Sense of Humour	5	29.5	7	41.3
Adaptability/Flexibility	0	0.0	3	17.6
Academic	0	0.0	5	29.5

Out of 34, *n* families responded to the different questions. With Autism (*n* = 17), Without Autism (*n* = 17)

Demographic Questionnaire

The demographic questionnaire consists of four open-ended questions. The questions include: (a) "How did you become aware of this intervention/why have you chosen this intervention?" (b) "Please explain why your child's autism prevented you/your spouse from going to work," (c) "Do you have any concerns about your children who do not have autism which you feel may be due to their sibling's autism? If you circled yes, please specify your concerns" (see Table 6), and 4) "Is there anything else which you feel the researcher should be aware of? Please feel free to attach additional pages." In some sections, participants would leave it blank or write N/A across that section, suggesting that it may not have been relevant to them.

Though given the opportunity to do so, no parent of children who do not have autism completed these sections. A table was also provided to parents to complete. In this table, parents recorded the types of interventions they sought, the intensity of the intervention per week, the duration of the intervention across the child's lifespan, the duration they had to wait between requesting this intervention and when they received it, as well as what the source of their referral to the intervention (refer to Table 7 for an illustration of this information).

Generally, the source of referral would include doctors, psychologists or other professionals with some expertise in autism or developmental disorders. However, in some instances, the interventions were a requirement by the B.C. Ministry of Children and Families in order to receive funding for intervention services. Thus, parents would indicate this as the source of referral. Interestingly, only one parent (6%) of a child who has autism cited medication as a means of intervention.

Parents of children with autism reported that they had missed on average 3.93 days of work in the past year due to their child's disorder. The reasons provided tended to relate to attending appointments with specialists, as well as meetings at the child's school for planning and implementing special programs. Several parents ($n = 7$, or 41%) reported that one or the other parent was not able to work due to the symptoms and needs associated with the child's disorder (e.g., "I can't work due to being sole caregiver and case manager. Prevents me from being able to do work due to large numbers of interruptions and other behavioural interventions"), while one parent (6%) reported working several jobs in order to provide his child with the intervention services he requires. The themes identified among the concerns about

siblings of children with autism focused on concerns that the parents spent so much time providing care and ensuring the needs of the child with autism are met that the other children do not receive as much attention (e.g., “It’s difficult to spend quality time with them doing parent/kid things (i.e., normal things),” “We give her so much support, time and energy—they can’t help but feel frustrated. We get respite and this gives them special time,” and “I worry that I spend so much time researching and being an advocate for [child’s name] that I am short-changing the other four children at times”), that expectations for the sibling without autism may seem unfair (e.g., “It’s difficult for them to understand why roles are different for them,” “Often, family routines and activities are modified to suit [child’s name], not them”), and that they experience social isolation as a result of their sibling’s disorder (e.g., “I’m concerned that they are held back from social functions”).

Several themes arose from the open-ended question: Is there anything else (e.g., concerns, difficulties you have encountered as a result of autism, autism symptoms, and/or services) which you feel the researcher should be aware of? Please feel free to attach additional pages.

These themes included: concerns regarding schooling, funding for intervention and services specific to autism, sleep deprivation, and the impact of the presence of a child with autism. Concerns regarding schooling reflected that school teachers and administrators in the public school system are not equipped or prepared to deal with autism in the regular classroom setting (e.g., “School district is unprepared to deal with a child with autism and unwilling to understand. He is very unhappy there and hates school,” “School needs to develop better curriculum. Use

ABA if required for teaching adequate and appropriate behaviour supports and work on integration policy”). Funding issues varied from concerns about timely receipt of compensation for expenses related to government funded programs (e.g., “autism funding is very slow to pay services—should be through Ministry of Health, not Min[istry] of Child and Family”), to the lack of services available: “It is critical that somehow parents be compensated as the caregivers as full time work isn’t an option—financial hardships are certainly an issue,” and, “There is no consistent available advocate or other support for using autism funding and others. The case management needs take all my free time, preventing me from creating income.”

Parents also cited a concern about the lack of age-appropriate services, geared toward addressing needs specific to developmental ages and stages: “My only concern are the lack of services after they enter grade school. The hospital services and adaptation services (private) are for preschoolers and adolescents. There needs to be better services and monitoring during 6–12 years old.”

One parent also indicated a concern for the lack of knowledge about autism within the medical community: “In the medical community, they don’t know enough on autism to handle their ongoing needs. Same for schools.”

There appeared to be a positive relationship between the comments parents made about the presence of a child with autism and their annual household income. While parents whose annual income tended to fall between \$0 to \$45,000 tended to comment on the hard work and lack of support they receive, as incomes increased, parents made more positive comments, acknowledging the additional difficulties they

encounter as a result of their child's disorder, but the focus of their comment would return to their love for their child and how much they enjoy their child.

