

**CHILDREN WITH AUTISM AND THEIR SOCIALIZATION:
THE REPORTED EXPERIENCES OF MOTHERS**

BY

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**A thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of Master of Education**

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
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ABSTRACT

The research on the deficits in the social interaction of children with autism has focused mainly on quantitative and qualitative measures in artificial environments. These deficits are not well understood. The purpose of this qualitative study was to gain a better understanding of the social development of children with autism through an exploration of the reports of the experiences and perspectives of these children's mothers. Five mothers volunteered to participate in the study. Four mothers individually and one with her husband, were each interviewed for approximately two hours. The children with autism were between 6 to 12 years of age; they were diagnosed with autism at least three years prior to the time of the interview and attended mainstreamed schools in Winnipeg. The interviews were tape-recorded and transcribed verbatim. The transcribed interviews were analyzed for emergent themes. Three main themes were found: I. Mothers' experiences coping with autism and their children's social deficits affect how they first come to view and relate to the children; II. Mothers' perspectives on their children's characteristic ways of relating provide deep insights into these children's social deficits and the contexts in which those deficits occur; III. Mothers, through their special relationship with the children have learned effective strategies to facilitate the social interactions and integration of their children. Mothers' experiences illustrated that these mothers face many

challenges and difficulties coping with their children's autism and social deficits that limit and strains on their relations with their children. Due to these challenges, at the beginning, the mothers were unable to foster optimally their children's early social development. The mothers' insights into and specific accounts of the children's ways of interacting were a basis for a better understanding of these children's social deficits as well as potential capabilities. Mothers' statements showed how, based on these children's patterns of social interaction, the parents learned effective ways to socially facilitate and help integrate their children into the community. Implications for professionals were set out. The findings clearly suggest how the social development of children with autism can be better understood by qualitatively analyzing the main caregivers' accounts of their experiences with their children.

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This thesis is dedicated to my dear father, Salvador Caponetto (1925-1988).

TABLE OF CONTENTS

ABSTRACT	ii
ACKNOWLEDGEMENTS	iv
DEDICATION	v
CHAPTER 1: INTRODUCTION	1
CHAPTER 2: REVIEW OF THE LITERATURE	5
Overview of Social Functioning.....	5
Research on Deficits in Social Interaction	7
Studies and Self-Accounts on the Lived Experiences of Parents	9
The Gendered Nature of the Caregiving Role.....	12
CHAPTER 3: RATIONALE.....	15
CHAPTER 4: BACKGROUND INFORMATION	18
Historical Tracings of Autism.....	18
Diagnostic Criteria and Main Characteristics	20
Course of Autism	21
Comorbidity and Differentiation from Other Disorders	23
Epidemiology	27
Etiology	27
Assessment.....	28
A Brief History of Approaches and Treatments.....	31
Education	35
Mainstreaming and Social Skills Training	37
Personal Involvement with Children with PDD.....	41
CHAPTER 5: METHOD	43
Recruiting the Participants	43
Participants.....	45
Pilot Interview.....	47
Interview Questions	48
Data Collection	49
CHAPTER 6: RESULTS AND DISCUSSION.....	51
Initial Analysis of the Interviews.....	51
Fieldnotes.....	51
Transcribing the Interviews.....	53
Analyzing the Transcriptions	56

Structure of Data Collection	58
Formal Analysis and Discussion.....	60
Theme I Mothers' experiences coping with autism	62
(1) Difficulties in Obtaining a Diagnosis	63
(2) Receiving and Coping with the Diagnosis	67
(3) The Dilemma of Finding Effective Interventions and Help....	71
(4) The Daily Challenges of Raising a Child with Autism	75
(5) The Effects of the Child's Autism on the Siblings.....	77
Theme II Mothers' perspectives on their children's characteristic ways of relating	81
(1) Clear Evidence of Communication and Social Deficits During the Toddler Years	81
(2) Severity of Communication and Social Deficits as they Change with Time.....	87
(3) Difficulty Expressing and Understanding Emotions.....	89
(4) Restricted Preference of Behaviours, Interests, and Routines	91
(5) Strengths and Abilities.....	94
Theme III Mothers' learned strategies to facilitate social interactions	97
(1) Social Interactions and Relationships between Children and Mothers	98
(2) Children's Social Initiations in Some Situations.....	103
(3) Beneficial Interactions and Relations with Siblings and Peers	107
(4) Mothers as Facilitators and Interpreters of Social Interactions	114
(5) The Importance of Mainstreaming and Social Skills Training	116
(6) The Crucial Goal of Training and Educating the Community about Autism	118
Summary	121
CHAPTER 7: LIMITATIONS AND IMPLICATIONS	126
Limitations of the Study.....	126
Implications for Future Research.....	128
Implications for Professionals and for the Researcher	129
CHAPTER 8: CONCLUSION	133
REFERENCES	134
APPENDICES	143

Appendix A

Information Letter to Participants.....	143
Consent Form	146
Carta de informacions para Parents (Spanish Version).....	148
Permiso.....	152

Appendix B

Interview Guide.....	154
Guia de la Entrevista.....	157

Appendix C

Letter for Recruiting Agencies	160
Advertisement to Recruit Participants.....	162

CHAPTER 1

INTRODUCTION

Autism, a lifelong developmental disorder, has been widely studied (Konstantareas, 1989). Autism is considered a spectrum disorder because its symptoms can present themselves from early childhood in a broad variety of combinations, ranging from mild to severe (Rutter & Schopler, 1987). Although some individuals present only slight delays in language, others need assistance in handling ordinary day-to-day self-care activities. However, serious deficits in social interaction, social behaviours, and social skills are the most common hallmarks of autism (Stone & Greca, 1986; Volkmar, Carter, Grossman, & Klin, 1997). These deficits are particularly evident during the preschool years: Young children experience great difficulty with "normal" or "appropriate" social interactions; they typically fail to respond to social contact, initiate play, and initiate social interactions (Rutter & Schopler, 1979).

Although many of the deficits in the social interactions of children with autism have been documented in the clinical literature, these problems remain among the least understood aspects of the disorder (Lord, 1995; Schopler, 1995). One major weakness in the literature is that most studies have been limited to quantifiable measures (e.g., frequency of eye gaze) and to qualitative, descriptive observational data collected in artificially constructed situations (Howlin, 1986;

Volkmar, Carter, et al., 1997). In addition, only a few researchers have studied the deficits in the social interactions of elementary-age children with autism within the children's real-life social environments (McGee, Feldman, & Morrier, 1997). Such deficits in social interactions cannot properly be studied in isolation from other aspects of individuals' functioning in everyday life (Lord, 1991).

Another weakness in the literature is that many studies have failed to consider developmental changes in children with autism over time. As Van Meter, Fein, Waterhouse, and Allen (1997) pointed out, autistic social deficits do not simply reflect delayed social development, but social dysfunction that affects early emerging social behaviours which lead to variations in developmental profiles. According to these authors, progress in daily living and socialization is highly variable and perhaps less predictable among young children with autism.

Although the social difficulties of children with autism persist over time, their social functioning matures and changes throughout their lives, just as it does with "normal" individuals. In fact, the nature of the process underlying social gains of children with autism during their middle childhood remains relatively unstudied (Volkmar, Carter, et al., 1997).

Socialization is a complex process of interactions between an individual, those in his or her immediate context, and other people in a social environment; it affects all the participants in a social interaction. The socialization depends

greatly on the understanding of the people involved, the structure of the situation, and the larger social context in which the interaction occurs (Kasari & Sigman, 1997). To date, however, most studies of children with autism have emphasized the quantity of appropriate and undesired behaviours; qualitative assessments and analyses (e.g., of choice-making, social attachment, social interest) have been given little consideration (Howlin, 1986).

Such gaps in the literature on the social deficits of these children would be addressed by an investigation of the ways in which caregivers, according to their reports, interact with children with autism. As Adams, Wilgosh, and Sobsey (1990) concluded, qualitative studies of parents' lived experiences are necessary to supplement quantitative and impersonal research findings. With qualitative studies, the researcher is able to study the whole setting, the people, their experiences, and their points of view all together in context (Bogdan & Biklen, 1992). The experiences of the parents of children with autism can provide a uniquely important basis for understanding the children's deficits in social interactions within the particular social environments and developmental frameworks in which the problems occur.

The purpose of the present thesis is to gain a better understanding of the social development of children with autism through a qualitative study of the experiences and perspectives of these children's mothers. Reports of these

mothers' experiences and perspectives were gathered in face-to-face interviews so as to gain insight into three areas related to the mothers' involvement in their children's social development. The first area is the formative experiences of the mothers as they come to understand their children's serious and perplexing social difficulties. These experiences provide a starting point to understand the mothers' challenges and the early mother-child interactions. The second area involves the mothers' perspectives, their perceptions and feelings about their children's social interactions in context. The third area is the mothers' experiences in fostering these children's social interactions and social skills. The last area in particular will, it is hoped, shed some light on how other people involved in these children's lives may facilitate interactions that are more successful and provide better support for the education and integration of these children into their communities.

CHAPTER 2

REVIEW OF THE LITERATURE

Overview of Social Functioning

The social functioning of children with autism tends to improve with age. For example, although toddlers with autism tend to lack responsiveness to human physical contact, such as cuddling, older children with autism become more interested in physical contact, and more willing to engage in interactions with other people (Volkmar, Carter, et al., 1997). A handful of studies which reviewed home videos of toddlers with autism have shown that toddlers exhibit fewer social and joint-attention behaviours, and show many autistic symptoms such as isolation and indifference (Volkmar, Carter, et al., 1997). Most researchers assert that social deficits characterize early mother-child interactions, including deficits in imitation, mutuality, and reciprocity (Howlin, 1986).

During later childhood and adolescence, positive social outcomes develop, such as increased sociability and social interest. Over time, social attention and interest tends to expand significantly, interventions and practice facilitate more positive social outcomes. Sometimes, sociability expands to the extent that adolescents with autism may develop some of the interpersonal skills necessary to relate to others (Volkmar, Carter, et al., 1997). Yet, despite gains in social skills, even higher-functioning adults with autism, who exhibit a range of positive social

outcomes, continue to have difficulties in developing friendships and relating with others, and a limited scope of interests and activities (Stone, 1997). In fact, there is some controversy about how social deficits and social gains in children with autism develop over time. The early deficits in the social interactions of children with autism greatly affect both their social environments and their experiences, which has three major negative social consequences (Howlin, 1986).

First, reciprocity of social interchange may fail to develop. Thus, even when older children become motivated to interact with and relate to others, their attempts lack sensitivity and the understanding that communication involves turn-taking (Howlin, 1986). Mutual and cooperative behaviours typically remain absent, and individuals with autism continue to have great difficulty taking into account others' feelings and points of view (Volkmar, Carter, et al., 1997). Furthermore, these children's poor communication skills impede their participation in social interactions, and their social deficits limit their communicative functioning. Children with autism, according to official criteria experience difficulties in comprehending abstract concepts, feelings, and humour, as well as in interpreting and using nonverbal body language and in inferring ideas (American Psychiatric Association, 1994, pp. 66-71; the Diagnostic and Statistical Manual [4th ed.]; hereafter "DSM-IV").

Second, their perceptions and elicitation of contingent social responses tend to be impeded. For instance, children with autism may lack the ability to perceive the contingencies between their behaviours and those of others. In addition, their ability to display behaviours that typically elicit predictable responses is also impaired (Howlin, 1986).

Third, the social deficits of individuals with autism seem to impede the acquisition of socially transmitted knowledge; they typically lack basic knowledge of self and others. Their lack of ability to adapt learned social skills, and to generalize social rules or conventions to different social situations, make social interactions and relationships difficult (DSM-IV, pp. 70-71; Howlin, 1986).

Research on Deficits in Social Interaction

Over the past decade, a substantial body of research on the social interaction of individuals with autism has emerged (Volkmar, Carter, et al., 1997). To date, three main approaches have been taken in studying the socialization of children with autism. These approaches are as follows: (1) at the simplest level, analyses using only quantitative measures, such as duration or frequency of peer contact; (2) at a higher level, more informative qualitative measures, such as descriptions of both social interactions and other behaviours that may influence such interactions; and (3) at a more comprehensive level, interactive measures to analyze the possible relationships between the different types of behaviours.

As previously mentioned, most of the studies on the social deficits of individuals with autism have been limited to quantifiable areas, such as the frequency of contact with peers (Howlin, 1986; Volkmar, Carter, et al., 1997). Although quantitative measures have positive features including accurate measures, replicability, and desirable scaling properties, they do not address the qualitative nature of social interactions (e.g., social awareness) (Haring & Breen, 1992). More subtle aspects of social interactions, such as the development of empathy, and the quality of social interactions must be better understood (Volkmar, Carter, et al., 1997). Further research into these aspects of social interactions is required (Kamps, Leonard, Vernon, Dugan, & Delquadri, 1992).

Although the interactive measures approach is the most comprehensive of the three approaches described, initial studies of the deficits in social interactions of children with autism have shown that the interpretation of direct observational studies needs to be treated with caution (Howlin, 1986). Preconceptions about the nature of autism can lead to erroneous conclusions, even in studies that incorporate highly reliable measures of behaviour. To better interpret data in studies of the social deficits of children with autism, it is important to consider behaviours within a developmental framework, and according to the specific social context in which these behaviours occur. Common interactive measures used to study behaviours displayed during social interchanges and to formulate

hypotheses about appropriate social interactions (Howlin, 1986) do not provide in-depth information regarding the day-to-day real-life interactions. As Kasari and Sigman (1997) have proposed, studies should examine the interactions between children with autism and their parents, and connect the parents' perceptions of those interactions with objective and quantitative measures. Further, parents' perceptions and how they view their child with autism play an important role in parent-child interactions as well as the children's other interactive behaviour (Kasari & Sigman, 1997).

Studies and Self-Accounts on the Lived Experiences of Parents

The number of studies that focus on the lived experiences of parents with children with severe developmental disabilities is growing (e.g., Adams et al., 1990). However, most qualitative studies about parents' lived experiences with, and perspectives on, their children with developmental disabilities tend to lack focus on a particular population in a specific area. Apart from parental self-accounts, there are few direct studies of how parents cope with a specific diagnosis, such as autism, and even fewer about how their responses to the diagnosis may differ from the responses of parents of children with different severe developmental disabilities (Prizant & Wetherby, 1988). The following brief review of literature on the effects of severe developmental disabilities on

parents is not undertaken for its own sake but is intended to shed light on a critical variable in the children's social development and social interactions.

Research on parents of children with severe disabilities has revealed that the parents' level of stress is influenced primarily by two factors: the severity of their children's disabilities, and number of child-care demands and responsibilities for their children which their disabilities entail (Adams et al., 1990). Studies of how parents cope with severe developmental disabilities have demonstrated that caring for children with developmental disabilities generally presents a more challenging experience than caring for children with a chronic physical condition (Siegel, 1997). When receiving the child's diagnosis, parents of children with severe developmental disabilities, initially experience a family crisis that marks the starting point of an infinite course of grief. Their grief tends to wax and wane over time: Developmental disabilities do not end in the way that terminal illnesses do; grief is less likely to resolve completely. For instance, the lack or delay of milestones in the development of children with developmental disabilities seems to cause their parents more concern and stress about the future adjustment of their children than is experienced by parents whose children's prognosis may be more definite (Siegel, 1997).

A qualitative study by Adams et al. (1990) has indicated that the extent of the disabling conditions and care-giving demands closely relate to the great

variety of problems and high needs of parents. Therefore, as with other children with developmental disabilities, understanding the life cycle of families facing autism is an important step, not only in helping the children affected by it, but also their families. There are multiple aspects in which autism affects the individual; it affects almost every aspect of the family life and it needs to be treated as a family, and even as a social issue, instead of a problem of the individual (Norton & Drew, 1994). The success of intervention programs not only depends on the progress of the child, but also on the family's adaptation and involvement (Schopler, 1995).

In particular, Siegel (1997) stated that the limited research on parents' experiences suggests that in comparison with other developmental or learning disorders, autism is a more difficult disorder for parents to face. The specific diagnostic features of children with autism may present parents with special challenges in recognizing and accepting their children's disabilities. Their "normal" physical appearance frequently challenges parents' awareness that something is wrong, and many times diagnosticians initially fail to recognize the signs of autism and leave parents confused about their children's behaviours. Even after the children are diagnosed, parents often are confused about which behaviours are part of the disorder and which behaviours may be due to their failure to make the children behave as well as possible. In addition, these children's excessive early indifference to parents, lack of fear response to

strangers, and instrumental usage of affection may often decrease parental affective motivation and affective demonstrations (Siegel, 1997).

Most parental self-accounts have described the experiences of caring for their children with autism as very challenging regardless of the level of intellectual functioning. Parents who do not understand why their children behave as they do, often feel quite frustrated with their children's behaviours (Moreno, 1992). Due to the great variety of symptoms and the severity of symptoms experienced by children with autism, parents are exposed to a variety of experiences and challenges. Personality variables, family ecology, and many environmental factors (e.g., the degree of social support, effective treatment in place, and marital satisfaction) affect how parents and families adapt to autism (Siegel, 1997). One needs to understand this adaptation since it is an essential variable in accounting for the children's developing social interactions. As with other children with developmental disabilities, understanding the life cycle of families facing autism is an important step in helping the children affected by it.