During recruitment, one parent indicated opinions that there needs to be more research focusing on interventions and how they impact the family, as well as the child. This parent also stated that he thought the reason it was difficult to recruit participants whose child with autism was school-aged was the fact that these parents have been participating in studies and actively seeking assistance and/or intervention services for numerous years. This could be supported by the fact that one person who contacted the researcher for more information about the study decided not to participate. When asked why she had chosen not to participate, the parent cited the fact that no intervention service would be provided to the child. Another parent indicated that parents often get frustrated with participating in studies but never learning of the results or getting feedback.

In terms of sleep deprivation, parents indicated that due to the poor/inconsistent sleep patterns of their child with autism, their own sleep (as well as that of siblings) was interrupted on a regular basis: "Sleep deprivation is a big problem. There are good periods, but sleep disturbances are common for [child's name]. These affect mostly [child's name] and his parents, but also his siblings, when he goes through periods of difficulty falling asleep," and "Our child almost never sleeps for more than two hours at a time, so we find it hard to get through the days."

Finally, parents of children with autism indicated that they were unprepared for the extent of the impact the presence of a child with autism would have on their family: "The overall [illegible] on the family is quite unbelievable. We have very

little peace and the respite has been lifesaving for us. I would never have known how significantly it can impact a home.

Table 7

Types of Intervention Sought Children with Autism Had Participated In

Type	%	<i>n</i>	Length in Months	Intensity (hours/week)	Duration of Waiting	Sources of Referral
Occupational Therapy (OT)	23.5	4	10.00	1.00	7.00	Intervention Agency
Speech and Language Pathology (SLP)	41.3	7	40.80	1.00	6.00	Intervention Agency
Behavioural Intervention (BI)	35.4	6	21.25	1.00	3.75	Support Group, Doctor, Required for Funding
Best Practice (e.g., combined OT, SLP and BI)	41.3	7	24.57	12.42	2.28	Intervention Agency, Personal Research
Music Therapy	35.4	6	29.91	0.75	1.00	Other Parents

Note: Percentages in each row represent the percentage of participants who reported using these interventions. *n* = 17

Summary of Chapter Four

In this chapter, the quantitative findings are presented and discussed. These findings reflect statistically significant differences between the two groups in terms of: the importance they place on their homes, the satisfaction they report related to their neighbourhoods, communities and friendships. In addition, families of children with autism reported earning statistically significant differences in annual household income from their counterparts. Among the families of children with autism, those with higher annual household incomes had access to more interventions and of longer durations. They also reported shorter waiting periods to access such programs than did those with lower household incomes.

The qualitative analyses reflected a slightly different perspective than did the quantitative analyses in that though there were somewhat limited statistically significant differences within the domains of quality of life, in the qualitative analysis, parents of children with autism reported frustration and concerns regarding their child with autism. Parents of children who do not have autism were less likely to respond to open-ended questions regarding issues which prevented them from achieving satisfaction within each of the domains of quality of life. They also tended to report fewer concerns associated with their child and to make more comments regarding the best things about their child.

Chapter 5

Discussion

This chapter is intended to reflect upon the findings conveyed in the results section. Theoretical, practical and research implications are discussed, with suggestions provided for future research. An attempt will be made to merge the findings with the ABCX model, as well as with the positive disintegration in order to support the argument that while families of children with autism do face difficulties, they can also adapt and function. Further discussion of themes and issues which arose in the findings will be reflected upon.

Differences

While there were limited statistically significant differences in the quantitative analysis, some differences were found between the families of children with autism and those of children who do not have autism. For instance, in terms of quality of life, families of children with autism differed significantly from those of children who do not have autism in the domains of satisfaction with neighbourhoods and communities, indicating they experienced rejection and sometimes felt unsafe in their neighbourhoods and communities. They also differed statistically significantly in terms of annual household income. Furthermore, those families of children with autism whose incomes were higher tended to have accessed a greater number of intervention services and achieved access to these services sooner and more frequently than did those whose incomes were lower. Upon analysis of the qualitative data, it was discovered that though families of children with autism did not score statistically significantly lower on the Quality of Life Inventory, they tended to report

a greater number of difficulties which prevent them from realizing a satisfactory quality of life. Furthermore, they described various complications which reflected a number of areas in which their lives had been rendered more difficult as a consequence of the presence a child with autism.

Theoretical Implications

Quality of Life

The quantitative findings, with regards to the QofLI results, support the ABC-X model of stress, as well as Dabrowski's theory of transformative disintegration (1976), whereby families faced with difficult situations will, over time, accommodate the situation and eventually, adapt to their circumstances. This adaptation can be seen among the families of children with autism, as these families have been coping with autism and its related behaviours and needs for 6 to 12 years. Parents of children with autism tended to report similar QofL as those of children who do not have autism. In addition to this, the frequency with which parents of children with autism indicate concerns across several domains in the lives of their children, as well as themselves, supports Perry's (2004) contention that the ABC-X model and theories of integration of stressful circumstances do not reflect the ongoing nature of developmental disorders. This was further demonstrated by those who indicated variations in their experiences at given points in their child's development; this is worthy of further examination.