The Gendered Nature of the Caregiving Role

In the past three decades, more women than ever before have joined the labour force and began to share more child-rearing responsibilities with their spouses, but there continues to be a clear division in gender role expectations and responsibilities between mothers and fathers. The characteristic gendered division

of childcare in most families continues to be the traditional one. Mothers are typically the main caregivers for their children and fathers are expected to provide materially for the family (Traustadottir, 1991).

As Traustadottir pointed out, this traditional gendered division of roles and pattern of family life has been widely criticized in the literature; but this criticism seem to have not reached most research in the field of disabilities. However, studies that do include fathers as well as mothers of children with disabilities (e.g., Adams et al., 1991) tend to find that mothers' life worlds are more strongly influenced than are fathers'. In comparison with their spouses, the lives of all the mothers who participated in Adams' et al. qualitative study were largely centered around and deeply influenced by their children with disabilities. The mothers, as the main caregivers, spent most of their time serving the basic needs of their children and feeling overwhelmed by the amount of work that their children require. Life restrictions, physical, and mental strain on a daily basis are characteristics of mothers far more than fathers of children with severe developmental disabilities. Mothers are also more likely to use their experiences with their children for personal development. Therefore, the primary care link to the mother will be a key determinant of the child's sociability.

It is not surprising, then, that mothers are usually the primary participants and informants in studies in this area of disability. Parental self-accounts of

parents of children with autism have been mostly written by mothers (Seligman & Darling, 1995). Fathers' perceptions and experiences of having a child with developmental disabilities have often been reported by their spouses (Seligman & Darling, 1995; Traustadottir, 1991).

Because the lives of mothers of children with developmental disabilities appear to be the most affected, they have been and continue to be the focus of research in this area (Traustadottir, 1991). Therefore, qualitative studies on the experience of mothers have great potential value in understanding family functioning and, therefore, the development of the children's social skills.

CHAPTER 3

RATIONALE

There are gaps in the literature on the social deficits of children with autism; the complex nature of their socialization process is not well understood, especially as it unfolds in a naturalistic setting. These gaps can be addressed in part by direct, in-depth investigation of the experiences and perspectives of parents of children with autism. Parents' perspectives on their children's behaviours in day-to-day interactions are based on their expectations for their children's development and behaviour, their understanding of and attitude toward their children's difficulties, and on their feelings regarding their own ability to cope with their children's problematic behaviours (Kasari & Sigman, 1997). Hence, qualitative assessment of parents' experiences and perspectives are essential to help understand the family matrix in which the children's social development occurs. Qualitative studies of mothers' experiences, of their reports of mother-child interactions, can ultimately lead to a better understanding of the social deficits—as well as possible areas of capability—of children with autism.

Based on clinical experience, researchers have suggested that parents of children with autism possess an experience-based or lived understanding of their children. In particular, because of the gendered division of roles, mothers of children with severe disabilities are the typical and routine caregivers

(Traustadottir, 1991); hence they may be considered experts on their children. Mothers, not only because they are their main caregivers, but because they are greatly involved in their children's lives, know their children best. Mothers of children with autism know their children's needs, and styles of interacting and learning because they become quite involved in the treatment programs of their children, and play a critical part in these programs. Together with their children, they take on the challenges of living with autism (Siegel, 1997). If one understands the challenges faced by the mother, one can gain insight into the mothers' perspectives and interactions with the child. There are virtually no direct empirical studies of how mothers cope with the diagnosis of autism and how this affects mother-child interaction (Siegel, 1997). As Siegel (1997) hypothesized, the study of grief responses is an important part of understanding the larger picture of successful coping with the diagnosis of autism. Furthermore, studies on the experiences and perceptions of mothers of children with autism can provide more detail about the uniqueness of the children's disabling conditions and individual characteristics.

The present study aims to gain a better understanding of the social development of children with autism through the mothers' reports of their experiences and perspectives on their children's social interactions. The focus of the qualitative analysis is on mothers' in-depth reports of their own experiences

with their children, their perceptions and feelings about their children's social interactions according to the social and developmental context in which those interactions occur. As it was indicated previously, the main goal of this study is to gain a more enlightened understanding of the children's deficits and strengths based on first-hand accounts of the mothers: In most cases they are persons closest to their children with autism.

CHAPTER 4

BACKGROUND INFORMATION

Historical Tracings of Autism

Although reports of isolated cases of very young children with mental disorders and marked distortions in their development date back more than a century, the actual differentiation of these conditions is a much more recent phenomenon. During the first half of the twentieth century, such cases were believed to represent the early onset of adult-type psychosis, and were given a variety of labels, such as dementia precocissima or childhood schizophrenia (Rutter & Schopler, 1987).

In 1943, Leo Kanner identified autism, set forth a diagnostic criterion for autism in terms of specific child behaviours, and indicated that these behaviours were distinctive from other disorders that had later onset. However, even after autism was identified, the overall climate of psychiatric thinking led to the conception of autism as a form of schizophrenia that had an early onset. Therefore, the confusion of autism with "childhood schizophrenia" continued for more than a decade (Rutter & Schopler, 1979).

It was not until the 1970s that the need was recognized to differentiate between severe disorders starting during infancy and those beginning later in childhood or adolescence. It was also necessary to differentiate between disorders

characterized by a loss of reality testing, such as schizophrenia, and those characterized by a serious abnormality in the developmental process itself, such as autism (Rutter & Schopler, 1987). Moreover, it was important to distinguish between the developmental disorders which affected speech and language and those which affected a variety of psychological functions (Powers, 1988). In 1980, the Diagnostic and Statistical Manual (3rd ed.) (American Psychiatric Association, 1980; hereafter "DSM-III") classified autism as a Pervasive Developmental Disorder (PDD) to pinpoint the widespread distortions of development and the separation of autism from other disorders (cited in Rutter & Schopler, 1987). PDD is a broad classification or descriptive term for individuals who present a triad of impairments involving communication, socialization, and thought processes (Rutter & Schopler, 1987).

Children with autism usually show a combination of bizarre behaviours, developmental delay, and developmental deviations. The first two sets of features are frequently found in autism, but the third group most clearly distinguishes it from other conditions (Rutter & Schopler 1987). The other recognized subcategories considered PDD are Asperger's Disorder, Disintegrative Disorder, Rett's Syndrome, and PDD Not Otherwise Identified (PDD-NOS). The term PDD-NOS is given to individuals who do not meet all the criteria for any one of the described subcategories (DSM-IV, pp. 71-72).

Diagnostic Criteria and Main Characteristics

At present, the medical and scientific communities use common and broad diagnostic criteria for the identification and treatment of autism. These diagnostic criteria are currently found in the American Psychiatric Association's (1994) Diagnostic and Statistical Manual of Mental Disorders (4th ed.) ("DSM-IV"). Therefore, the DSM-IV diagnostic criteria for autism are described and used in this thesis. Despite conflicts over the appropriateness and stigmatizing effects of the term "mental disorder," the DSM IV continues to use the term for the classification of these conditions. The disorders are described and divided into types based on specific criteria set out in the manual.

The DSM-IV diagnostic criteria for autism include twelve symptoms or impairments in the areas of reciprocal social interaction, verbal and non-verbal communication, imaginative activity and activities or interests. The child must display six of the twelve symptoms, with at least two from the reciprocal social interaction area and one symptom from each of the other two areas before being diagnosed as having autism (DSM-IV, 1994, pp. 70-71; Schopler, 1995). Another criterion is that there is no period of normal development in the child's history or if reported, this period should not be after three years of age. In addition, the deficits are not better accounted or better described by the criteria for Rett's Syndrome or Disintegrative Disorder (p. 71). Furthermore, the criteria can be met

through different combinations of features presented in a clear developmental progression by age (DSM-IV, 1994; Szatmari, Archer, Fisman, & Streiner, 1994).

The impairment in reciprocal social interactions in children with autism is gross and sustained. Individuals may lack eye contact, imitation, joint-attention social behaviours, and social interests (DSM-IV, pp. 70-71; Volkmar, Carter, et al., 1997). The impairment in verbal and non-verbal communication skills is also marked and sustained. Individuals with autism may be delayed in or lack the development of speech. Their grammatical structures are usually immature, and their use of language is repetitive and stereotyped. Their language comprehension is deficient most of the time: they do not seem to understand simple questions or jokes. Imaginative play is often absent or considerably impaired. Individuals with autism are also characterized by restrained, repetitive, and stereotyped patterns of behaviour, interests, and activities. They may resist or be highly distressed by minor changes in routines or environment, such as a change in the route to school. Odd movements, mannerisms, or postures are also common (DSM-IV, pp. 66-71).

Course of Autism

The onset of autism is early in life and its course is continuous. The patterns of onset of symptoms are quite varied. In some cases, symptoms become apparent within the first year; in other cases, the onset of symptoms seems to

follow a period of initial normal development (Stone, 1997). In addition to evident deficits in communication, socialization, and interests, another diagnostically relevant feature in infancy is abnormal sensory-perceptual responses, which seem to lessen with time (O'Neil & Jones, 1997).

Although intellectual abilities tend to remain relatively stable, social functioning usually improves after five years of age. However, even those individuals who markedly improve socially will never achieve "normalcy" (Volkmar, Klin, et al., 1997). Older children with autism may possess excellent long-term memory abilities, such as remembering exact historical dates or chemical formulas, but the information may be repeated out of context (DSM-IV). Although major behavioural problems lessen during adolescence, aggression and temper tantrums may return, and many (25%) individuals develop seizures in adolescence. Adolescents and young adults who have an intellectual capacity for insight may become depressed in response to their impairment (DSM-IV, 1994). Language skills, (e.g., communicative speech) and overall intellectual ability are the strongest predictors of ultimate prognosis. In approximately one-third of cases, some degree of independence is possible; a smaller number of individuals with autism live and work independently in adulthood (DSM-IV, pp. 66-69; Rumsey & Hamburger, 1988).

Comorbidity and Differentiation from Other Disorders

Various conditions have been associated with autism, but no clear pattern or relation has been identified. These conditions include diverse infectious diseases, such as congenital rubella; antigen abnormalities; inherited disorders, such as tuberous sclerosis; and biochemical abnormalities, such as high serotonin blood levels (DSM-IV, pp. 68-69). However, at present, these are not diagnostic conditions for autism (DSM-IV); they are only indirect manifestations of pathologic mechanism(s) at work (Phelps & Grabowski, 1991).

Individuals with autism may present a range of behavioural symptoms, such as hyperactivity, short attention span, self-injurious behaviours, and temper tantrums. They also tend to produce bizarre responses to sensory stimuli (e.g., an over-sensitivity to touch). They may have abnormalities in eating, sleeping, or moods. They may lack fear of real dangers (e.g., fear of strangers), and have an excessive fear of harmless events, such as the sounds of a doorbell (DSM-IV, pp. 66-71).

Although autism occurs in children with different levels of intelligence, the majority of cases are associated with a diagnosis of mental retardation (or IQ of approximately 70 or below with onset before 18 years of age) (DSM IV, 1994). According to DSM-IV, approximately 75% of children with autism function at a retarded level and about 30% of individuals with autism are of average

intelligence. However, regardless of the general level of intelligence, the profile of cognitive skills in children with autism is often uneven; for example, a four and 1/2 year old child may be able to read, i.e., show hyperlexia (DSM-IV).

The issue of comorbidity is further complicated by the nature of autism. Its symptoms change with time, age, and developmental level. Thus, it is not surprising that individuals with autism are difficult to diagnose (Volkman, Klin, et al., 1997). Disorders such as Mental Retardation, Rett's Syndrome, Schizophrenia, Selective Mutism, Fragile X Syndrome, and Landau-Kleffner Syndrome are sometimes confused with autism because they present similar symptoms and can coexist with each other (DSM-IV, pp. 66-69; Wing, 1997).

Autism differs from mental retardation in several obvious ways. Although most children with mental retardation exhibit appropriate social needs, such as seeking attention and contact with others, most children with autism are usually unresponsive to social cues and physical contact. Another distinctive feature of autism is neurological abnormalities; that is, while children with severe mental retardation often have seizures in infancy, autistic children who develop seizures tend to have them later in life. In addition, children with autism also differ from children with mental retardation in their patterns of cognitive and physical development. In children with autism, the overall performance is uneven with significant variation across all IQ levels, while in children with mental retardation;

performance presents pervasive impairments with little variation in competencies. Furthermore, children with autism typically show a "normal" or almost "normal" pattern of physical development, but children with mental retardation may not (Phelps & Grabowski, 1991).

Autism is different from Rett's Disorder in sex ratio and pattern of deficits, especially physical deficits. Rett's Disorder has been reported only in females. It is characterized by an apparently normal development, followed by a deceleration or regression of development, and the social interaction difficulties it presents tend to be transient (DSM-IV, pp. 71-73; Phelps & Grabowski, 1991). Autism also differs from Childhood Disintegrative Disorder, which has a distinctive pattern of developmental regression after at least two years of normal development. Schizophrenia differs from autism in terms of age at onset, level of intellectual functioning, language difficulties, and the presence of hallucination or delusions. While the age at onset in schizophrenia is usually adolescence or early adulthood, the onset of autism is in infancy (Phelps & Grabowski, 1991). Moreover, while a loss of reality sense and deviant use of language characterizes schizophrenia, autism is characterized by a serious abnormality in the development of language process itself (DSM-IV, pp. 69-70; Rutter & Schopler, 1987).

Asperger's Syndrome is very difficult to distinguish from autism, and there is still considerable debate about whether they are distinct PDD or whether Asperger's is only a form of higher functioning autism. There are a number of similarities and coincidences in the diagnostic criteria postulated by Kanner and Asperger that have led many investigators to the conclusion that autism and Asperger's are the same disorder. Although the differential diagnosis of Asperger's syndrome primarily involves autism without associated mental retardation, when autism is present without mental retardation in the form of High Functioning Autism (HFA) other differential features have to be considered. According to the DSM-IV (pp. 75-77), Asperger's can be distinguished from autism by the normal development of language in individuals with Asperger's. HFA differs from Asperger's syndrome in that its onset is usually earlier and its outcomes are more negative than those of Asperger's syndrome. While behavioural mannerisms are usually absent in Asperger's, motor "clumsiness" and a family history of similar problems are more frequently related to Asperger's syndrome than HFA (Wing, 1997).

Autism is also confused with Developmental Language and Speech Disorders, such as Aphasia, deafness, and hearing impairments. Once peripheral hearing loss is ruled out, differences in non-verbal communication may be used to distinguish between children with severe language disorders and children with

autism. While children with aphasia generally make eye contact and rapidly achieve meaningful communication through using gestures, children with autism do not (Phelps & Grabowski, 1991).

Epidemiology

Recent estimates of the prevalence rate of autism range from two to five in 10,000 for typical cases (DSM-IV, p. 69), increasing to 17 in 10,000 for closely related conditions requiring similar services. When the whole spectrum of the disorder is considered, the rate can be as high as 23 in 10,000 (Hornby, Atkinson, & Howard, 1997). Autism has been found throughout the world among peoples of every racial, ethnic, and social background. Autism and PDD are four to five times more common in boys than girls (DSM-IV, p. 68), however, more girls seem to suffer severe retardation than boys. In Canada, autism is diagnosed in four to five per 10,000 children (Konstantareas, 1989).

Etiology

Recent advances in neurological technology, genetic research, and medical reports have shown empirical evidence that autism is biologically determined by multiple causal mechanisms (Phelps & Grabowski, 1991). There is a genetic relation in autism that remains unclear. Siblings of children with autism are at higher risk of having autistic-like characteristics and language developmental disorders (Phelps & Grabowski, 1991). The identified medical cause of fragile X

accounts for between 5% and 17% of the cases of autism. However, in the great majority of cases, there is no single identifiable medical cause, but a variety of possible ones (Rumsey & Hamburger, 1988).

The behavioural, emotional, and cognitive symptoms presented by individuals with autism indicate that their Central Nervous System is altered. The early onset, the pervasive nature, and the chronicity of autism also point directly to brain abnormalities. Although imaging studies show abnormalities in most cases, a specific pattern has not been found. Several non-specific neurological characteristics, such as primitive reflexes or delay in hand dominance, may also be observed (DSM-IV, pp. 66-71). Research has shown that many autistic individuals have abnormalities of the brain, but that the abnormalities differ from one person to another. For instance, some studies have indicated that low-functioning children between four and twelve years of age have EEG readings that resemble the brain-wave pattern of a two year old (DSM-IV).

Assessment

Most autistic children need to be assessed and helped with their problems as soon as possible. Today, children are more likely to be diagnosed when they are between 18 months and five years of age. Many of the assessment instruments to diagnose autism have adequate reliability and can discriminate between autistic children, mentally challenged children, and children from "normal" samples.

However, these instruments do not seem to provide satisfactory solutions to the problems of individual diagnosis (Rutter & Schopler, 1987). It is difficult to recognize some of the symptoms in infants, and even when they are found, it is hard to make specific suggestions for each individual family. Early identification is also made difficult by lack of appropriate referrals, lack of parent's knowledge of access to services, and differences among infants' profiles (Prizant & Wetherby, 1988). Therefore, it is very desirable to employ naturalistic observations and scales utilizing observational techniques for which there is ample evidence of reliability, construct validity, and discriminant validity (Phelps & Grabowski, 1991).