A longitudinal study which examines how these phenomena occur in the lives of children with autism, as well as in the lives of their family members is necessary. According to Cashin (2004), Perry (2004), Scorgie and Sobsey (2000), and Soresi,

Ferrarai, Wilgosh, and Scorgie (2003), upon diagnosis of a child's developmental disorder, families undergo a period of re-examining and adapting their roles, goals, economic resources, and routines to accommodate the child's needs. Furthermore, they must learn about autism, how to access the services and resources their child will need, and cope with their own feelings about their child's disorders.

Despite the similarities in terms of quantitative scores on the QofLI, when individual domains of QofL are taken into consideration, statistically significant differences were found between families of children with autism and those of children who do not have autism in terms of the importance upon which families of children with autism placed on their homes, as well as satisfaction with their neighbourhoods and learning opportunities. The anecdotal data parents provided regarding their homes included safety issues (e.g., parents would prefer to live in areas with lower crime rates) and satisfaction with the current state of their homes (e.g., preference for larger homes or backyards) differed from those provided by parents of children who do not have autism. Additionally, social support available to the family can be examined to determine whether there is a correlation between types of and access to social supports and QofL to determine whether these contribute to adaptation of families in the presence of a child with autism.

Parents of children without autism tended to report that they wanted to improve their homes through renovation or interior design, while parents of children with autism reported a desire for safer locations and housing which met the needs of their child with autism (e.g., suitable to accommodate home programming). Despite these differences, both groups of parents reported that their desire for changing their

housing situations was hindered by a lack of financial resources, indicating deficits in terms of Schalock's (1996) second domain of QoFL.

According to Schalock's (1996) model of quality of life, safety is the first domain of consideration when determining predictors of QoFL. In the present study, the need cited by parents of children with autism for safer housing suggests that this population has greater difficulty in attaining safe housing, thereby influencing their quality of life. With regards to the fact that parents of children with autism tended to report significantly lower annual household incomes, the inability of this population to attain housing which they feel is safe may have been due to their lower material well-being, the second domain within Schalock's model of QoFL. Furthermore, these families indicated that within their neighbourhoods and communities, they experienced or perceived low levels of acceptance and understanding along with high rates of rejection. This suggests that public perception of individuals with autism is negative.

In an examination of how stigma impacts public health, Link and Phelan (2006) identified five ways in which this occurs: (a) identification and labelling of human differences, (b) stereotyping of the labelled person, (c) separation of the labelled person from the mainstream group of people, (d) discrimination and loss as a result of separation by label, and (e) mobilisation and exercise of power among labelled individuals. Those authors further identified three types of discrimination: (a) direct discrimination, whereby, rights and/or privileges are actively withheld on the basis of status or label, (b) structural discrimination, whereby the structure of an organization or system prevents participation by those of a certain status or label, and

(c) insidious discrimination, whereby negative attitudes and preconceived ideas about an individual or group of people within specific status or label. This latter type of discrimination appears to be common among the respondents in this study whose child has autism.

Parents of children with autism in this study indicated that they their neighbours and communities did not understand their child's disorder and, consequently, were not interested in interacting with the family members. According to Link and Phelan (2006), this type of insidious discrimination can have profound impacts on those discriminated against in several ways. The individual or group who are the subject of discrimination tend to act less confidently, avoiding situations in which negative attitudes about them may be reinforced (e.g., in the case of autism, any situation which may elicit stigmatizing behaviours may be avoided), and acting defensively toward others who may pose the threat of having negative attitudes toward them. Consequently, the individual or group often reports experiences of strained or constricted social interactions, more constricted social networks, a compromised quality of life through the prevention or reluctance to pursue interests, low self-esteem, depressive symptoms and unemployment.

As demonstrated by the significant differences in the scores attained by families of children with autism when compared to those of children without autism, the former do report receiving less social support from the mainstream than those who are not related to an individual with autism. Despite this finding, it is difficult to determine what the extent of the impact stigma and discrimination against children with autism, as well as their families is. This is because in studies examining

discrimination, researchers tend to only consider one aspect, rather than breaking the stigmatizing characteristic down into smaller, measurable variables (Link & Phelan, 2006). For instance, in the case of autism, it would be necessary to not only measure the discrimination and attitudes of others toward the disorder itself, but also toward mental health, the behaviours observed within the individual who has the disorder, characteristics about family members, the cause of the disorder, etc.