Rating scales and questionnaires range from fewer than 20 to over 200 items; items are selected in the three main areas of impairments: socialization, communication, and repetitive or stereotypic interests and activities. These scales differ in terms of the number of items each includes and in the focus of their composition (Mesibov, Schopler, Schaffer, & Michel, 1989). The observation periods that the scales are intended to cover range from very brief observations of less than half an hour, to relatively long observations of up to five days. Scales also differ in the extent to which they score frequency of behaviours or degree of impairment. Even though some scales provide general suggestions regarding an appropriate context for observation, none of them is specific concerning the ways

in which to structure observed children's behaviours and activities or the extent to which to structure them (Lord, 1991, p. 74).

The Childhood Autism Rating Scale (CARS) is the most widely used form of diagnostic instrument available for autism and is applied to planning, treatment, and evaluation. It is an objective, behaviourally based rating system, consisting of 15 items on which children can score between 1 to 4; 1 indicating age-appropriate behaviour and 4 indicating severely abnormal behaviour. Each item taps behaviour related to areas such as relationships with others, imitation, emotional expression, body use, peculiarities in object use, verbal and non-verbal communication, activity level, and intellectual ability (DiLalla & Rogers, 1994).

Parent interviews are commonly used together with observations and rating scales. Several semi-structured interview protocols provide information relevant to the diagnosis of autism. Important areas to be explored during semi-structured interviews include the following: prior developmental history, social behaviour, speech development, self-stimulation or self-injury, affect, insistence on maintenance of sameness, isolated skills, and other behaviours (Sattler, 1998).

The more structured the interview, the easier it is to obtain consistency among interviews. The items in the structured interview need to be precisely formulated to provide a useful and clear description of the child. When using direct ratings from the parents, the interviewer needs to ensure that he or she and

the child's parents share a common understanding of the problem, and what behaviours represent a problem, as well as the same reference options for scaling severity. For instance, asking a parent of a young autistic child whether the child is "affectionate" is not appropriate without describing exactly what is meant by the term. Another way to ensure useful information about the child, is by asking broad questions that encompass a range of behaviours (Lord, 1991).

If possible, the child with autism should be interviewed. It is essential to find out as much as possible about the child's communication skills from parents, teachers, and other people involved with the child before the interview is conducted. Sattler (1998) suggested that when interviewing children with autism, the interviewer has to talk slowly and simply, use short sentences, be concrete, avoid complex sentences or words, and also be prepared to repeat or rephrase sentences. It is important for the interviewer to have the child's visual attention while the interviewer speaks to help the child attend to and process speech to answer questions.

A Brief History of Approaches and Treatments

From the 1940s to the mid-1960s, a psychiatric approach to intervention prevailed in the treatment of autism in both Canada and the US. This approach emphasized medical treatment and the placement of children and adults with Autistic Disorder in institutions, segregated schools, and segregated living

arrangements. Then, in the late 1960s, behavioural treatments became very popular. Based on the premise that every behaviour is learned, therapists and educators actively worked to teach the child missing skills and more appropriate ways to interact with people and things (Mesibov & Shea, 1996).

One of the most widely used treatments for children with autism is behaviour modification. Since 1973, empirical results from behaviour modification techniques have been both positive and negative (Lovaas, 1987). On the positive side, behavioural treatments can build complex behaviours, such as language, and can help decrease undesirable behaviours, such as aggression. On the negative side, treatment gains have been specific solely to the particular environment in which the behaviour was learned. To facilitate better results with these techniques, they have to be used with consistency, intensity, appropriate "artificial" reinforcers, and controlled learning and maintenance (Rutter & Schopler, 1979).

Lovaas (1987) has developed and tested a behavioural-intervention program called Applied Behavioural Analysis (ABA) that has been proven to be successful in many cases (see also Green, 1995). The treatment is based on a program of research based on longitudinal studies that began in 1970. The conceptual basis of the treatment is operant theory, and it relies on discrimination learning data and methods (Lovaas, 1987). ABA focuses on trying to teach every

skill that the child with autism does not demonstrate--from relatively simple responses, such as looking at others, to complex acts, such as spontaneous communication and social interaction; each of these skills is broken down into small steps (Green, 1995).

Initially, each step is taught one-on-one, later, if possible, these steps are taught in groups by presenting specific cues or instructions. Appropriate responses are followed by consequences that have been found to function effectively as reinforcers. A high priority is to make learning fun for the child. Another priority is to teach the child how to discriminate between different stimuli. Problem behaviours are carefully not reinforced. Systematic analyses are used to determine what events act as reinforcers for those undesirable responses. In this way, teaching trials are repeated many times, initially in rapid sequence, until the child performs a response readily without adult-delivered prompts. ABA also includes helping children develop age-appropriate interests, to make friends, to adjust to and learn in regular classes (Green, 1995).

The effective and ethical use of the ABA requires dedicated training of parents and special-needs workers or aides. Its success depends on the amount of time spent on treatment and how early the treatment starts. The treatment should be implemented as soon as possible, the sooner the better. It should be used for at least two years and put into practice during most of the child's waking hours

(Green, 1995). This intervention is expensive, requires a great commitment, and is time-consuming (Lovaas, 1987). However, many parents learn to be consistent, effective behaviour-change agents for their children, and can play "a vital role" in their treatment (Green, 1995).

In the mid-1980s, a more multidimensional or multi-disciplinary approach to treatment and intervention became popular. This approach includes: 1) the development of more comprehensive assessment services; 2) better educational strategies and the increased availability of integrated school options; 3) more support for parents; and 4) a wider range of community-based, supported living day options and working arrangements for adults with autism (Mesibov & Shea, 1996).

Now, more than ever before, the preferred approach to treatment is multidimensional, reflecting the nature of the disorder. Due to the complexity of the clinical manifestations of autism, the multiple aspects in which the disorder affects the person have to be considered. This approach is more humanitarian and holistic than its predecessors were. Most importantly, it increases the involvement of people with disabilities and their families in the direction of services and daily decision-making. Unusual behaviours are regarded as attempts by the person with autism to communicate rather than oppositional behaviours (Mesibov & Shea, 1996). Therefore, families, people with autism, teachers and other professionals

must work together to find how to understand these children's behaviours and adapt their environments to meet their needs and wants (Knoblock, 1987).

Assessing a variety of methods, and implementing interventions early and consistently are essential for effective results. Many research findings have indicated that intensive early interventions can compensate for neurological abnormalities and stimulate new connections in the brains of autistic children (McEachin, Smith & Lovaas, 1993). Early intervention may also prevent the development of undesired behaviours, and reduce social isolation and withdrawal (Prizant & Wetherby, 1988).

There are also some drug and diet treatments that have, in some cases, been found to reduce or alleviate a few symptoms. For example, chlorpromazine (Thorazine) and haloperidol (Haldol) decrease undesirable behaviours and hyperactivity (Green, 1995). These treatments are not discussed in this thesis.

Education

The education of children with autism has varied greatly in both mainstream and "special" schools. According to some educators, the best strategy for teaching children with autism is to make learning functional. The term "functional" has been used in many different ways, but most commonly, it means to teach skills that match the needs of the learners with what they need to be able to do in their communities. Functional curricula facilitate the development of

skills that are essential for the participation of the child within diverse integrated environments (The Institute for the Study of Developmental Disabilities, 1992).

Interactions play an important role in determining any child's quality of life. This is especially so for a child with autism. Therefore, it is essential to consider the difficulties of children with autism within an interaction framework. This framework considers the child with special needs as one member of an interaction; the other members with whom the child interacts are seen as equal contributors in the interaction. Thus, both members are equal contributors in determining the degree of handicap or disability, and the quality of the interaction. The interaction framework holds that "a two-way interaction between handicapped children and adults leads away from the view that there is a deficit in the child to one where it is the responsibility of both child and adult to find a way to be together to fulfil on another's goals" (Knoblock, 1987, pp. 194-195).

This framework views the interaction as the focus of interest when evaluating and educating children with disabilities. Although children with autism are distinguished by their poor social relations and their reluctance to initiate social encounters, once placed in supportive classrooms and exposed to positive social interactions, many of these children accept or even enjoy physical contact and some social initiations. This demonstrates that, contrary to earlier

beliefs, these children are able to benefit from teaching approaches that build on existing skills and add new skills to the child's repertoire (Knoblock, 1987).

It is important to attend to the elements that facilitate this learning-teaching behaviour, which appears to occur largely as a result of the interactions of the people in the classroom with one another and with the environment. Therefore, researchers should probably use students' conceptual learning and problem-solving and interaction skills as a main outcome measure for evaluating teacher and classroom effectiveness (Mesibov & Shea, 1996).

Mainstreaming and Social Skills Training

In Canada, the right of children with disabilities to have access to an education in regular schools was asserted in *Carreire v. Lamont Co. School Bd.*, before the Charter of Rights and Freedoms (Charter) came into being (Smith, 1997). Section 15 of the Charter, under equality rights, stipulates: "every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability" (cited in Smith, 1997). In educating those with developmental disabilities, the only real resistance to such measures has been made on the bases of the higher costs an equal right to access entails, and on the

lack of teachers qualified to administer medication or perform medical procedures required by the child during school hours (Smith, 1997).

School programs and classes seem to be evolving towards mainstreaming or inclusion, from segregation to integration (Mesibov & Shea, 1996). Although the term 'segregation' implies that students with disabilities are educated in special classes, separate from children without disabilities, there is variation in how the terms, 'inclusion,' 'integration,' and 'mainstreaming' are used in the educational system. That is, there is no single terminology (Harris & Handleman, 1997). Although the definitions given to these terms vary, the main concept behind them is that students with disabilities can and should be educated, with appropriate support services, in the same setting as their normally developing peers (Mesibov & Shea, 1996). Mainstreamed classes are developed within the regular education model (Harris & Handleman, 1997). The term "mainstream" will be used in this thesis to refer to the regular class as a home base where the child with autism is placed and educated, although there may be periods of withdrawal from class.

Today, more than ever before, a considerable number of children with autism are attending their neighbourhood schools with most of the supports they need to receive an appropriate education (Stainback, Stainback, & Forest, 1989). Therefore, their integration into regular classes needs to be well assessed and

facilitated. More acceptance and understanding of individuals with autism is necessary to attain positive outcomes of mainstreaming (Mesibov & Shea, 1996).

Descriptive research has shown that children with severe disabilities, such as autism, interact with children without disabilities more frequently in integrated settings than in segregated settings (Goldstein, Kaczmarek, Pennington & Shafer, 1992). However, integration only seems to be successful under certain conditions, which include the following: 1) adequate preparation and training for all involved-administrators, teachers, parents, and children with and children without disabilities; 2) flexibility in establishing different contexts for integration; and 3) active promotion of positive contact between children with and children without disabilities. Moreover, integrated school programs have to be designed with the strengths and needs of the individual children in mind (Goldstein et al., 1992).

Studies of integration programs that focus on meeting these conditions have suggested that children with autism have a desire and some capacity for positive social contact, for learning the language of social interaction and for substantial gains in their social development (McHale & Gamble, 1986). Children with autism are able to imitate appropriate social behaviour and learn many social and leisure skills if these skills are assigned a high priority and instruction is adapted to their learning needs and styles (Henning & Dalrymple, 1986).

Four approaches used to promote social development in children and youth with autism have been investigated: 1) Direct Skill Instruction: first one has to identify the social skills that need to be developed, then determine the steps required to build those skills and provide practice in a variety of setting; 2) Antecedent Prompting Procedure: the teacher prompts the child to engage in some kind of interactive behaviour, which is responded to positively by both peers and the teacher; 3) Peer-Initiated Strategies: socially competent peers are taught strategies to initiate and encourage social interactions with children with autism in natural settings; 4) Peer tutoring: socially competent classmates learn how to use effective teaching techniques and positive reinforcement to teach academic subjects to their peers with autism. Studies indicate that there are many benefits of these four approaches when they are based on the already established ways of interaction (Goldstein et al., 1992).

Social skills training at the level of a dyad increases the rate of social interaction directly by reinforcing and prompting peers with autism to initiate interactions or social responses (Goldstein et al., 1992). However, persistent deficits in generalized social gains are likely to go unnoticed if the observations do not sample how a child actually spends his or her time throughout the day (McGee et al., 1997).

Personal Involvement with Children with PDD

I had my first contact with children with autism and other PDD eight years ago. Since then, the complexity of these children's behaviours and the enigma of their social challenges have captivated me. In particular, in my work facilitating an in-home and school-transition program, a child with Rett's Syndrome named Mary (pseudonym) had a great impact on my life. When I started to work with Mary, it was hard to picture how to develop an effective educational program to facilitate her inclusion in a mainstream kindergarten class. Mary, a six-year-old girl, was unable to communicate either verbally or non-verbally, and had severe difficulties with her motor skills. She was a very anxious girl who exhibited some stereotypic behaviour patterns, including breath holding and hand wringing. Her mental age was approximately that of a three-year-old, and she was not interested in interacting with other children except to touch or explore their faces or hair. Only as I worked closely with Mary, her parents, and other people involved in her daily life did her fuller integration become more attainable.

Working together with her parents and learning from their experiences, especially their experiences with Mary, were essential to the success of Mary's integration program. As the Department of Education and Science guidelines for parental involvement state: "assessment should be seen as a partnership between parents, teachers and other professionals in a joint endeavour to discover and

understand the nature of the difficulties and needs of the individual children. Close relations should be established and maintained with parents" (Aarons & Gittens, 1992, pp. 72-73). In my involvement with Mary, I not only learned from her parents, but also I became quite close with them. Her parents were extremely helpful in teaching me about their child's needs, difficulties, and preferences, as well as in assisting and working side-by-side with the multidisciplinary team.

In learning to interact, connect, and work with Mary, the lessons I found most valuable were those I learned from her parents. It was my experience with Mary and her parents that inspired me to focus this study on parents' experiences and perspectives of their children with autism, their ways of dealing with their children's social difficulties and the manner in which these parents interact with their children. By learning from parents' experiences and perspectives, caregivers and professionals may be able to help these children to socialize and integrate into the society.

CHAPTER 5

METHOD

Recruiting the Participants

Five mothers (one of the mothers was accompanied by her husband) were recruited to participate in the study through four sources. First, two therapists and a social worker from the Outreach Department of the St. Amant Centre informed some of their clients about the study. Second, a family physician asked a few of her patients with children with autism if they would be willing to participate in the study. In addition, both the Autism Society of Manitoba and the Ontario Society of Autism advertised the study in their respective newsletters. The advertisement described, in non-technical terms, the study and its purpose (Appendix C).

In order to ensure some commonality among the participants, purposeful sampling was used as the method of selection. This sampling method is commonly used in analytic induction to select participants who are believed to facilitate the expansion of the developing theory (Bogdan & Biklen, 1992). Mothers eligible to participate in the study fulfilled the following three conditions: 1) their children had to be between six and twelve years of age; 2) their children had been diagnosed more than three years earlier as having autism; and 3) their children had been attending mainstreamed schools for more than one year. These conditions and their purpose to ensure some commonality among the participants

and to focus on elementary school-aged children with autism in mainstreamed schools were made known to the prospective participants before volunteering to participate in the study.

After the prospective participants were identified, I telephoned each of them to invite them formally to participate in the study, and to ensure their informed consent. During our telephone conversation, I explained to the participants the study's purpose and the length of time the interviews would take. The participants were also informed about: 1) the nature of the information they would be asked to share; 2) my responsibilities as the interviewer and researcher; 3) their right to request to review a transcript of their interview before it was included in the thesis, and to receive a summary of the study's major findings as soon as possible after the study had been completed; 4) their right to refuse to answer any question or to withdraw from the study at any time without penalty; 5) the possibility that concerns or feelings might arise from the interview, and that I would be available to discuss them if they wished, since I was qualified to do so based on my training as a psychological consultant and experience as a facilitator; 6) the possibility of a second or follow-up interview, and its possible content (Appendices A and B).

Times and places for individual interviews were arranged with each participant. Before beginning the interviews, I thanked the participant for taking

the time to be interviewed, and asked him or her to carefully read and sign a letter of consent (Appendices A and B). The appropriate current Ethical Standards and Guidelines for Research Involving Human Subjects were followed.

Participants

The participants included five mothers of children with autism. One father was present to help his Spanish-speaking wife in answering some of the interview questions in English. Because the father's responses were mainly clarifications of the wife's responses, they were considered as part of his wife's responses. Therefore, five mothers of children with autism were interviewed for the data collection of this thesis. All of the participants except one were married; the participant who was divorced had shared custody of her child.

All of the mothers who participated in the study were volunteers. Like most mothers of children with autism, they were very dedicated to the education and treatment of their children. There are other reasons, however, for believing these mothers were from quite a select group. These mothers had sought help from different resources and had been involved in their children's lives, education, and treatment since their children's birth. They had been the main caregivers and educators of their children; therefore, they were very experienced and quite knowledgeable. They had kept themselves informed-as active advocates of their children, and they were glad to participate in this study.

All of the participants were Canadian citizens and each had lived in Manitoba for more than two years. They were, however, from different ethnic backgrounds. The participants were assigned letters in alphabetical order according to the order of their interviews. Mother A and Mother D were English-speaking Canadians who had always lived in Manitoba. Mother B, Father B (her husband), and Mother C were Spanish-speaking Canadians, and Mother E was a French-speaking Canadian who had spent most of her life in Manitoba. While Mother B and her husband (Father B) had lived in Manitoba for more than ten years, Mother C and her family had moved to Manitoba only two years ago and was interviewed in Spanish because she was not able to communicate fluently in English at the time of the interview. The consent form and all information about the study were translated into Spanish (Appendix B). Mother C requested to have her daughter, who was fluent in English, review the translation of her interview.

The participants' children were given pseudonyms to ensure anonymity and confidentiality. The participants and children were: (1) Mother A had a six-year-old boy, Kevin, who had been diagnosed with autism three years ago; (2) Mother B and husband (Father B) had an eight-year-old boy, Ryan, who had been diagnosed three years ago; (3) Mother C had an eight-year-old boy, Paul, who had been diagnosed six years ago; (4) Mother D had a ten-year-old boy, Mike, who had been diagnosed six years ago and; (5) Mother E had a six-year-old girl, Julie,

who had been diagnosed three and a half years ago. All of the children had lived with their mothers since their birth and had been attending regular schools for over one year. Based on the mothers' reports, it appears that the level of functioning of their respective children varied considerably. While two of the children (Ryan and Paul) were still having difficulties with both verbal and non-verbal communication, some self-care skills, and academic skills, the other three children (Kevin, Mike, and Julie) were quite verbal, of seemingly average intelligence and learning within their grade level at the high-functioning level of the autistic spectrum.

Pilot Interview

The first interview of the study was used as a pilot interview for assessment of the formulated questions and the elicited responses. This allowed for any necessary adjustments. Hence, with the permission of the first participant, the verbatim transcript and analysis of this interview were shared with each member of my thesis committee in order that they might offer advice and recommend changes. The complete data collection, adjustments, and rationale for adjustments based on this pilot interview were included as part of the study. The analysis of the pilot interview showed that the questions and the format of the interview fulfilled the purposes of this study. The direction and order of the questions appeared to enable the participants to focus their responses on their

children's socialization and social interactions. The number of interview questions also seemed to be adequate for the purpose of this study, and I was able to obtain relevant descriptions and details. The content of the formulated questions appeared to be relevant to the mothers' experiences and areas that are of concern in their and their children's lives.

Interview Questions

I went to each interview with a written interview protocol and the same key questions for each participant. This ensured that the focus of the interview was going to be the socialization and social interactions of their children. The written protocol included 19 questions concerning three main topics. The questions addressed mothers' daily social experiences and interactions with their children, their views about their children's social difficulties, needs, and skills, and challenges involved in raising and educating their children.

Queries focused on specific social difficulties, social interactions, individual characteristics of their children, and how they have evolved or changed over time. I also asked about the kind of responses these children give to and receive from siblings, peers, and others when relating to them in specific situations. Questions were also included concerning the mothers' perceptions of their own role as facilitators of their children's interactions and the supports they receive at home, school, and day care.

Although the interviews were guided by the written protocol, the interviews were open-ended in terms of the participants' responses and the nature of the dialogue between the participants and myself. The questions allowed the participants to feel free to express their opinions and experiences from their own frames of reference. In some cases, I spoke very little, only asking the written questions or re-directing the interview. In other cases, I had to repeat or rephrase some questions, or make encouraging comments to elicit an answer from the participant. Sometimes, I added extra questions to clarify a response, to pursue a particular idea or line of thought, or to ask for anecdotes that illustrated their answers. I did not ask questions that were not relevant or that were answered as part of other responses. At other times, I needed to refocus the interview back to the topic by asking questions that were specific.

Approximately two hours were requested from each participant. Only on one occasion, with Mother B, a second twenty-minute interview was conducted. During this follow-up interview with Mother B, several of her responses from her in-depth interview were discussed to obtain further information and to clarify my understanding of her responses.

Data Collection

The data collection was based on in-depth interviews with the participants. In-depth interviews are sometimes termed "unstructured," "open-ended," or

"flexibly structured," because "the researcher is bent on understanding, in considerable detail, how people such as teacher, principals, and students think and how they came to develop the perspectives they hold" (Bogdan & Biklen, 1992, p. 2). This "flexibly structured" format is especially useful when one wants to focus on specific topics, but it also allows participants the flexibility to speak freely (Sattler, 1998). The interviews were used to gather descriptive data in the mothers' own words, in order to develop insights on how they interpret their experiences with their children. Efforts were made to develop rapport with each participant. Good interviewers are those with whom the participants feel at ease and free to talk without restrictions. Therefore, good interviewers collect rich data filled with comments, details, and examples that reveal the mothers' perspectives more clearly (Bogdan & Biklen, 1992).

CHAPTER 6

RESULTS AND DISCUSSION

Initial Analysis of the Interviews

Field Notes

My analysis of the interviews began as I was conducting them. During the interviews, I was both an interviewer and an observer. One of the hallmarks of qualitative studies is the continuous process of data analysis while the data is being collected (Lutfiyya, 1989). The field notes and observer's comments were written right after each interview for accuracy of impression. Although mothers did not participate in the write-up of field notes, they were informed of their purpose. Field notes consist of two kinds of materials: descriptive and reflective. While the descriptive material attempts to capture a word-picture of the setting, people, actions, and conversations as observed, the reflective material attempts to capture the observer's point of view, ideas, and concerns. Although the entire setting or picture cannot be completely captured, researchers try to transmit as much as possible on paper (Bogdan & Biklen, 1992).

I also sought to record, in the field notes, the participants' non-verbal responses in order to capture the complete or whole context of the participants' responses. Their body movements, facial expressions, tone of voice, and response times were also noted. In addition, I observed my own responses to the

participants, in terms of my verbal and non-verbal responses, as well as my inner responses of emotion or thought, such as my most salient feelings of surprise, concern, and enthusiasm. I recorded all my various thoughts and general impressions of each particular interview on a tape recorder. The mothers were welcoming, open, and friendly, and made me feel comfortable in their homes. Although three mothers showed some signs of sadness, embarrassment, or nervousness in their voices or facial expressions, all the mothers finished the interview on a very positive note, and they did not ask to discuss any concerns or feelings after the interview.

Basic information, such as the date, time of day, description of the setting, and atmosphere of the interview was also included in my Observer Comments (OC). All of the interviews took place at the participants' homes at a time that was most convenient for them. The interviews were conducted in the family room or kitchen of each participant's house. There was always a table between the participant and me.

On three occasions, only the participant and I were present in the house, and the atmosphere was very calm and quiet. However, in the case of Mother B and Father B, the grandmother of the child milled about in the background while the interview was conducted. The mother made apologetic remarks concerning the distraction. This caused some deviation from the topic of conversation, and

influenced my train of thought. However, I was always able to re-focus and re-state my last question, or the last response of the mother. On another occasion, Mother E's child, Julie, was playing in another room while the interview was conducted. She was quite active, and at several points interrupted the interview. In this case, the child's presence facilitated my understanding of what the mother was describing. According to the mother, the child was displaying typical behaviours that were not due to my presence at the scene. Overall, I was on these occasions careful to acknowledge the interruption and return to the topic of discussion.

Transcribing the Interviews

As soon as possible after each interview, I began to transcribe the audio-tape. This process involved listening to each sentence spoken by the participant and then recording the interview verbatim. By listening and re-listening to each segment of the tape, often sentence by sentence, I was able to notice changes in each participant's tone of voice, moments of silence, vocalizations between words, laughter, and other sounds made during the interview. Then, by listening to each question and each response, I was able to remember the context of each question. In this way, I began to internalize what I was hearing and writing so that I could decide how best to transcribe speech patterns.

I tried to have the written transcript reflect as precisely as possible the original spoken interview. Commas were used to denote slight pauses, while ellipses were used to represent longer pauses. I also employed exclamation marks where the participant made vigorous comments, and I underlined the words which the participants stressed or emphasized in their speech. Every word and vocalization that I could hear on the tape was included in the transcription, such as *hmmm*, as well as habitual phrases (i.e., *you know?*) in order to convey the complete rhythm of the conversation.

Then, each transcribed interview and the observer comments were read in an attempt to reconstruct the whole interview. For example, I paid attention to the ways in which the participants responded to each question and to the interview as a whole. During my transcription of the audio-tape, I continued to analyze the interview by adding comments about my observations, thoughts, reflections, and feelings. I tried to include comments about the non-verbal communication between each participant and myself during the interviews. For instance, I recorded comments about facial expressions and gestures I made to encourage the participants to talk more about a topic.

Throughout the interviews, I maintained eye contact except for those times that I looked down at the page to remember the exact wording of a question. I also tried to respond to the participants' responses and anecdotes in a natural way

by using my own body language, tone of voice, encouraging comments, and the occasional remark (such as, "*hmmm, OK, good!*"). Furthermore, my emotional responses varied during the interviews: at times, I found myself feeling surprised, enthusiastic, sad, and puzzled over the responses or comments. I noted those feelings, and I was able to remember them while I was writing the field notes and transcribing the interviews.

The reports on the non-verbal communication of the participants helped me recognize how they influenced my responses. If the participant smiled or seemed content, I would take it as a cue to encourage them to provide more details about what she was describing. When the participant was very emphatic about a comment, I felt obliged to ask if I understood precisely the point they were trying to make. However, if the participant lowered her tone of voice or appeared sad, I would proceed more carefully in asking for more details by, for example, lowering my tone of voice or slowing my speech. My responses to the participants' non-verbal communication are common social influences in our day-to-day interactions.

The participants also responded to me according to my non-verbal communication: when I was surprised by their responses, the participants would smile or in another way acknowledge my reactions. However, I tried to maintain a neutral decorum, answering naturally and spontaneously.

I conducted and transcribed each of the interviews over a three-month period. Each interview was conducted approximately two weeks apart from the others, except for the second interview, which was conducted a month after the first interview. Each audio-tape took a minimum of 20 hours to transcribe. One hundred and twenty pages of transcripts were collected from the five interviews.

Analyzing the Transcriptions

After transcribing the first two interviews, I began to compare and contrast the participants' responses. To that end, I wrote down the similarities and differences between the two participants in the observer comments in the transcriptions. My impressions and ideas about the data being gathered were also included. The analysis and data collection took place in "a pulsating fashion—first the interview, then analysis and theory development, another interview, and then more analysis, and so on" (Bogdan & Biklen, 1992, p. 72).

Although the initial method of data analysis was comparison and contrast, as I conducted the interviews I began to realize that there were more similarities than differences among the participants' responses. In fact, the similarities appeared to be much more salient and predominant than the differences among the participants. The analysis of the transcripts served as a data bank of the materials from previous interviews from which I could draw elements for further reflection

or for comparison with subsequent interviews. For example; as I was listening to Mother B describe the difficulties she had with her child, I recognized that:

OC: This participant's description of her child's difficulties is almost the same as the description provided by the previous participant. A couple of times, it seemed to me as if these mothers were describing the same child. Each mother described her child's "structured and ritualistic play" in similar ways by using the same example of how her child tends to pick two kinds of blocks and line them up one after the other over and over again...

While acknowledging this mental process, I tried not to be influenced by it during or after the interviews were conducted. I avoided telling mothers what other mothers had said, and whether or not their responses concurred with my other findings. However, during the last two interviews, I did catch myself, a couple of times, mentioning to the participants what other anonymous mothers had said. I included my comments to those participants in the observer comments. The mothers did not seem at all surprised by my comments; rather they acknowledged them with a "*Hmmm,*" or "*Right!*"

Although I paid careful attention to both the similarities and differences between the participants' responses, my analysis of the transcripts focused mainly on similarities. That is, I compared the participants' responses and clustered them

according to the most common topics of discussion and similar experiences. This process of comparing and finding the similarities among the participants' responses allowed me to create a clear picture of these mothers' common experiences and perspectives. However, in this process I might have focused too much on the commonalities and missed some differences or special circumstances. For example, although the individual experiences of the kind of supports each mother had were mentioned, the differences among the supports were not discussed.

Structure of Data Collection

Once all the interviews were transcribed, I looked for significant and repeated phrases and sentences that stood out from the transcriptions to develop coding categories. The common statements from the transcripts were organized into three preliminary coding categories for further analysis.

The first category, focused on the mothers' formative experiences with their children and how those experiences influenced the mother-child relationship; it included statements about the mothers' experiences interacting with and relating to their children daily, in particular those statements that referred to the challenges, difficulties, and satisfactions that mothers experienced and to the effects of these experiences on the mothers' interactions with their children. The subdivisions for this category were: (a) daily living and mothering a child with

autism; (b) seeking professional help and a diagnosis; (c) coping with the diagnosis; (d) seeking and facilitating intervention; and (e) autism affects the entire family in different ways. Although it is presumed that the issues of these subdivisions indirectly bear upon the children's social development, the qualitative details are primarily to help understand the mothers' experiences as contributing to strains on the family's functioning and support for the child.

The second category, which focused on the children's characteristic social functioning viewed from the mothers' perspectives, included the mothers' statements describing their children, and the social difficulties their children faced. While I was collecting these statements from the transcripts, I realized that the mothers' descriptions could be further divided into three areas, the same main areas that are used to diagnose autism according to the DSM-IV criteria. Therefore, this second category consisted of three main descriptions: (a) qualitative impairment in communication; (b) qualitative impairment in social interaction; and (c) restricted repetitive and stereotyped patterns of behaviours, interests, and activities.

The third category focused on these children's patterns of social interaction as well as the ways in which these mothers help their children and facilitate their social interactions with others. It included statements that described ways in which these children and their mothers interact and relate with one other. It also

consisted of statements mothers had made about how they facilitated their children's integration into the community. The subdivisions for this last category included: (a) daily mother-child interactions, recognizing progress and establishing a relationship with their children; (b) mothers as social skills trainers and facilitators of interactions; (c) essential elements for their interactions; (d) the importance of their children with autism being exposed to and interacting with children without disabilities; and (e) the need to educate others in the community about autism.

Formal Analysis and Discussion

The formal data analysis was conducted based on the preliminary coding categories. In analyzing the data, I found consistent, emergent themes. A theme is defined as a concept or idea that emerges from the data: "some signal trend, some master conception, or key distinction" (Bogdan & Biklen, 1992, p. 186). Because the themes emerged from the categories, the data analysis is now presented in the same manner in which the data were organized; I then relate my understanding under three emergent themes: I. Mothers' experiences coping with autism and their children's social deficits affect how they first come to view and relate to the children; II. Mothers' perspectives on their children's characteristic ways of relating provide deep insights into these children's social deficits and the context in which those deficits occur; and III. Mothers, through their special

relationship with the children have learned effective strategies to facilitate the social interactions and integration of their children.

The three emergent themes, as briefly described, were found to encompass and explain the greatest amount of data closely related to the social interaction and socialization of the children. Within each theme, several subthemes were formulated to further organize the data.

This chapter is organized around the three themes and their subthemes. These themes and subthemes are discussed in context with documentation of the variation within each sub-theme according to the interviewers' comments. The discussion includes both my analyses of the related research literature and my personal experience as a researcher. The themes, together with the literature review and background, are used to develop findings and implications.

Theme I: Mothers' experiences coping with autism and their children's social deficits affect how they first come to view and relate to the children. Five subthemes are included:

- 1) Difficulties in obtaining a diagnosis;
- 2) Receiving and coping with the diagnosis;
- 3) The dilemma of finding effective interventions and help;
- 4) The daily challenges of raising a child with autism; and
- 5) The effects of the child's autism on the siblings.

Theme II: Mothers' perspectives on their children's characteristic ways of relating provide deep insights into these children's social deficits and the context in which those deficits occur. Five subthemes are present:

- 1) Clear evidence of communication and social deficits during the toddler years;
- 2) Severity of communication and social deficits as they change with time;
- 3) Difficulty expressing and understanding emotions;
- 4) Restricted preference of behaviours, interests, and routines;
- 5) Strengths and abilities.

Theme III: Mothers, through their special relationship with the children have learned effective strategies to facilitate the social interactions and integration of their children. Six subthemes are involved:

- 1) Social interactions between children and mothers;
- 2) Children's social initiations in some situations;
- 3) Beneficial interactions and relations with siblings and peers;
- 4) Mothers as facilitators and interpreters in social interactions;
- 5) The importance of mainstreaming and social skills training; and;
- 6) The crucial goal of training and educating the community about autism.

Theme I: Mothers' experiences coping with autism and their children's social deficits affect how they first come to view and relate to the children.

As the mothers in this study described their experiences, the likely effect of those experiences on their children's development became evident. At the

beginning, these mothers had many negative experiences with finding answers, support, guidance, and help; those experiences hindered their children's social development. These mothers did not have the understanding nor the means to provide the initial social stimulation, extra supports, and training these children needed during their early years. The children clearly received less than optimum help through no fault of the mothers.

(1) Difficulties in Obtaining a Diagnosis

The mothers in the study indicated that beside the difficulties they started to experience with their children, one of the hardest challenges that they had to face was searching for and obtaining a diagnosis. Although all the mothers suspected that there was something "definitely wrong" with their children from their first year of life, it took a long time to convince doctors that there was something wrong with their children. Three of the mothers in this study said that they felt as if they were exaggerating their concerns, because several professionals, not just doctors, disregarded their observations and experiences. They had to see several doctors and receive many inaccurate responses before they found a doctor who took their concerns seriously. Mother A described her search for medical help as a "real battle." Four of the mothers expressed their great disappointment with the health care system. For example, Mother E explained:

Like I took her to many doctors... and many doctors told me, when she was like three or three and a half: "Oh, she is not talking! Don't worry, she will catch up when she goes to school, don't worry!" You know. (Sic) And if I hadn't pushed, where would she be?