In terms of mental health, stigma can have a profound impact on health care provision. According to Corrigan (2004), the stigma associated with mental health problems or disorders have two common consequences: (a) those suffering from the disorder do not seek the assistance they require, and (b) the treatment is not fully adhered to for fear of further stigmatizing oneself. Those suffering from the mental health problem often cite fear of being perceived negatively or blamed for their problems as a reason for not seeking assistance, as well as denying the existence of a problem. As mentioned in the literature review of this study, the presence of a child with a developmental disorder has been associated with depressive symptomatology. Given that the families of children with autism have cited a perception of negative attitudes toward them and their child with autism, one suffering from depression or other mental health problem may resist seeking assistance for fear of the responses from others. Further research is required in order to determine the extent to which parents and siblings of children with autism suffer from mental health problems themselves.

Regardless of the quantitative findings made using the *QoLI*, there are some differences in terms of the concerns the two groups had, as reflected by the comments

made in sections for open-ended questions. Upon examination of the anecdotal data, as well as the concerns parents of children with autism had, it becomes apparent that the issues, stresses, and concerns among this population are different from those of children who do not have autism. For instance, only one (5%) parent of a child who did not have autism cited bullying as a concern and this participant was concerned that her child bullied other children. Conversely, 9 (53%) parents of children with autism cited that their child had been bullied or victimized by others.

Bullying impinges upon one's material, social, and physical well-being, all domains that Schalock (1996) suggests are important in determining QoFL. This suggests that such experiences, significantly more prevalent among children with autism than among those who do not have autism, detract from the QoFL of an individual with autism. According to independent t-tests, a child's access to intervention does not significantly affect whether or not the child will be bullied by his/her peers. Thus, while interventions may provide a child with autism with the skills to interact effectively in his/her environment, it will not serve to prevent bullying and victimization by peers.

In an exploratory study, Sweeting and West (2001) found that children with a disability tended to report having been bullied significantly more frequently than did those who do not have a disability. Through personal experience and observation, I have found that implementing a brief program which introduces children with the concept of autism, as well as providing examples of sensory experiences that a child with autism may have, often serves to reduce bullying toward and increase respect and/or interest in the child with autism.

In the past, parents of children with autism with whom I have worked have indicated that sending a letter home to parents explaining the disorders, behaviours, and other symptoms often serves to reduce bullying and increase positive interactions not only with the other children, but with parents of the child's peers. However, an exhaustive search using PsychArticles, PsychInfo, EbscoHost, and ERIC yielded no research regarding bullying toward children with autism or prevention thereof. Thus, further research must be conducted in order to determine the nature of bullying experienced by children with autism, as well as how to prevent bullying toward this population.

Family Support

Parents of both children with and without autism reported similar availability of support from their parents, spouse or partner's parents, relatives, spouse or partner, spouse or partner's friends, participant's own children, co-workers, family or child's physician, and school or day care centres. However, there were significant differences found among the availability of support respondents reported among their own friends. In this regard, parents of children who do not have autism reported receiving more support than do parents of children with autism. This may be explained by a study conducted by Jones and Passey (2004).

In their study, examining family adaptation among parents of children with developmental disorders and behaviour problems, Jones and Passey (2004) found that parents of children with developmental disorders reported that others viewed their child negatively and in turn, responded to the family members negatively. Parents also reported not receiving sufficient support or having lost supports available to them

previously. The participants in their study reported feeling as though others blamed them for their child's difficulties. Finally, as demonstrated in the current study, parents reported concerns that their child was not accepted by others, participated in fewer extra-curricular activities and had fewer friends, it is possible that these families simply do not have as many opportunities to form relationships and social networks available to families of children who do not have autism.

Parents of children with autism reported significantly greater availability of support from parent groups, social clubs or organizations, church members or ministers, early childhood intervention programs, professional helpers and professional agencies. Considering previous findings (e.g., Dyson & Fewell, 1986; Warren-Adamson, 2006), whereby parents of children with developmental disorders often tend to cite as their primary sources of support the professionals and others involved in assisting them, this is not surprising. The sources of support that these parents cited as providing support are ones which would often not be needed, and therefore not sought after by parents of children who do not have autism.

In her study examining the impact of intervention on parent-child relationships in families of children with autism, Summers (2001) found that satisfaction with parenting a child with autism was significantly correlated with annual income and parent education. This supports the present study's findings that parents of children with autism tended to make more positive comments about their child and their love and enjoyment for their child as socio-economic status increased. This does not suggest that parents of children with autism tend to love their children more if they have more money. What it may imply is that parents of children with

autism have more opportunity to enjoy their children when they have greater financial resources. According to Schalock's (1996) model of QofL, material well-being is a determinant of QofL.

As statistically significant differences were found between annual household income and the amount and length of intervention children with autism received, it may also be that those children receiving higher amounts and lengths of intervention display fewer challenging behaviours. In her study, Summers (2001) found that parents of children receiving intervention reported a decrease in difficult behaviours. However, further research would be necessary in order to determine whether this is the case with the current population.