In addition, Mother E explained that another doctor, after assessing her child on two occasions in her office, came to the home to assess her child, and only then was the doctor able to recognize that the child had autism. Unfortunately, such experiences are typical of the experiences described in the self-accounts of mothers of children with autism. Parental self-accounts indicate that there is a real lack of trust in mothers' daily experiences and "wisdom" (Moreno, 1992; Siegel, 1997). Moreno (1992) pointed out that only a few mothers are lucky enough to find a doctor who from the beginning listens and addresses their concerns. Many health professionals fail to recognize the autistic symptoms due to their lack of experience and training (Konstantareas, 1989).

All of the mothers in the study experienced a great deal of insecurity and fear before their children were diagnosed because they did not know what was wrong with their children. The four mothers who had an older child or children in addition to the child with autism felt secure about their "maternal instinct," because they recognized that there were developmental differences between their

children. However, Mother D, who had only one child, had only suspicions: at first, she thought that her child was merely "a very difficult child," and that she lacked the skills required to discipline him. As was mentioned in the literature review, even for mothers, it is very difficult to identify symptoms of autism during a child's early years because these children appear physically "normal" (Siegel, 1997). Therefore, it is common for mothers of undiagnosed children with autism to believe or feel that they must be bad mothers for their children, who appear to be healthy and "normal," to behave as they do (Moreno, 1992).

The mothers in the study also mentioned that the lack of understanding about their children's behaviours made them feel very frustrated and affected their interactions with their children. For example, Mother E said: *"... so I got really frustrated and I thought inside myself that if she wasn't or she didn't want to talk... I was talking to her all the time and I wouldn't get any response, so I gave up. I thought: "Oh, fine! You don't want to talk to me; I won't talk to you either. So, I was in for a bad start..."* Thus, her great despair and inability to get a response from her daughter made her give up trying to interact because she thought that her daughter was purposefully ignoring her instead of having a problem with social interactions.

Although the literature (e.g., Moreno 1992; Siegel, 1997) has indicated that the failure to receive an early diagnosis adds to the mothers' stress of coping with

their children's difficult behaviours and deficits, the literature has not explored from first-hand data how this failure and stress affect their interactions with their children. The mothers' initial lack of understanding about their children's deficits and lack of information about how to help their children severely limited their interactions with their children in the early years. During their children's first three or four years of life, the mothers did not know how to respond to their children's social isolation and withdrawal, thus these children missed opportunities to receive more social stimulation geared to their capacities and needs.

It is also unfortunate that these mothers not only have to deal with the stresses of their children's deficits; they also must advocate for their children, and fight for their children's right to a diagnosis. This struggle requires time and energy that could be used more productively helping their children. In turn, their children fail to receive the early interventions they need to facilitate the acquisition of speech, self-help, and social skills. As was mentioned in the literature review, early diagnosis is essential because it is the first step in helping parents develop awareness of what they may face as parents of a child with autism, of possible interventions or therapies available for their child (Konstantareas, 1989), as well as how they can facilitate their children's social development.

(2) Receiving and Coping with the Diagnosis

Although four of the mothers in the study suspected that something was not quite right with the development of their children, all of them felt a great shock when they finally received the diagnosis of autism. As the mothers described it, their shock incapacitated them to such an extent that they were unable to listen to anything after hearing "autism" or "developmental disorder," and while some of them broke down in tears, others were not able to react at all. They explained that, no matter how prepared for the worst they tried to be, actually receiving the diagnosis was a great scare.

All the mothers indicated that, at the beginning, they went through a period of denial or great despair. They had many disturbing thoughts and questions about the future. The mothers indicated that the doctors and the multidisciplinary team of professionals who gave them the diagnosis should have been better trained to anticipate their reactions and to assist them through the shock. Mothers D and E thought that the diagnosticians should have helped them prepare for the diagnosis. Mothers D and E also felt that they should have been given some time to process the news before the doctors began to talk about the delays, disabilities, and hardships that these children might experience. Instead of first listening to how the mothers felt about the diagnosis and addressing their main concerns, the professionals gave them a brief and clinical explanation about autism and its worst

case scenarios without considering their reactions to the diagnosis. Furthermore, Mothers B and C complained about the lack of information given about the options and resources available to them. For Mother C, who received the diagnosis in Guatemala, her country of origin, the diagnosticians even suggested to her that, somehow, it was her and her husband's fault that their child had autism:

When they told me it was autism, the only thing that they asked me was that if I had dropped him or something.... They asked me if I had dropped him when he was little or if my husband or I used to drink before we had him. And I told them that "no! I did never drop him, and I don't drink or smoke and my husband never used to drink or smoke...

It was surprising to hear that doctors were perceived to lack understanding of these mothers' struggles with the diagnosis. Even more surprising was that in some countries the belief still exists that autism may be caused by the parents. There is, however, empirical evidence that autism is biologically determined with multiple causality mechanisms (Phelps & Grabowski, 1991).

Although there has been no direct study of the specific grief and coping responses of mothers of children with autism, the literature review on mothers coping with developmental disabilities has indicated that most mothers go through

a period of bereavement and grieving (Siegel, 1997). Parental self-accounts suggest that when parents receive the diagnosis of autism they experience a unique process of mourning for the loss of the dreamed-of child. This process seems to stay with these mothers in varying degrees (Moreno, 1992). If these mothers feel overwhelmed and deep sorrow about their children's diagnosis, they are not going to be able to provide their children with the help and supports they need.

The mothers in the study also mentioned that they did not receive much support from their extended families, nor did friends know how to offer or give them support. The mothers commented that the fact that their children had autism put a lot of strain on their families and friends, which they were not able to handle. At the beginning, these mothers' "coping process" was based on searching for answers and treatments for their children. This was truly an "isolating process." Mother D said: *"My husband and I just relied on each other for support. There was no one else, we only had each other, and you just cope with one day at the time."* Mother E explained:

...grandmothers and uncles on one side of the family gave up on her [the child] because they said 'Oh, she doesn't want to get close to us, we can't touch her, so why bother' You know? And on the other

side of the family, her grandmothers really want to get close to her and love her, but they don't know how...

This lack of support for the mothers may greatly affect the children in many ways. If these mothers do not have the supports they need to cope better and to be able to share in the caring responsibilities of their children, they may easily fall short of energy trying to help their children. In addition, as three of the mothers commented, due to the lack of friends and extended family members who can be involved in their children's lives, their children did not have many opportunities to interact with others. For example, Mother E commented that her child was very surprised and restless about my presence in their house, because they almost never have visitors. Mother D explained that the only opportunities that her child has to socialize with others when at home, are the times that sales or delivery people come to the door. The mothers also indicated that their children rarely interact with neighbours. As Siegel (1997) has suggested, the degree of social support, effective treatment in place, and marital satisfaction among other factors affect how these families adapt to autism. Only when these mothers received more help and support, were they better able to provide more help and support to their children.

(3) The Dilemma of Finding Effective Interventions and Help

Four of the mothers in this study reported that, in the beginning, they felt that professionals were not able to help them or provide support in their search for the best care for their children. Professionals' lack of sensitivity about what the mothers go through on a day-to-day basis was very disconcerting for these mothers. They were only able to find support when they joined or contacted associations such as the Manitoba Autism Society. Mother E, for instance, described her great anger about how hard it was to receive medical attention and how she continues to feel resentment toward professionals:

...I am disappointed in the medical profession, I really am. ...I have gone to three or more doctors and... That's what they are there for! (Sic) ... And even if... she would later catch up on her speech, why take a chance? You know. Even if it was only a speech delay why take a chance. It is still a speech delay, even if it is not autism or another PDD, or whatever, it is still a delay, she is still not at her level! So, let's do something! Why not suggest speech therapy or something. They didn't recommend anything!

Three of the mothers (Mothers A, C, and E) explained that they had to search for more effective programs outside their provinces or countries. On the one hand, Mother C, who could not find any kind of help for her child in her

country of origin, decided to emigrate to Canada in search of treatment for her child. On the other hand, Mothers A and E, based on their own search for information, decided to learn about the successful intervention known as Applied Behavioural Analysis (ABA). Training in ABA is not available in Manitoba, so these mothers had to search for resources outside the province. Mother E took her daughter to Montreal for a six-week intensive training in ABA. This program was expensive, but very successful for Julie (pseudonym). According to Mother E, Julie was not talking at all, and could not sit up for even a few minutes before she started the ABA program. Thanks to the ABA program and her mothers' involvement in it, Julie learned to sit, pay attention, and ask for what she wanted. Mother E said that she could not understand why mothers are not offered more assistance in finding and taking advantage of intervention programs such as ABA. This mother said that she continues to receive support from the program every three months through videotapes and correspondence. Mother E also praised Families for Effective Treatment of Children with Autism in Manitoba, an organization of mothers who believe in the success of ABA. This organization helps mothers to become better informed about and, therefore, better able to cope with the challenges they face trying to put an ABA program in place for their children. Mother A, who brought an ABA expert to her home for intensive training, commented:

I've also had Dr. Sam Slider come up from California and spend a two day session on Applied Behaviour Analysis and he set up a curriculum for Kevin which we ran in the home for several months and then in the day care as well. And he still has what we call a card time at the day care, where he works on certain things....

Although all of the mothers in the study described their process of finding help as a hard, isolating, and long process, eventually with time and perseverance, when they found professionals who were helpful, these mothers became more able to facilitate large improvements in their children's social responses and skills. In time, most of these mothers have learned from professionals and have become main therapists and teachers for their children. Mother D said: "*We took him to different therapists like a speech therapist, we have done occupational therapies since he was four or since he was diagnosed. As he goes through them, we learn about it and we continue them at home...*" As the mothers apply the techniques they have learned from professionals over time, these mothers become more successful at facilitating their children's learning. This finding is congruent with the contention of Marcus, Kunce, and Schopler (1997) that parent-professional collaboration is essential to building potential skills and competencies for both child and family.

Marcus et al. (1997) indicated that there are many advantages to mothers serving as active change agents in their children's intervention. These advantages go beyond the improvement of the children's condition in that they benefit the whole family. For example, the mothers' active involvement increases their feelings of competence and self-efficacy, and makes it possible to maintain and generalize those feelings to other areas.

Three of the mothers in this study indicated that they felt "lucky" for the kind of close relationship they have with the people who work with their children. Four of these mothers said that the ideal mother-professional relationship is a collaborative one. These mothers needed the collaboration of professionals to make several difficult decisions about their children's education and treatments. Those decisions are hard for mothers to make because there are not absolute rules for selecting the best programs and placements for children with autism; such choices depend on the needs of the individual child and family. The mothers seemed to recognize and value especially the knowledge and advice of professionals who realize that there is merit in "maternal instinct" and judgement.

The mothers' accounts agreed with that of Moreno (1992): "the issue of where to go to get the best help for a more able autistic child is one that begins with the mothers' first awareness of symptoms. Basically, this problem never ends" (p. 93). It depends on the child's individual needs and characteristics.

Moreno concluded, "only when mothers and professionals cooperate, respect one another, and work as a team are the child's very best interests served" (pp. 94-95).

(4) The Daily Challenges of Raising a Child with Autism

When the participants in the study were asked about their experiences of daily living and raising a child with autism, three of the mothers described their experiences as "*hard*" and "*challenging*," while the other two mothers characterized their experiences as being "different" from raising their "normal" children. For example, Mother A responded: "*It is challenging. It is a daily challenge because, ah... a lot of the things that other mothers or other children take for granted as being 'normal' situations can be traumatic situations or more difficult situations for the child depending on what his fears and his difficulties are....*" Mother C answered: "*Well, it has been very hard. One always wants that all one's children are normal, right? He always needs more than my other two children do and also it is hard to understand at times what he wants.*"

These findings are similar to the descriptions in parental self-accounts and reports in the literature, that even though over time, most children with autism become more independent and sociable, parenting continues to be quite challenging for most parents (Moreno, 1992). However, this study also found that when the mothers were able to change their expectations and felt less frustrated,

they were better able to provide the kind of consistent supports their children needed, and that allowed them to connect with the children.

The mothers had to change their expectations for their children and learn to accept them and connect with them in special ways. Each mother in the study went through early times when she was not able to communicate and interact with her child with autism. However, at the time of the interviews they said that they valued immensely every moment of attention, affection, enjoyment, and simple carefree time that they can share with their children. For example, Mother C recounted,

...He began to sit with us in the living room and things like that. Because before even when we would put the TV on, and something that he liked... But now, I ask him to come to the living room to watch the TV and he comes and watches TV with us. He only watches the programs that he likes, and not the ones he doesn't like to watch, but he does sit with us anyway.

The mothers also mentioned that with the improvement in their children's abilities to communicate, have some control over the environment, and socialize, their most upsetting behaviours, such as aggression, sleep disturbances, and self-stimulatory and self-injurious behaviours decreased. With the decrease of such upsetting behaviours, the mothers worried less and they found it easier to relax a

little bit more with their children. Once these children became more adept at interpersonal communication, they began to express their frustrations in more "conventional" ways. Therefore, once again, one sees the importance of these mothers' experiences regarding their ability to cope with discrepancies between behaviour, interactions, and expectancies regarding their children. As Kasari and Sigman (1992) suggested, it appears that the perceptions that parents had of their children's behaviour from the day-to-day interactions with their children, expectancies for their children's development and behaviour, and their own feelings played an important role in actual parent-child interactions. Socialization is reciprocal in nature; the mothers' actions influenced their children's responses and vice versa.

(5) The Effects of the Child's Autism on the Siblings

The mothers in the study indicated that as individuals and mothers, they had to adapt and "drastically change" every aspect of their lives to accommodate the special needs of their children with autism. In addition, they said that the disorder affected their other children in many ways. Discussing one of her daughter's interactions with her son with autism, Mother A commented: *"his oldest sister speaks to him in the same kind of way I do. She changes her language when she talks to him and she simplifies it, and it is quite amazing how she has adapted her own social interactions to fit with his."* It is common that

older siblings adapt their own social interaction patterns to their younger sibling with autism (Schopler, 1995). On the other hand, younger siblings can be influenced or affected negatively by their older siblings with autism. Mother E explained: *"...because my oldest child is autistic, the other two young ones are not following the proper examples and they haven't had the opportunity to learn the proper speech and proper examples from my oldest one."*

Previous researchers (e.g., Schopler, 1995) have tended to focus on the negative aspects of having a sibling with autism because there is a tendency for siblings of children with autism to become their sibling's interpreters, protectors, and guardians. However, the mothers in this study described the negative experiences as well as the positive ones. When I asked the mothers about their interactions as a family, most of them answered that their children were very loving and caring toward their sibling with autism, and had formed close relationships. Most of the mothers mentioned that their children work on different things together. Mother A said:

So there are lots of things that we work on doing together. Some of the things are quite a struggle because he doesn't do things in the same way or because he doesn't understand when to stop things and the girls get upset and things. But they are very willing and accepting of him to take part in all of those things, and they

understand that he has a right to play with them, at times, and do the same kinds of things...

It was interesting that Mother A said, "*there are lots of things that we work on doing together,*" reflecting the considerable effort needed to facilitate social interactions and learning among children with autism and their siblings. At the same time, these mothers also indicated that these interactions and learning benefit both their children with autism and without autism.

All of the mothers who had other children appeared to be quite concerned with being fair to all their children and found that it was essential for them, as parents, to remember that their children without disabilities are growing "normally" and need to have their own private time, groups of friends, and activities without having to share always with their siblings with autism. They actually found that by sending their children without autism to a different school from their siblings, they minimize the pressures these children may feel at times. These mothers believe that this practice of sending their children to different schools does not limit the opportunities for social interactions between siblings, but rather it strengthens those social interactions because their interactions are not forced upon each other. (These social interactions between siblings are discussed in more detail in theme III).

In reviewing the subthemes of theme I, one sees that the children's patterns of delays occur in the difficult context of mothers' experiencing stress, grief, shock, and confusion during the early years of their children's lives. Despite the strong needs of the children, the mothers initially were not in the best or even in a satisfactory condition to meet the extra challenge. Initially, these mothers were in a continuous state of searching for answers and help that were hard to find. They did not have the understanding nor the skills to respond to their children's unique needs and social deficits. These mothers tried many different ways to reach their children without any initial success. Their method was initially based on trial and error, a method that is entirely the opposite of what these children need. As was mentioned throughout the literature review, children with autism need early interventions that are consistent and provide them with a predictable environment and with routines that can maximize these children's chances to respond to social initiations. At best, we found that these mothers eventually found the supports they needed and learned ways to foster their children's social development. These supports and interventions through no fault of the mothers came into effect in a delayed manner that would appear to detract considerably from the optimal social development possible for these children.

Theme II: Mothers' perspectives on their children's characteristic ways of relating provide deep insights into these children's social deficits and the context in which those deficits occur.

When describing their children with autism all of the mothers mentioned similar common characteristics. The mothers' descriptions generally were congruent with the official criteria in DSM-IV that provide for a diagnosis of autism. Yet the mothers' perspectives yielded deeper insights into the common labelled characteristics of these children in specific contexts and according to a developmental framework. The mothers' accounts provided a wealth of information about these children's deficits in social interactions.

1) Clear Evidence of Communication and Social Deficits During the Toddler Years

The mothers indicated that they began to notice their children's communication and social difficulties during their children's toddler years. The mothers were first concerned about their children's lack of communication, eye gaze, imitation, and responsiveness to any kind of social interaction. Four of the mothers reported that, at the beginning, they wondered whether their children were deaf or "compromised" in some other manner. For example, Mother B commented that, when Ryan was a toddler "...*He would not respond when we talked to him, he would seem to be deaf or pretend to not hear us. He would look*

away, and not to our faces and he did not have the same kind of contact like the other kids." These concerns match the concerns cited in the literature on children with autism and in parental self-accounts (Schopler, 1995).

On the one hand, according to Mother B, Father B, and Mother C, their children (Ryan and Paul respectively) are still having problems communicating in both verbal and non-verbal ways. For instance, Mother B said: *"Well, he (Ryan) finds some words to communicate; he uses a few words to indicate what he wants, for example, he will say 'coke' or 'leche' that means milk in Spanish. But, mostly, he points or shows us with his actions what he wants."* On the other hand, Mothers A, D, and E explained that although their children (Kevin, Mike, and Julie respectively) are able to "use verbal communication quite well," their usage is inflexible and repetitive. Their communication repertoire is limited to concrete topics strictly from their own perspective. Mother D illustrated this limitation:

His (Mike's) discussions are always about something concrete... and if we do talk about something abstract or about emotions or something like that, he is usually not interested... He perseveres on something or on a subject, as most of them do.

Mike was not interested in abstract issues because it was apparently very hard for him to understand and discuss them. Children with autism have great difficulty

comprehending abstract concepts, nonverbal language, and inferred ideas (DSM-IV, 1994).

All of the mothers indicated that their children seem unable to use communication as a "collaborative exchange of ideas." As Mother D said of her son, Mike: *"he doesn't have that give and take of communication or conversation."* Mothers A, D, and E are quite content with how their children are progressing in their social and communication functioning, although they are concerned about their children's lack of "social depth" and language skills. Mother A appeared to be quite enthusiastic talking about Kevin's progress with social interactions. In an up-beat and very expressive tone of voice, she said:

...He asks questions now, he is just beginning to ask questions, and those are some of the things we have worked on. "Who is there? What is that?" He does use whom, what, and where. When and why questions are still very difficult, they are too abstract for him.

Mother A however, seemed to continue to be very concerned about her child's limitations in communication and social skills. She lowered her tone of voice and spoke in a serious manner about his autistic characteristics. Mother A commented: *"But, there are other times where he... when other children talk to him and he doesn't respond to them either, you know? So, there is still a real mix of his autism and some appropriate social skills."*

Mothers A and E also noted that their children had problems learning to talk and using language to communicate in social situations. Mother A indicated that her child lacks social depth and social understanding. Both mothers suggested that their children's communicative repertoire is very limited and appears to be motivated mainly by the desire to maintain order in their surroundings. Most parental self-accounts indicate these problems consistently (Howlin, 1986).

All of the mothers expressed their initial concerns about their children's social behaviours or lack of them. The mothers indicated that, at the beginning, their children did not respond to any of their social attempts. Their children did not respond to physical contact (e.g., cuddling) or facial expressions (e.g., mothers' smiles), and they lacked attachment behaviours. Mother C said: *"he never had any problem with letting himself be held or kissed and hugged, but he wouldn't respond, I would kiss or hug him and he would just stay still. He would just let us hug or kiss him, but that was all. He would prefer to be left alone..."*

Mothers D and E viewed their children's lack of responsiveness as a sign that they did not need physical contact or touch. They perceived their children as building walls around themselves to avoid human contact because they did not understand or see the point of "love" or "affection." For instance, Mother E said: *"...when she was a toddler; no, she didn't need to be hugged, she didn't want anything and*

she didn't love anything. She was just here because God had put her there existing, but she didn't respond to anything." The mothers appeared to have an initial impression that their children did not need any kind of affective demonstrations. It must have been devastating for these mothers to not receive any kind of affective or positive response from their children. Their perceptions and initial inability to form bonds with their children, might have made them feel upset and very discouraged about their situations.

Another common characteristic that four of the mothers mentioned was their children's lack of awareness of other people during their toddler years. Their children's ability to acknowledge the presence and actions of other people seemed impeded, they used to act as if others did not exist. For example, Mother A explained: *"...and the solitary play, and with even his lack of awareness of his sisters in the same room, or other family members in the same room became more and more abnormal."* Other studies, referenced in Volkmar, Carter, et al. (1997), also have found that during early childhood, the general impression is often one of social aloofness.

The above mentioned concerns are similar to the concerns widely documented in the literature on children with autism and in parental self-accounts (Moreno, 1992; Schopler, 1995). However, by asking the mothers in this study to describe their children's actions and responses in different situations, it became

obvious that with time, the children had begun to seek out their mothers and interact with them in special ways. For example, Mother A said that when her child was feeling distressed or anxious, "...*he did seem to like to be cuddled, and held tightly.*" Mother D said that her child was affectionate with her and her husband, and that he did respond to her affection and did seek her comfort when he was upset. Furthermore, Mother C, like the other four mothers, indicated that her child responded differently to his nuclear family than to other members of the family and strangers. Although these children are not able to demonstrate the "typical" bonding or affectionate physical contact that "normal" children do demonstrate, these children do recognize their caregivers and they do seek assurance and comfort from them.

Although most toddlers with autism seem to lack social interest, they do not actually have a total lack of social interest. Some social skills do begin to emerge during the early years. These children do begin to seek out their parents and interact with them in special ways (Volkmar, Carter, et al., 1997). Therefore, it is important that mothers do recognize those initial attempts to communicate and that the establishment of the mother-child bond may be delayed. There are many experimental studies that found that children with autism do not show fear of strangers (Howlin, 1986), however, those studies had been conducted in

artificial settings, where the children were already unresponsive and distressed because they were not in their familiar environments.

2) Severity of Communication and Social Deficits as they Change with Time

Four of these children with some aid or facilitation are communicating and participating more in social interactions now. With speech therapy, interventions, education, and their own efforts, all of these children became able to make requests, indicate their preferences, and communicate more clearly. Two of the children (Mike and Julie) are quite verbal. All of the mothers indicated that their children's social skills have improved over time. The mothers' reports suggested that with time and consistent training, their children progressed in their socialization and social interactions. This is something that was obvious in the case of Mothers A and E. Mother A commented:

Well, he had definitely made a lot of progress, he is excited to see me when I come to pick him up at school or at day care or wherever I am picking up from, dropping him off. He has to blow me a kiss goodbye and runs to the window and blows me more kisses. There are a lot of strong social bonds between him and me, and between him and his siblings, and between him and his father.

Mother E also indicated that her child, Julie, has progressed a lot in the last couple of years. It was hard to believe that Julie did not communicate and had

severe social difficulties when she was a toddler, because she seemed quite verbally expressive, affectionate, and happy at the time of the interview. In fact, while her mother was answering the questions, I could hear Julie laughing and repeating what the characters were saying in the movie she was watching. Julie can be heard in the background of the audio-tape. As the children grew up, their improvements or progress became apparent, and the mothers began to feel more connected to their children and realized the importance of their efforts.

With time, these children with autism appeared to become more sociable.

Mother D explained:

...He (Mike) likes to "socialize" when someone comes to the house and he likes to have people coming to visit. He likes the social contact, but he just doesn't know what to do with it, once he gets them here. He is very awkward, and he doesn't know how to... or what to do after that first step. I think that he would be appropriate in a greeting, but that's all...

Although young children may show little interest in establishing relationships and fail to reciprocate in social interactions, older individuals with autism may want to establish relationships, but they lack understanding of human social conventions and social skills to do so (DSM-IV, 1994; Howlin, 1986; Schopler, 1995). The motivation to interact seems to be present but the

reciprocity and skills to maintain social interchanges are missing. Therefore, despite these children's social accomplishments and improvement over time, they continue to have some social difficulties. Their attempts to participate in social interactions and conversations appear awkward and inflexible. Their problem thus, becomes a lack of social skills rather than a lack of social interests (Howlin, 1986). Therefore, Mother E stated: *"mothers of children with autism have to never give up and really work on connecting with their children because it is possible! These children need to get out there in the social world and be exposed to others."* The mothers found that it was essential for them to be persistent in reaching out to their children and to continue to express their love to their children.

(3) Difficulty Expressing and Understanding Emotions

Although four of the mothers indicated that their children display affection and positive emotions now, it is very hard for these children to understand and express emotions "appropriately." Mother A said: *"He does seem to demonstrate affection now. Sometimes, it is not appropriate! He doesn't always seem to have learned the social contact for that, but he seems very comfortable with that, I mean, with affection."* Mother D who has a ten-year-old son (Mike) commented:

He always invades personal space, which is really hard because he is in your face all the time and the children really don't like it. He is

inappropriate as far as hugging goes, if he is happy and he wants to tell a classmate that he is happy, he will hug them, which I mean it doesn't go over well with children nine or ten years of age. So, he is... really inappropriate in that way.

However, three of the mothers in this study indicated that their children do make eye contact, express affection, and show other kinds of social behaviours in varying degrees within their limitations. Mother E described the change in her daughter's ability to express affection:

...but she now shows her affection, like I can say she really loves her dad now because when she sees him she jumps and gives him a hug, but before she wouldn't. When she sees a kiss on the cheek in a movie or something, she will come to me and give me a kiss, and so, she has begun imitating, you know? She knows now that a kiss and a hug mean love and affection...

By considering the social context in which these affective displays occur, opportunities such as these can be provided more often in their daily lives. Some of the progress that these children made in their affective displays is striking.

The mothers also discussed that although their children may have strong feelings for others, and sometimes show some signs of empathy, most of them seem to lack understanding of others' feelings and actions. Mother E pointed out

her concern with whether Julie really understands the purpose of hugs and affection. For example, Mother E explained: *"I am not sure that she knows exactly why I need a hug, but she gives it anyway, so... (laughs). And she is only a kid still. I have been told that autistic children do mature and some really make it in life, so..."* These mothers appeared to believe that their children's main difficulties are, as many researchers have concluded, severe deficits in interpersonal understanding and personal relatedness (Hobson, 1993). This is discussed in the literature on children with autism and parental self-reports; it is believed that these children lack innate empathy, that is the ability to interpret and respond to other people's emotional needs (Moreno, 1992; Schopler, 1995). Therefore, although children with autism become better able to express and show affection and feelings, they continue to need help with social conventions and expectations. They need people who, like their mothers, can interpret the social world for them. (This point is further discussed in Theme III.)

(4) Restricted Preference of Behaviours, Interests, and Routines

Another common characteristic that the mothers mentioned about their children was their repetitive and stereotypic patterns of behaviour. The mothers expressed concerns about their children's "odd" and self-stimulatory ways of playing from the time they were approximately one and half years old. Mother A described her son's behaviour:

...he started more solitary play, and more obsessive types of play where he used to line up little tiny animals or toys on the coffee table and he would go around the entire inch of the coffee table and then come inside with the next row and the next row, and if you broke that chain of animals or characters, or change the order in which they were in, it would be very distressful and upsetting to him.

In addition to their preference for repetitive play, as they get older they became interested or "fixated on certain kinds of toys." They spent a great part of their time playing the same way with one toy or focusing on what they use for stimulation.

The mothers also mentioned that their children seemed to need routines and stability in their lives. They explained that, especially when they are younger, they could not deal with changes in the environment. For instance, Mother A explained:

...we would go into the car, you know? It was a battle to get him to go for a ride in the car, and once we got him in the car, he was fine, but then when you shut off the car to get out to go somewhere, that was very difficult. He would be upset, that would be upsetting to him again because he couldn't deal with all these transitions or

changes. As long as he could do one thing and one thing only, he was happy.

It is extremely challenging for these mothers to deal with their children's lack of tolerance to change. These children prefer only familiar situations. It is beneficial to use examples of actual real-life situations to understand truly the kind of small changes that can be very difficult for these children.

It is clinically known that these children need high predictability and get very upset when things are not as they expect them to be (Howlin, 1986). It is important to understand how this need for a high degree of predictability is likely to interfere with these children's social development. The mothers explained how they try to follow daily routines and to maintain consistency in the environment for their children to be able to learn as much as possible from their daily social experiences. However to try to provide consistent or similar social situations is very difficult, if not impossible. As Dawson and Galpert (1986) indicated, "although mothers do tend to provide contingent, predictable responses to their children's behaviour, the degree of predictability in naturally occurring interactions may not be sufficient for the autistic child to benefit from it" (p. 247). (Strategies to help these children cope with changes and respond to different social situations are discussed in Theme III).

(5) Strengths and Abilities

The mothers also mentioned some strengths and abilities that were common among their children. Four of the mothers said that their children had fast visual memory for concrete things. Mother E described her child by saying: *"She is very smart. She has a great memory! Like two years ago, I taught her how to match words, two words that were printed and then match those with a picture and she stills remembers it today..."* Mother B and Father B talked also about their child's visual "ability":

Yeah, because he is very smart, some things he learns very fast and he seems to know things that we will never be able to learn. Like he seems to know what CD is the one he wants by looking at the label without seeing the cover, I don't know if he reads the label or what... He also knows his way around the city, he knows the way to school and other places like the doctor's office...

Individuals with autism are known to be very fast visual learners. As Temple Grandin (1995) indicated, she has an excellent visual memory and she has found that using visualization or visual thinking is a great asset in her career as a livestock equipment designer. Her visualization has also helped her make sense of the social world around her. The systems that process visual-spatial problems seem to be intact in individuals with autism (Grandin, 1995).

Three of the mothers (Mothers A, D, and E) indicated that their children were doing well academically and learning some subjects even faster than their peers. Mother D, referring to Mike's academic skills, said:

In Math, he does great! He does OK; academically he does fine except for language and French is tough and he doesn't like it because he says that when he says it, it doesn't sound correct to him. He is perfectionist in that, like he wants to do everything perfectly right at the beginning.

Mathematical skills are quite common among individuals with autism. They appear to have a great facility to understand, use, and memorize numbers (Schopler, 1995).

These mothers indicated that their children were working very hard at learning as much as they could and cooperating more with the people who work with them. It is important to recognize these children's great effort in overcoming their sensory difficulties, asocial, and aggressive behaviours. For example, Mother C mentioned: *"He is very cooperative. The bus driver told me that he has progressed a lot this last year because he is very active in school, he collaborates, and he does what the teachers tell him to do. So, she congratulated me..."*

Mother C also described the activities that Paul helps with at school. He takes the attendance books to all the classrooms, he communicates effectively by using

pictures, he goes shopping with his teacher, and prepares his own lunch and gets ready to go home almost on his own.

These mothers recognized their children's strengths and efforts. They focus on their children's progress in managing or overcoming their difficulties and they base their hopes for their children's immediate futures on those strengths. For instance, Mother C said: *"All that really gives me some hope and relief because that means that he is progressing and relating more. So, he is letting others guide and help him too, so he is more helpful and that is very good!"* Mother E: *"So, I think that her intelligence will be what will save her, herself for the future, like what she learns I know she won't forget, so I hope that will save her."* By identifying their strengths and abilities, we can focus and use them to help these children manage or overcome their difficulties and deficits.

In summarizing the major findings of theme II, one can notice the mothers' identified particular deficits and problematic ways in which these children interacted. The accounts enable one to get a sense of the quality of the interactions that the quantitative measures do not yield. One can see malleable action patterns not just fixed symptoms or standard deficit labels. The mothers help us, the researchers, to better understand the dynamic of social interactions that these children seem to miss, and give insight into the children's difficulties in interaction with others.

These mothers' descriptions or perspectives indicate that, although they had had severe difficulties interacting with their children initially, when they learned that their children had autism and became more knowledgeable about how to help them, their efforts became more successful. As the mothers learned to work at building connections with their children and the children began to respond more, they became more hopeful and confident in their attempts. It is important to see these children's progress in the context in which it occurs.

During middle childhood, these mothers became more consistent in using the strategies they had learned and, in addition, they began to receive more supports from the education system. The efforts of these mothers never end, they have to continue to provide their children with the help and the social supports they need to interact with other people. Although improvements are varied and these children may never achieve independence in social situations, the children's improvements seem to give the mothers more hope and willingness to continue to provide their children with supports and to seek for the help they need.

Theme III. Mothers, through their special relationship with their children have learned effective strategies to facilitate the social interactions and integration of their children

Social interactions play an important role in determining any individual's quality of life. Therefore, it is important to consider these mothers' experiences in

an interaction framework, in which the mother is a member of an interaction, and the other member of the interaction is the child with special needs. Mother-child interactions are the basis for social development. Thus, both members are important contributors in determining the degree of handicap or disability, if any, and the quality of the interaction (Knoblock, 1987). The interactions between the mothers and their children shape the experiences out of which the mothers try out strategies and learn which are effective. Within close mother-child relationships, the mothers, in their daily efforts are able to provide a substantial degree of assistance to their children's social learning and development.

(1) Social Interactions and Relationships between Children and Mothers

The mothers' reports indicate that all of them interacted consistently with their children while working on social and communication skills with them. They showed many signs of being very dedicated to teaching their children's language, communication, and social skills and emphasized the importance of regular daily practice for their children's learning. It seems probable that the only way that these children had learned their basic communication and social skills through a great deal of training and repetition. These mothers spent a great part of the time applying techniques that they have learned, and taking every opportunity to teach and learn with their children. Mother A narrated:

And we have our bath-time routines, where there is a lot of verbal stuff that I work on with him, like I would ask him to ask me to turn the water on instead of just standing there. He loves his bath, so it is a real good motivation to get some language out of him. And... most of our interactions have to do with his daily routines, keeping him... or letting him know what is up coming for his routine, and talking. And bedtime is story-time; there is a book...