Only one parent (5.9%) of a child with autism cited medication as a means of intervention for his/her child. In their study of intervention usage among children with autism, Hume, Bellini, and Pratt (2005) found that 27.7 % of the participants they surveyed used medication at some point in their development. While this is a pertinent issue, there are many variables that would influence medication use among children with autism between 6 and 12 years old. For instance, the type of medication prescribed would depend upon the symptoms (and intensity thereof) exhibited by the individual child. It would also be influenced by the developmental and chronological age of the child, as well as parents' preferences and/or attitudes toward medication. These variables are valid and worthy of consideration in future research. However, they are beyond the scope of the present study.

Family Environment

Not surprisingly, the *FES* found that families of children with autism scored significantly differently from families of children without autism. Specifically, families of children with autism reported lower cohesiveness, expressiveness, higher rates of conflict, and lower rates of independence than did families of children who do not have autism. These findings replicate results made in previous studies examining families of children with developmental disorders where families of children with developmental disorders reported higher rates of conflict and lower levels of harmony, depending on whether or not the child had a developmental disorder and if so, the severity thereof (Dyson, 1997; Perry, Harris, & Minnes, 2004).

The experience of low rates of cohesiveness, expressiveness, and independence, as well as high rates of conflict is predictive of high rates of stress (Perry, 2004). Furthermore, high rates of stress influence one's experience of a low QofL. Those suffering from high rates of stress also tend to experience hypertension and other health problems, thereby further decreasing their ability to enjoy life (Corrigan, 2004). In the present study, families of children with autism tended to have more visits to health professionals. Further research would be necessary in order to determine whether families of children with autism visit health professionals more frequently and if so, whether this is due to autism-related stress health problems.

The discrepancy between *FES* scores and QofL scores may be indicative of transformative disintegration (Dabrowski, 1976). Families of children with autism tend to report similar satisfaction with several aspects of QofL. However, they also report greater familial distress, indicating that they have incorporated low rates of cohesiveness, expressiveness and independence, as well as high rates of conflict into

their daily family lives. This suggests that they have integrated the experiences of heightened family distress into their day-to-day experience, such that this distress no longer appears to be an effect of family trauma, supporting Perry's (2004) contention that the distress resulting from the presence of a developmental disorder within a family occurs across the lifespan. It is therefore, inaccurate to consider the presence of a child with autism as a traumatic event, as suggested by the ABCX model of stress.

Child Behaviour

It is not surprising that children with autism had statistically significantly different scores (e.g., higher and more likely to fall in the clinical range) on various subscales of the *CBCL* than did children without autism, as they suffer from a pervasive developmental disorder, impacting several aspects of their functioning. Interestingly, when asked to identify the best things about their children, parents of children with autism tended to refer to their child's development and rate of skill acquisition, whereas parents of children who do not have autism tended to identify personality features of their child. Nevertheless, both sets of parents tended to identify sense of humor and temperament among the best things about their child. This supports Cashin's (2004) findings whereby parents reported that the most reinforcing interactions they had with their child were when the child demonstrated some kind of connection to them. Parents cited occasions as simple as a time when both they and their child were laughing and it was clear that they were laughing for the same reasons as being highly reinforcing and connecting experiences with their child.

Practical Implications

Among the concerns parents had for their children with autism, bullying was mentioned by 9 (53.1%) of parents. The experiences with bullying and victimization reported by parents of children with autism included physical assault, name-calling and humiliation by peers. In one case reported by a parent, it also included refusal by a teacher to assist in problem-solving with parents or disciplining the bullies. It is possible that the teacher was unaware of the extent of the bullying that was taking place. According to Heinrichs (2003), teachers self-report that they are aware of and intervene on bullying 71 % of the time, whereas their students reported that teachers were aware of and intervened 25 % of the time. Thus, it is possible that though teachers are aware of bullying, there are incidents which occur unnoticed. Bullying and victimization are not limited to children with autism.

In a study examining the experiences of students with moderate learning difficulties, Norwich and Kelly (2004) found that this population was bullied regardless of attendance at mainstreamed or segregated schools for children with special needs. In the latter case, the instigators tended to be children from local mainstream schools, while in the first case, the bullies were the children's classmates. While it is not uncommon for bullying to occur, especially to children who are somehow stigmatized, it is necessary to take measures in order to prevent it (Heinrichs, 2003).

In her discussion on implementing anti-bullying programs in schools, with special consideration to students with special needs, Heinrichs (2003) suggests that it is imperative that bullying programs be designed taking into consideration the school and the needs of those who attend or work at it. Teachers and students need to be

included in assessments prior to developing and implementing anti-bullying programs. Furthermore, she suggests that when children with special needs are involved, consideration needs to be given to their specific needs (e.g., teaching children to recognize what the motives of others are, helping them plan how they will respond or remove themselves from the situation). Finally, she recommends that regular class meetings and discussions need to take place between students and teachers to help children to understand the impact of this behaviour, as well as how to deal with it. This time should be spent discussing consequences of bullying, where punishments are clearly outlined, as well as social skills training for both the targets and the bullies.

Parents indicated concerns about the lack of availability of services for children with autism falling within the ages of 6 to 12 years old. According to their accounts, there are services available to young children, as well as adolescents transitioning out of the school system, but very few services available to school age children. Parents indicated that though they are willing to pay for intervention services, they have difficulty accessing services or programs, due to over-enrolment.

Many parents also cited concerns regarding funding to access services for their children. These concerns ranged from the fact that while they are reimbursed for some of their intervention expenses, the government is slow in doing so, to the fact that the needs and requirements their children have prevent them from earning sufficient income. Considering parents of children with autism earned significantly less than those of children without autism, a system whereby funding is provided in a timely fashion is necessary. This is especially true when 2 (13%) of the parents of

children with autism indicated that they are earning between \$0–\$25,000.

Furthermore, the suggestion that sufficient services are not available for this age group causes concern for parents attempting to access services for their child.

According to Lewis and Sanmartin (n.d.), Canadian health care priorities are determined depending on the numbers of people waiting to access specific services. The authors argue that because Canada's population is ageing, a majority of health care dollars are spent on providing services specific to ageing and elderly people at the expense of service and care provision to other less prevalent populations. This may be what is occurring in terms of service delivery to school age children in Canada. As participants in Victoria, British Columbia, Toronto, Ontario, and Montreal, Quebec, all cited the lack of services for school age children with autism, it is apparent that this problem is not limited according to region, but may be reflective of a problem occurring across Canada.

It seems that one of the major dilemmas preventing service provision is the complexity of integrating services effectively across a variety of public organizations. According to Hoggett (2006), one of major difficulties faced by public organizations is that they must deliver services and programs which meet the needs of those they are designed to serve, while also considering the values of the public. In the case of autism, this may be further hindered by the stigma associated with mental health issues. A failure by the majority to acknowledge and understand the needs associated with mental health, namely, autism, results in a lack of support by the majority, to support initiatives and those public organizations striving to serve those in need of them. The claims of the participants in the current study that their relatives,

neighbours, and communities fail to understand the disorder, demonstrates this breakdown. Autism is a pervasive disorder which impacts all aspects of an individual's functioning. While it does impact learning and academic abilities, autism is not solely an educational problem and should therefore not solely be addressed and served by educational organizations. Nor is it solely a social problem, despite the presence of significant social deficits and difficulties. Autism is also health problem, as it is neurological in nature and can impact one's ability to communicate pains or illnesses, hindering the receipt of treatment. In order to achieve adequate service delivery, it is necessary for those public organizations involved in service delivery on all three realms to work cooperatively and collaboratively in order to provide services to all who need them. Autism is a lifelong, pervasive disorder, effecting transformations and development unique from that of individuals with other developmental disorders, as well as typically developing individuals, within the afflicted individual, as well as within those who care for and interact with him/her on a regular basis.

Research Implications

In the present study, the parents will have had opportunity to undergo these transformations and learning experiences. As Cashin (2004) was able to demonstrate in his study, parents claim that upon diagnosis of a developmental disorder, the following year is a period of crisis. Thus, it would be useful to conduct this study among families of recently diagnosed and younger children. For instance, Giacomo and Fombonne (1998) found that parents attained diagnoses of autism for their child when he/she was approximately 24.1 months old. Thus, cross-sectional and

longitudinal studies would be required in order to determine whether parents of children with autism undergo transformative disintegration, resulting in QofLI scores which are more similar to those parenting children who do not have autism as the child ages.

According to Moos and Moos (1994), individuals within a family tend to report significantly different experiences on the Family Environment Scale. This reflects how, despite the transactional nature of developmental disorders, each individual interprets his/her experiences living with an individual with a developmental disorder will differ, according to a number of factors. This study only examined the QofL, as reported by one respondent within the family. In order to glean information about each family member's experience and perceived QofL, it would be necessary to conduct a study, replicating these methods, but extending them to include all possible members of the family, taking into consideration the age of not only the child with autism, but also all family members.

The quantitative and qualitative data extracted quite different findings in terms of the experiences of parents of children with autism. For instance, there were few statistically significant differences in terms of the QofLI. However, upon examining qualitative data, the issues preventing families of children with autism from realizing QofL equal to those of families whose children do not have autism were numerous and quite significant (e.g., inability to work/earn an income due to the needs of the child, living in unsafe housing situations due to a lack of financial resources, bullying of the child). This demonstrates a need for mixed methodology when examining

families of children with autism. However, this phenomenon is not unique to the study of children with developmental disorders.