Mother E described how she began trying to have small conversations with her child about what she knows or what she is interested in, and at the same time began trying to incorporate new concepts into her vocabulary: "... Like, we were outside before you got here and we were walking, so I was asking her "what are you doing?" and she would say "I am walking" and "what did I do?" "You walked," and things like "I am pulling," I am pushing," "oh, you pushed." So all the time I am teaching her concepts... Mother E, as did all of the other mothers, helped her child to use communication in a social context so that the child will be able to be more involved in the social world.

All of the mothers said that it is essential to recognize and comprehend the main difficulties and strengths of these children before trying to help them. The mothers also commented how they use their children's visual-spatial skills to help their children develop language or communication and understanding of the social

world. Three of the mothers discussed how they use pictures and concrete symbols or objects to begin to communicate with their children. Social stories or tangible picture books, role-plays, videos, and dramatization were used to provide the context of a specific social situation, and such visual techniques were very effective. They also discussed how they, as well as their children's aides, help the children prepare for changes and facilitate transitions. In this way, these children are able to adapt to changes. For instance, Mother A recounted,

At the Day Care they went to Adventure City last week, so they sent home a little book with social stories about the field trip to Adventure City, so he would have the opportunity to know what to expect and what the sequence of events would be. And that helps him to be prepared for changes... or for when the situation actually comes...

Most of the intervention strategies that the mothers mentioned are similar to the ones suggested and used by most therapists. They have been systematically investigated when used by therapists (e.g., McClannahan & Krantz, 1993), but they have not been studied when used by mothers in the naturalistic context of day-to-day situations. By listening to these mothers' accounts of how they use these strategies during daily routines, one comes to understand the skills and dedication that these strategies require on the part of the mothers or other

caregivers. Some mothers may have become experts at using these strategies because they have been using them regularly.

All of the mothers indicated that although their children were not able to receive intensive treatment or intervention during early toddler years, the children had been making tremendous and generally consistent progress since they began their interventions. These mothers have been essential agents in their children's interventions, and they were determined to continue their work. Mother D talked about how parents practice social skills at home; she said, *"So, we have tried to do role-plays with him, we have tried different games like social skills games that we make up and get him... we give him 'what if' situations, like 'what if someone does this or that?' So, we did a lot of those kinds of things to help him..."*

In developing and successfully using their strategies, these mothers emphasized the necessity of showing total acceptance of the children. As Mother E stated: *"I began this program thinking that I would be able to get my child to come into my world, but the fact is, that she has allowed me to get into her world, and that is the key or point."* This idea of the mother entering the "child's world" is a very good illustration of the kind of understanding that these mothers have for their children. A similar insight was described by Kaufman (1981) in his book, A Miracle To Believe In: "we decided to join our son in his world with love and acceptance, to understand and know his universe by participating. Our major

thrust began with imitating him, not just as a tactic or strategy, but sincerely being with him..." (p. 16).

According to the mothers, it is very difficult, but essential in helping these children, to find the balance between knowing when to accept the manner in which these children cope with interpersonal communication and social deficits and when to challenge them even more. The mothers had learned to accept their children as they are, but at the same time, they have set goals about asking every day a little more from their children. For instance, as the children began to express their needs and wants, mothers expected that their children also learn to respond partially to the needs and wants of mothers. This expectation was illustrated by Mother E: *"I am not sure that she knows exactly why I need a hug, but she gives it anyway..."*

The mothers said and indicated that they have been able to form relationships with their children. They described their relationships as filled with feelings of closeness and understanding between their children and themselves. For example, Julie had progressed a great deal since she was a toddler. While I was interviewing Mother E (Julie's mother), Julie came into the room a few times, and she appeared to be a very expressive, content, and loving child. Julie jumped into her mother's lap and began talking to her, while looking into her eyes, touching her hair, and hugging her. These social changes in the children are not

given much attention in the literature (Norton & Drew, 1994). Usually researchers have focused on the lack of affective responses. However, by studying children with autism in their natural environment, one realizes that many of these children can show spontaneous expressions of affection, which some of them learn to demonstrate in the comfort of their homes. Researchers would do well to explore the natural environments in which these children develop and interact with others.

(2) Children's Social Initiations in Some Situations

When the mothers were asked if their children initiate interactions with them and other people, different responses were given. Three mothers (Mothers A, D, and E) responded that their children initiate social contact in a few different situations. Mother C responded that her child only initiates contact with other people when he wants food, drink, or physical comfort. The other mothers (Mothers B and C) said that their child rarely initiates interactions.

Wing (1997) indicated that according to their responses, children with autism can be placed into three groups that were classified by Wing and Gould (1971) as: the "active but odd" group, the "socially passive" group, and the "aloof and indifferent" group (cited in Wing, 1997). The children in the "active but odd" group do approach adults and peers, but in a repetitive, one-sided, and rigid fashion. The children in the "socially passive" group rarely or never make

spontaneous social initiations, but they accept initiations by others and take a passive role in games initiated by sociable peers. The "aloof and indifferent" group of children is not interested in interacting with other people except for the purpose of obtaining something (i.e., food or physical comfort) (Wing, 1997). Many of the mothers' accounts might be categorized according to Wing's proposals, as indicated by some of the excerpts below. Yet it is also true that the mothers did not themselves categorize and label their children's abilities as innate characteristics. The mothers did not think of the children in the Wing categories, and even where criteria fit, the mothers generally believed change was possible. Mothers' accounts showed richness, variation, and a sense of possibility even when the child would appear to fit one of Wing's categories. For example, Mother A's child, Kevin, would appear to fit in the "active but odd" group, at the time in question. Mother A said:

He initiates a few different kinds (of interactions). He initiates if he wants something, and he will ask me. He will be downstairs and he'll yell; "mom, apple juice" or "mom, snack!" or something like that. He'll indicate that he is hungry and wants something to eat. But, he will also come and say; "mom, play monster," which is a monster game that we play around the house where I'm the monster

and the kids run, scream, and yell, and run and hide in the bedrooms, you know? He'll come and ask...

Mother D's child, Mike, might be considered to fall in the "socially passive" group. Mother D commented that although Mike did interact with his peers in the classroom, it was hard for him to initiate social interactions on his own. Yet he was able to work well one-on-one with some aid on school projects. However, he rarely initiated spontaneous social initiations with other children. Mother D explained:

He can work one on one, and perhaps in (a group) with a couple of children... At recess, he has no idea what to do, he can't approach a group of kids; he doesn't know how to approach a group of kids to ask if he can join in. And, oh I don't know, there are so many things... He has no idea about that, we work on that all the time, but it doesn't really come easily to him.

It can be seen that Mike cannot simply be characterized as "socially passive." According to her he did have difficulties, but, as she implies, with effort, some progress did come to him.

Although Mother B and Father B answered that their child, Ryan, does not know how to initiate interactions, when asked for more details, they mentioned that Ryan asks for help or for interaction when he needs or wants something.

Thus, Ryan might appear to have the characteristics of the "indifferent and aloof" group. Father B said:

Well, it is very difficult to say because he doesn't... I don't know. He doesn't have the social skills to initiate an interaction, like if you ask him a question and he doesn't respond. He may be able to respond to a question about what he wants to eat or drink, but that's all, and if he doesn't want to respond, he won't...Now, he uses the word "help." I taught him to start with the word "help" when he needs that I help him with something...

Thus, although Ryan's patterns of interaction might appear to show indifference, the mother indicated that he did not have the skills to respond to social interactions. As previously mentioned, these children appear to not have a total lack of social interest, but rather lack of social skills to demonstrate that interest.

The mothers pointed out the importance of teaching their children the skills and means to initiate social interactions, as well as responding quickly and consistently to their children's attempts to initiate interactions. These mothers believed that their children's attempts to interact with other people and to become more self-reliant need to be supported and facilitated. All the children with autism in this study first began to use communication and social skills only to obtain what they needed and wanted, and a couple of these children are still at this

stage. However, according to their mothers, communication was the first and most important step in connecting with their children.

(3) Beneficial Interactions and Relations with Siblings and Peers

All of the mothers, with the exception of one who had other children beside the child with autism, were pleased with the kinds of social interactions their children maintained with their siblings. Although the children with autism who interacted daily with their siblings had a limited range of activities, they liked or wanted to interact with their siblings. They were able to participate actively in those interactions. For example, Mother A said:

So, generally they get along and they have a very close bond, and they do this.... Ah..."pretend play" or "role-play" that they re-enact scenes together, and they love to do that and they get along quite well with that!...

The role-play, yeah... Well we have costumes that are left over from previous Halloweens that are... they can bring the costumes to play and they will dress up. He will dress up as the beast and his sister will dress up as the beauty and they will play "the Beauty and the Beast," and they will act out scenes of the movie sometimes right down to the dialogue...

It was impressive how this child, Kevin, could play so well with his sisters and memorize all the lines of the different dialogues. He appeared to be a "natural actor" and this kind of game must have helped him a lot with his communication and social skills. His siblings seemed to be quite close with one another and enjoyed each other. These kinds of interactions between siblings have not been well studied in the literature, although it seems to be an area that can offer important insights into the dynamics of how they interact with each other. From these interactions and relations these children also learn basic social skills and the dynamics of interactions.

Although Kevin had common interests and played successfully with his sisters, he had difficulties knowing when it is "time to stop" or to play something else. He is quite selective in what he wants to play and he has strong preferences. More "imaginative" or self-structured games were more challenging for him. As Mother A indicated:

But there come times, when he wants to continue to do that, even almost to obsession, and the girls are finished playing that. They don't want to play it anymore. He has a difficulty trying to break that.... that playing, and moving on to something else. So often, I have to intervene and get him involved in something else...

Although it takes time and effort, these children were able to have strong connections and relationships with siblings. These children's social interactions seemed quite positive and fulfilling for both children with autism and their siblings. As four of the mothers mentioned, their children had special bonds and they "adore" each other. On the one hand, children with autism are learning and practicing social skills in a safe environment with children whom they trust. On the other hand, the siblings of children with autism are learning to be more accepting and understanding about differences and they are learning to interact and relate with their siblings in special ways.

A commonality among the mothers in this study that is not usually found or described in self-accounts or studies was that they provided their children without autism with their own private time, groups of friends, and activities away from their siblings with autism. They found that by allowing their children to have their own time and space away from each other their interactions and relationships were strengthened.

The mothers explained that once their children start to feel comfortable in their classes and with their classmates, they begin to interact more with their peers. They indicated that their children interact with children without disabilities more frequently and benefit from their interactions more in mainstream programs. When asked about Mike's relationships with his peers, Mother D answered:

I have to always initiate it. Oh, but I shouldn't say that, that is not true. There was a child, last year, that Mike started to like a lot, and this boy had ADHD. So, I thought that it was interesting, like if Mike must have known that there was something about him or something attracted him to that boy... But, no, there are not kids phoning and asking to come over or anything like that. No, he is out of the loop for that kind of stuff.

In addition, Mother D pointed out that her child's classmates are patient and understanding of her child despite his egocentric perspective and apparent lack of understanding about others' feelings and actions. She indicated, however, that sometimes her child's egocentric behaviours may also create conflicts with peers. This mother believed that her child needs to be in control all the time, but the problem may be more related to his inability to understand the perspectives of his peers, rather than a control issue. This was apparent when Mike explained how he was supposed to behave, but had difficulties putting what he knows into action and in trying to interpret others' feelings or actions.

Although these children appear to be quite interested in interacting with their peers, their lack of social understanding and social reciprocity makes it hard for them to maintain relationships with their peers without supports. Therefore, they need to receive special social skills training and constant support to maintain

their social contacts. All of the mothers agreed that the area of social skills training is the most difficult but most important area and that these children need constant practice and help. Explaining how Kevin learns and practices social skills at school, Mother A said:

...at school, he will ask, he usually seeks somebody else for the free play. And they would try to pair him with somebody every day, so that he has a playmate, so that he is not playing by himself at free playtime. So they will ask him, "who do you want to play with today?" and he will choose someone and he will go to them and ask them, "come play with me." He will tell them what it is that he wants to play... But after that, most of what he does with them is parallel play...

Three of the mothers described positive anecdotes about their children's social interactions with their peers. They talked about how some of their children's classmates are social helpers and models for their children. For example, Mother A said:

...well, it started off when he first started to go to school in the mornings that there was a girl that would blow a kiss to him every morning...she saw him blowing kisses to me while I was leaving one morning, so she started blowing kisses to him in the classroom and

he would blow kisses back to her because he knows how to do that.

And it became a kind of a little game between them, and now they have become pretty good friends...

This shows how natural it can be for children without disabilities to be attracted to their peers with developmental disabilities such as autism. It is important to give children like these an opportunity to establish social contacts and possible relationships such as this. Children are sometimes the best teachers of how to build "real human connections." That is, typical children usually use natural ways to relate to others; they tend to expect that other people will want to get close too. They seek others and they tend to accept more easily other children's limitations. Acceptance and inclusion of individuals with autism is necessary due to the positive outcomes of mainstreaming for both children with and without autism (Goldstein et al., 1992).

The mothers also mentioned that their children tended to interact more with certain peers than with others. They seemed to prefer the peers who had shown a special interest in them and who were willing to accept them as they "truly" are, without judging or trying to change them. They described the "helper peers" as very understanding and patient with their children, qualities necessary for any person who interacts with children with autism. For instance, Mother A stated: "Ah, but it seems to be the children who are... quieter, and... yet sociable, they're

still social because they will come up to him and initiate a "good morning" or a "hi Kevin, how are you doing?" kind of thing..." Peer social skills training is very successful when programmed adequately (Harris & Handleman, 1997). "Normally developing peers are valuable for modelling social skills and language for children with autism" (p. 666).

The mothers in this study indicated that in order to have successful social interactions with peers with autism, the peers without autism need to know and understand these children's limitations, needs, and characteristics in general. The importance of this last point is not usually discussed in the literature adequately (e.g., Harris & Handleman, 1997). It is very beneficial that teachers and mothers educate peers, especially those who are involved with children with autism, and socializing with these children. Mothers A and D said that it is necessary at least, to prepare classmates of children with autism before they start school. Explaining the difficulties and characteristics of children with autism to classmates enhances understanding and acceptance by peers. Mother D explained that at the beginning of each school year, she went to her child's new classroom to demonstrate to her child's classmates, with sensory and visual aids, how his difficulties could hinder or affect his functioning. Classmates have to be aware of these children's difficulties to know why they behave as they do and how they can be helped.

(4) Mothers as Facilitators and Interpreters in Social Interactions

All the mothers in the study said that they played the role of social interpreters and facilitators for their children. They described in detail how they facilitate social interactions between their children and others. For example, Mother A explained:

With children, umm, I'll facilitate or intervene in what ever is happening. So that if they say; "hi Kevin! Look what I brought today to school" and they have a toy or something, and he doesn't really acknowledge them.... I'll be usually beside him, and I'll squat down and I'll acknowledge that child and say interesting things about what ever is that that child has and then I will propose it to him and say "look, isn't this neat? I wonder what it can do?" to kind of engage him in or being aware that this child was talking to him. If the child says "good morning" to him, then I will lean down and say "you say good morning back"...And now he does that more often than not, on his own...

If it is an adult, I usually ask that adults come down to his level or squat down and to make that eye contact or to.... to try, or, I try to bridge the conversation in some way, talk about what is that they are doing or what they are asking of him and put it into

a....simpler language for him to be able to respond and understand...

These mothers seem to be great interpreters for their children, but it is unfortunate that they carried almost total responsibility of facilitating for their children in most social events (i.e., a birthday party) in order to promote social interactions. For example, Mother D said that it seems to be expected that she will accompany her son to events or activities in the community to be his facilitator. It would clearly be very helpful to children with autism if more people in the community and peers could learn to facilitate social interactions for these children. The techniques that these mothers use are not difficult to learn and apply. For example, Mother A used social stories, to explain to her child what to expect in certain specific social situations or changes in routines.

From their own experience with their children and on what has worked or has not worked for them, these mothers had valuable ideas and suggestions about how to help their children develop more social skills and integrate in their community. Their deep and unique perspective about their children's social development, preferences, and experiences is definitely of value when facilitating these children's social interactions and integration. However, only as more people in the community become more willing to learn from them, will integration of these children be more widely attainable.

(5) The Importance of Mainstreaming and Social Skills Training

Although none of the mothers in the study has sent their children to special classrooms so as to compare mainstreamed and special classrooms, all of the mothers gave strong reasons for believing that mainstream education is best for their children. For example, Mother A explained why she believes mainstream is important for her child:

...because there are certain expectations in, in the social world, in the classroom that are different than with his siblings. His siblings are much more accommodating, whereas children in the classroom are not as accommodating. Yes, they recognize that he is different, that he has different needs, but if he doesn't wait for his turn or if he takes a toy from somebody who is allowed to have it, they are going to get upset about it. So, he has to learn to deal with those kinds of things, and to meet those kinds of requirements in a different environment and with people who aren't his family...

All of the mothers mentioned that it had been very positive for their children to attend regular classes due to the opportunities for social interaction. However, all of the mothers indicated that for mainstreaming to be successful for their children with autism the instructional curriculum needs to include social skills training because competent social skills are essential for effective inclusion

of these children. Three of the mothers gave examples of how important social skills training is for their children. For instance, Mother D described how "social stories" are used in her child's school:

Usually, for example, when they wrote the story about his concert at school, they read it to him and then they practiced it many times. Like they would read it and practice walking up to the stage and they would read it again and practice it some more. So it isn't just reading it once and then doing it, it is a long process, they practice it many times and that helps... They have used many social stories at school, they have done them a lot for him...