In a study examining participants' reactions to a play, Blythe, Reid, Wright, and Geelhoed (2006) found that the emotional responses participants indicated in empirical measures were statistically significantly different from those cited during interviews. Participants also indicated frustration with the usability of the empirical measures (e.g., forced choice where no choice reflects one's true feelings). Similar experiences were demonstrated in the current study by those who circled several items on one likert scale, indicating different points in time that those ratings would be relevant. As Cresswell (2002) states, mixed methodology provides the researcher with the opportunity to glean rich information, insight and various perspectives into the research. A measure which examines all aspects studied in the present paper would be useful to employ when examining families, as their experiences can be subjective, yet measurable. The *QofLI* provides a good framework for such a measure with the opportunity to comment on each domain measured in an open-ended format, yet does not allow for measurement of issues specific to individuals with developmental disorders and the families thereof.

Limitations

While this study revealed some important findings, as well as implications for families of children with autism, there are some limitations. For instance, the sample size in the current study was relatively small and caution should therefore be used in generalizing these findings to larger populations. Furthermore, though this study examined family experiences and reports, only parents participated in this study.

Therefore, the findings can not be taken to represent the experience of living in a family of child of autism for others, such as siblings and grandparents.

Though rigorous alpha levels were used in the statistical analyses, it is also possible that some of the findings were due to chance. The participants completed a large quantity of questionnaire items in one sitting, which increases the likelihood that some findings were due to chance.

Finally, this research did not take into account the effect the types of behaviours common to the individual children with autism. It would be necessary to conduct observations of the child's functioning across a variety of settings in order to determine whether the children with autism were equally impaired and functioning at similar levels. This would also be useful in determining family interactions and cohesion among the participants. This type of observation was prohibitively expensive given the scope of the current study. For larger scale, more intensive research projects, this approach may be relevant.

Conclusion

This study attempted to answer the following questions: (a) Is there a significant difference between the quality of life of family members when a child between the age of 6 to 12 years old has autism and the quality of life in families of children of similar ages who do not have autism? and (b) If differences do exist, what are they? Quantitative measures and qualitative analyses revealed that there are significant differences in some areas of QoFL between families of children with autism aged 6 to 12 years old and families of similarly aged children who do not have autism. These differences were that families of children tended to earn lower annual

incomes, experienced different levels of social supports from different sources, experienced higher rates of conflict and did not receive adequate service delivery to meet their needs.

While qualitative data suggest that the presence of a child with autism influences QoFL, quantitative data are less conclusive. Thus, further research, with measures which will allow more in-depth and rigorous examination of QoFL within families of children with autism is needed. Intervention services had limited influence over QoFL, though families with higher incomes tended to receive more intervention services and reported greater satisfaction with their children. A need for better understanding and greater knowledge not only among the community, but among the medical and education communities was identified by parents as a need which will greatly enhance their QoFL, as well as that of their children. Knowledge and understanding serve as empowerment for those accessing services, but it can also empower those who provide the services, be it medical, educational, formal or informal social support to provide high quality services and care on multiple dimensions. The transactional nature of the family suggests that by providing better care and service to individuals with autism, the family will also benefit. Thus, in improving policy and practice around autism, families will thrive and those dependent upon the assistance of others will develop greater independence and ability to contribute to the community.

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Appendix A

Identification Number 05 _____

**Educational Psychology and Leadership
Studies (Special Education)**

***Letter of Introduction and
Participant Consent Form***

**The Quality of Life of Families of Children with Autism: A Comparison with
Families of Children Who Do Not Have Autism**

You are being invited to participate in a study entitled A Quantitative Inquiry into the Quality of Life of Families of Children with Autism: A Comparison Between Centre-Based Intervention Recipients and Non-Recipients that is being conducted by Heather Church. Staff working in the program were asked to distribute this letter to parents/guardians of children with autism between the ages of 6-12 years old. Your name/identity and that of your child were not revealed to me.

My name is Heather Church and I am a graduate student in the department of Educational Psychology and Leadership Studies at the University of Victoria. You may contact me if you have further questions by email at hchurch@uvic.ca.

As a graduate student, I am required to conduct research as part of the requirements for a Master of Arts in Educational Psychology. It is being conducted under the supervision of Dr Lily Dyson. You may contact my supervisor at (250)721-7816 or at her email address ldyson@uvic.ca.

The purpose of this research project is to determine predictors of quality of life in families of children aged 6 to 12 years old, who have autism and who are receiving formal intervention versus those who are not.

Research of this type is important because it will demonstrate whether there are significant differences in terms of family members' health requirements, development of siblings, and overall satisfaction with life among families with children with autism who are receiving intervention versus those who are not.

You are being asked to participate in this study because your child is either currently receiving intervention or has done so in the past.

If you agree to voluntarily participate in this research, your participation will include completing a package of questionnaires regarding family functioning, child behaviours of typically developing siblings (if applicable), health demands and access to social support. Completion of this package will take place at your convenience.

Two packages will be provided in cases where both parents agree to consent to participation. While I request that you complete the questionnaires independently, you may complete them in the location of your choosing.

Participation in this study may cause some inconvenience to you, including completion of four questionnaires, which may be time consuming (approximately 45 minutes to an hour of your time will be required).

1. There are no known or anticipated risks to you by participating in this research.

The potential benefits of your participation in this research include a demonstration of the influence intervention has over quality of life for families of children with autism.

It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will only be used if you give permission. In order to withdraw from the study, while protecting your confidentiality, please send a letter to me, quoting your identification number. All materials associated with this identification number will then be destroyed using a paper shredder.

In terms of protecting your anonymity each questionnaire package will be assigned an identification number. The researcher will be blind as to who receives which questionnaire package. Furthermore, staff at the centre from which you received this letter will not be aware as to whether you have consented to participate or not.

Your confidentiality and the confidentiality of the data will be protected by destruction of materials upon completion of the study. Individual identities will not be known to the researcher or others.

It is anticipated that the results of this study will be shared with others in the following ways: thesis and oral defense.

Data from this study will be disposed of upon completion of the study by use of a paper shredder.

Individuals that may be contacted regarding this study include Heather Church (hchurch@uvic.ca) and her thesis supervisor, Dr Lily Dyson (phone: (250)721-7816 (ldyson@uvic.ca)). For questions regarding patients' rights, Dr. Peter Kirk (Director of Research and Academic Development 250- 370-8620) may be contacted.

In addition to being able to contact the researcher and her supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Identification Number 05 _____

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix B

Permission to Reprint

Dear Heather:

I am delighted to give permission for you to use "Welcome to Holland" in the frontispiece of your dissertation. I'm so pleased that you think it has application to your thesis and data. And yes, while I originally conceived of it in a Down syndrome context, over the years it has become apparent that it can be applied to many other situations, any unexpected "change in plans."

I have a couple of requests -

1. I am enclosing herewith a complete and accurate copy of Welcome to Holland so you can be sure you are using an "authorized version." Its been used in many places and in many versions. I would appreciate your reprinting it unchanged and uncut, using this official version.
2. Please credit me as the author, using my full (three-part) professional name: Emily Perl Kingsley and the copyright notice:

© 1987 by Emily Perl Kingsley
All rights reserved
Reprinted by permission of the author

3. Please let me know that these conditions are acceptable to you.

Thanks again for your kind words about "Welcome to Holland." Best of luck in defending your thesis and in all your future endeavors.

Emily

Emily Perl Kingsley

Vita

Surname: Church

Given Names: Heather

Place of Birth: Toronto, Ontario, Canada

Educational Institutions Attended:

University of Victoria 2004 to 2006

Trent University 1997 to 2001

Degrees Awarded:

B.A. Trent University 2001

Publications:

Conference Proceedings

Hadwin, A.F., Church, H., Gress, C.L., Morris, R., & Winne, P.H. (2006). *The use of prompts, roles, and scripts in collaboration*. Submitted as a component of a four-part symposium on computer supported collaborative learning entitled: Advancing educational research on collaboration through the use of gStudy CSCL tools. Submitted to Canadian Society for the Study of Education, Toronto, Ontario.

Dyson, L., Church, H., Bilous, L., Myskow, S., Blom, R., Fremerlid, D., & Carlow, T. (2005). Promoting literacy skills in kindergarten children in low-income homes: A parent workshop program under school-research collaboration. *The 1st Asia-Pacific Regional Congress of International Association for the Scientific Study of Intellectual Disabilities (IASSID)*.

Scholarly Achievements

Church, H. (2005). *Providing Parents of Children with Autism with Skill Acquisition Updates*, Presentation at the Queen Alexandra Centre for Children. Those in attendance included autism interventionists, occupational therapists, speech and language pathologists, psychologists, and behavioural consultants.

Church, H. (2005). *Behavioural Assessment and Autism Intervention*. Lecture to a

fourth year undergraduate class (EDUC 421 Recognition and Analysis of Learning Needs).

Church, H. (2005). *Providing Parents of Children with Autism with Skill Acquisition Updates*. Presentation at the Queen Alexandra Centre for Children. Those in attendance included autism interventionists, occupational therapists, speech and language pathologists, psychologists, and behavioural consultants.

Church, H (2003). *Behaviour Intervention—Response-Cost: Stereotypic Vocalizations*. New Haven Learning Centre for Children Curriculum.

Church, H (2003). *Skill Acquisition Program: Sequences Numbers*. New Haven Learning Centre for Children Curriculum.

Undergraduate Thesis: Church, H. (*unpublished*). *The Impact of Marginalization to a People: A Needs Assessment of Hill Tribe People in Urban and Rural Settings*.

Invited Presentations and Seminars

Discussant: Varnish, A., & Bosacki, S. (May 2006). *Evaluation of an Emotion Intervention for Pre-Schoolers with Autism Spectrum Disorders*. I was asked to act as discussant for this presentation at the annual conference held by the Canadian Society for the Study of Education, Toronto, Ontario, Canada.