Teachers, aides, and even classmates can also help with teaching social skills to these children. Classmates can act as "effective tutors" for children with autism. In fact, development of social skills, social inclusion models and programming are at the heart of effective educational settings involving children with autism (Harris & Handleman, 1997).

Children with autism are able to benefit from teaching approaches that build on existing skills and add new skills to their social repertoire (Harris & Handleman, 1997). However, according to these mothers' experiences, integration only seems to be successful under certain conditions. This is consistent with the literature on mainstreaming of children with autism (e.g.,

Knoblock, 1987): when these children are placed in supportive classrooms, and trained and exposed to positive social interactions, many of them accept or even enjoy physical contact and initiations by adults and peers.

(6) The Crucial Goal of Training and Educating the Community about Autism

All of the mothers in this study talked about the importance of training teachers and aides to work with children with autism. It was essential for these mothers to ensure that the teachers who worked with their children had a good background, understanding, and experience working with children with autism. For instance, Mother A said that it was very fortunate for her child to go to a day care that *"had several staff members who were very experienced. He also got (sic) one-to-one aide, who was someone who was just a perfect match for him."* Then, Mother A explained the difference that training and knowledge about autism made on her child's teachers. She explained:

So they (teachers and aide) took part in the five-week seminar course that is offered every year for mothers and workers or teachers of children with autism. And that was the best thing that they could ever have done, because it put the whole disorder in its proper context and all the potential situations and problems that could arise with children with this kind of disorder. And so, they were much more ready to plan a proper curriculum for him ...

All the mothers stressed how important it is for children with autism to go to schools with multiple supports, particularly with knowledgeable clinicians in the area of autism and PDD. Professionals need to be able to effectively assess and develop plans of action for these children as well as to provide support to mothers and teachers. Having knowledgeable clinicians and teachers can make a whole world of difference for these mothers and children. Mother B explained:

Well, the best thing that happened to him was to be able to go to a school where they knew how to treat him and teach him. Last year, we changed him to this new school because in the other old one there were not special services for him. They had a special aide, but they didn't receive support from other therapists and psychologists. Now, in this new school there are many people who work and had worked with children with autism...

Finally, all of the mothers told of their perceptions of a need to educate people in the community as to what autism is, and how these children can be encouraged to interact, and how their social interactions can be facilitated. The mothers said that people need to be helped to become more aware of the basic knowledge that clinicians, mothers, and other professionals have about autism. For example, Mother E stated: *people in the society need to know that children with autism are not stupid, they may be very smart but they can't show it if they*

are not motivated and helped. They need the motivation and they need to focus on the positives..." "Mothers need to (sic) not give up on their children."

Children with autism can become valuable members of society with the support of professionals, mothers, and community. These mothers want to be able to take their children into environments where people are aware of both their limitations and their strengths. The experience of mothers is very valuable in informing the process of integrating children with autism in the schools and community. Inclusion or mainstreaming is successful when all the people involved, including peers, are prepared adequately for it and work actively to promote contact between children with and children without autism considering these children's individual strengths and needs. Additionally, mainstream classrooms were effective where there were appropriate supports and trained professionals available. However, more supports and awareness of people in the community, especially professionals and aides, are needed; these people might play an important role in facilitating social interactions of these children.

Through examining the subthemes of theme III, one sees how the mothers, in the daily interactions of these children, have found specific strategies to help the children develop important communication and social skills such as imitation, modelling, and role-playing. The children acquire all of those skills by the efforts of their mothers and other people involved in the children's lives. For these

mothers, learning strategies and practising them have become a main part of their lives. The strategies that these mothers use with their children, including role-playing games and social stories, help these children practice social skills regularly. For example, mothers described how they motivate their children to become interested in others. These mothers are the main facilitators of communication and socialization between their children and peers or adults. They interpret others' comments in simple language for their children and mediate their social interactions.

Summary

Three main themes emerged from the data collected: I. Mothers' experiences coping with autism and their children's social deficits affect how they first come to view and relate to the children; II. Mothers' perspectives on their children's characteristic ways of relating provide deep insights into these children's social deficits and the context in which those deficits occur; III. Mothers, through their special relationship with the children have learned effective strategies to facilitate the social interactions and integration of their children. The findings clearly demonstrate how the social development of children with autism can be better understood through these children's main caregivers' accounts of their experiences.

Theme I illustrated how the negative formative experiences of the mothers who participated in the study greatly affected the initial mother-child relationship. Such experiences interfered with these mothers' efforts to foster the social development of their children during the early years of their children's lives.

This study went beyond describing these mothers' experiences (i.e., Moreno, 1992) to exploring the effects or impact of those experiences on how these mothers first come to view and relate to their children. The mothers explained how their initial fears, frustration, and anger about their child's lack of responses affected their interactions with their children. These mothers felt very frustrated because not only their children did not respond to them, but also they did not find the answers and help they needed to understand their children's difficulties. The lack of understanding and supports initially led most of the mothers to give up trying to interact with their children because they felt helpless face with a child who appeared "normal" and whom doctors asserted was "normal." Therefore, initially, these mothers had to spend a great part of their energy and time advocating for their children's rights, instead of devoting that time and energy to their children. In fact, the mothers expressed their resentment for having to deal continuously with the bureaucracies of the health and education systems to receive what they needed.

Theme II demonstrated how the mothers' descriptions of their children's characteristic ways of interacting, their patterns of social interactions and social

deficits added important insights to the diagnostic criteria in the DSM-IV. The mothers provided deeper insights on their children's deficits in social interaction within the particular social environments and developmental frameworks in which the problems occur.

The mothers' reports indicated that as they were better able to adapt to their children's ways of interacting and their needs for routines and constant repetitions, their children became more willing to participate in social situations. The children also became more accepting of the assistance of a facilitator or interpreter. It is essential to explore these children's successes in context because only as these children are provided with the social stimulation and help they need, they are able to communicate and interact more successfully.

Theme III illustrated how through the mother-child interactions, these mothers were able to learn and develop effective strategies to help foster their children's social development. Researchers have indicated that children with autism need to be helped to understand and respond to social situations. However, researchers have not explored in detail, through first-hand accounts how mothers connect, persist, and in the end, significantly help their children with autism (Harris & Handleman, 1997).

In the present study, the mothers recounted specific ways in which they have learned to facilitate their children's social interactions and integration into

the community. These mothers tried to use each interaction with their children as a learning experience for their children and for themselves. For instance, the mothers learn to ask their children questions about the social context in which they are interacting in order to help the child notice social cues. They also help their children better understand social interactions by using “social stories” and role-plays. These mothers said that they form strong connections with their children through their daily interactions. In fact, the perceived components of the connections between mothers and their children, which are: perseverance, understanding, hope, love, trust, and acceptance, seem to provide a basis for the success of the strategies learned by the mothers. With the help of professionals these mothers have become a crucial part of their children's intervention programs.

The mothers also emphasized the importance of others (e.g., professionals, teachers, siblings, and peers) in their children's life and intervention programs. The mothers found that it is very positive for their children to attend mainstreamed classes where the children had many opportunities for social interaction. However, for mainstreaming to be successful for their children, the instructional curriculum needs to include social skills training that is essential for effective inclusion of these children. These mothers also strongly stated their views of how important it is to have professionals and teachers, who have

experience or are trained to work with children with autism, available to provide them with the help and support they need. They also emphasized the importance of considering the limitations and individual learning styles of these children to be able to increase and improve the quality of their interactions.

CHAPTER 7

LIMITATIONS AND IMPLICATIONS

This chapter is divided into three sections. The first section outlines the limitations of this study. The second section discusses implications for future research. The third section describes the implications for professionals and for the researcher.

Limitations of the Study

One limitation of the study is that the collected data only reflects the experiences of the five mothers who voluntarily participated in it. The participants were from a selective group of parents. First, all of the participants were mothers, except for one father who was present during his wife's interview to clarify her answers (English was not her first language). This study did not explore fathers' experiences and perspectives. Although gender shapes role and labour divisions and mothers typically continue to be the main caregivers of their children (Trausdottir, 1991), it is important to also study fathers' experiences to gain a more complete picture of the social development of the children and understanding of the families' dynamics. Secondly, all of the mothers in this study had sought help from the beginning of their children's lives. These mothers had a wealth of knowledge about autism because they have been very involved in their children's education and intervention programs. Therefore, the collected accounts represent those of a small and quite selective group of mothers.

Although there is evidence that most mothers of children with autism are often very involved in their children's lives and intervention programs, the present findings cannot be generalized to other mothers of children with autism.

This study focused mainly on the similarities among mothers' reports in order to provide a clear picture of these mothers' experiences with and perspectives on living with autism. There were many salient similarities among the mothers' experiences. Because of my tendency to focus on the similarities during the interviews, I might have failed to notice the opportunities for probing for differences. Although the different nationalities, ethnic backgrounds, resources, and number of children in the family were described briefly, due to the small sample of participants, no inferences could be made based on these differences. The effect of these demographic characteristics on the mothers' interactions with their children could not have been determined nor was it attempted.

Another limitation of this study was not having a second person to read, code, and evaluate the transcripts. An independent evaluator or reader could have read all the transcripts to help identify categories and themes in an unbiased manner. The identification of similar themes by the second reader would have helped strengthened these findings and allowed comparison between readers. Another evaluator may have found additional themes or could have broadened and/or deepened the scope of the identified themes.

Because the study was based on personal, face-to-face interviews, there are other possible limitations. Besides the interviewer's own attitudes, the interviewer's characteristics (e.g., sex, age, and profession), and reactions to the individual participants may have biased some of the answers (Judd, Smith, & Kidder, 1991). Social desirability is a part of being human and it may have coloured some of the mothers' accounts.

Implications for Future Research

There are several ways in which future qualitative research on the reported experiences of mothers of children with autism could be conducted so as to yield more insights into the social development of children with autism. These ways include the following: 1) future researchers could interview a larger and more representative sample of mothers of children with autism; 2) longitudinal studies, that is interviewing the mothers at different stages of their children development, could add new insights into these children's deficits in social interactions; 3) independent evaluators of the transcript as well as independent interviewers could have further validate future findings; 4) in addition to interviewing mothers, other people in daily contact with children with autism in order to obtain a fuller picture of these children's social development. Fathers' experiences and perceptions must also be studied in order to have a more complete understanding of parents' experiences and how those experiences affect the parent-child relationships. If possible, the experiences of siblings of children with autism should also be

explored; and 5) as was mentioned earlier, the key to successful interventions for children with autism is a strong and positive mother-professional partnership. Future qualitative studies need to focus more specifically on both mothers' and professionals' ideas on how to facilitate positive partnerships to improve the social adaptation and integration of these children.

Implications for Professionals and for the Researcher

The findings of this study have several implications for professionals in how to work with and help children with autism and their families. The success of intervention programs not only depends on the progress of the child, but also on the family's adaptation and involvement (Schopler, 1995). Therefore, as this study has illustrated, a better understanding of these mothers' experiences and perspectives is a critical component for planning and successfully carrying out interventions, as well as for more fully involving these children and their families in the community. This study identified the areas in which services for these children and their families could be improved. In order for these children to receive adequate supports in their social environments, their mothers need professionals who better support them with both their children's social difficulties and their coping process. They need to receive concrete information about what they might expect given their children's difficulties, as well as receive constant support, training, advice, and encouragement from professionals who appreciate and consider their experiences. Therefore, doctors and other professionals,

according to the mothers' perceptions, need to be better trained to diagnose these children as early as possible, and to help these mothers find the resources and assistance they need as earlier as possible.

In particular, these findings have specific implications for school psychologists given our unique role in bringing the family, school, and community together. It is essential for school psychologists to focus on comprehensive and ecological assessments of children with autism and their families in order to understand and provide the children and the mothers with comprehensive assistance, intervention, and support. School psychologists should also try to be directly involved with the mothers in order to be able to mentor and better support them in dealing with their children's social deficits and interventions.

Due to the importance of parent-professional collaboration in building potential skills and competencies for both child and family, it is important for school psychologists to facilitate this collaboration. All of the mothers who wish to participate in their children's interventions need to be helped to do so by providing them with the training, information, and support they need. School psychologists, where desired, should promote these partnerships; but it should not be expected that all mothers are going to be willing to enter into partnerships with professionals involving the interventions. School psychologists can facilitate successful partnerships between mothers and professionals, by mediating between

them and transmitting the mothers' views, input, and assistance. It is important for school psychologists to help other professionals to be willing to enter these partnerships with equal commitment and acceptance of these mothers as equal partners in their children's intervention programs. School psychologists can be of great help by educating teachers and aides about autism during their professional developmental training. It is also important to inform educators and other professionals of strategies for building rapport with these mothers, and (if needed) mediate between educators and mothers, and between other professionals and educators during team meetings and joint work. Furthermore, school psychologists can help mothers navigate through the advocacy system in integrated school options.

For me, a new researcher, the value in pursuing this qualitative study has been learning through active listening from the rich, experiences of mothers of children with autism. Through this study, I was able to see how these children's social deficits can be better understood when studied in context. The context of the family and its interactions is a basis for the children's social development. I was inspired by the participating mothers' responses and came to see beyond the diagnostic or clinical descriptions of these children's deficits. The mothers' experiences with their children, and how they contend with their social difficulties has helped me to see how for these mothers as well as for their children this is an ongoing process of learning, caring, understanding, accepting, and trusting. I

aspire to understand better these families' needs and their children's social challenges in order to facilitate successfully their children's socialization and integration. I hope to apply this important lesson of seeking for a more complete picture of children's difficulties.

CHAPTER 8

CONCLUSION

Autism remains, in many ways, a puzzling disorder. Although many of the deficits in the social interactions of children with autism have been documented in the clinical literature, they have generally not been explored qualitatively and in context, within the children's natural or real-life social environments. This study represents a step towards gaining a better understanding of the social development of children with autism through the qualitative investigation of the reported experiences of mothers of children with autism. This understanding, which is critical to working effectively with these children and their families, is not provided by quantitative studies, and yet has many implications for interventions.

In focusing on richness of detail, this study, and those which follow it can deepen the findings of previous studies and parental self-accounts. Mothers can be excellent guides for the rest of the community. Professionals can also learn a great deal from these mothers' experiences and perspectives in order to better facilitate these children and these families integration and involvement in the community. In order to respond to the common needs of children with autism and their mothers, it is important to explore the commonalities in the mothers' experiences. Yet, one should not forget that each family and person is unique, and each child has individual needs necessitating an individualized service plan.

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Appendix A

Information Letter to Participants

Dear Parent or Guardian:

I, Paola Caponetto, will be conducting a research study to fulfil the requirements of my Masters' of Education degree with specialization in School Psychology, from the University of Manitoba. The study will focus on the experiences and views of parents who have children with autism. The purpose of this study is to gain an understanding of parents' perspectives on their child's socialization. Socialization, in this study, is viewed as a complex process of interaction between the child and others in the child's social environment. This complex process of interaction affects both the child and those in interaction with the child. Therefore, I am inviting you to be a participant in this study.

The study will focus on your reports of your experiences living and interacting with your child. I will ask you about daily social interactions between you and your child, and in particular, how your child interacts with and responds to you. In this study, your views on how your child interacts with other people and how others interact with him/her, as well as the role (if any) you play in those interactions, will also be addressed.

With this purpose in mind, I would like to conduct an in-depth interview with you, and, if needed, a short second interview for purposes of clarification of

your responses and my initial interpretations. The interviews will be tape-recorded and transcribed verbatim. I anticipate that the first in-depth interview will take approximately one hour and thirty minutes, and the second follow-up interview will take approximately thirty minutes. Therefore, the total time required for your participation will be two hours. The interviews will be conducted at a time and place that is most convenient for you. You may with no penalty, decline to answer any question, end the interview, or withdraw from the study at any time. Please consider that, at times, talking about your personal experiences may cause some unanticipated feelings of sadness or embarrassment, which you may want to talk about with someone. Therefore, as an experienced consultant providing direct supports and facilitating services for children with PDD (Pervasive Developmental Disorder) and their families, I will be available immediately after the interview to address any concerns you might have as a result of the interview or an interview question.

To ensure your and your child's privacy and confidentiality, I will not use your real names or any other identifying personal information. I will substitute real names with pseudonyms throughout my data collection, analysis, and thesis. Nobody, other than myself, will have access to the recorded audiotapes, which I will transcribe, then erase or dispose of them. The anonymous transcripts will be

analyzed by myself, and apart from myself, only my advisor and two members of my thesis committee will have access to these transcripts.

Please indicate on the next page, or contact me personally by telephone or by mail, if you would like to receive a summary of the study's major findings. At your request, I will send you a summary of the study's major findings after the study is completed. You may also read a copy of the interview transcript by contacting me or requesting to do so after your participation. If you wish to obtain additional information or to discuss this matter further with my thesis advisor you may contact my advisor, Dr. Riva Bartell. Thank you very much for your collaboration; please do not hesitate to contact me if you have any questions, or to request a summary of the study's main findings, if you do not indicate your request below in the consent form.

Dr. Riva Bartell can be reached at the Faculty of Education, University of Manitoba, Winnipeg, MB, R3T 2N2; Tel: (204) 474-9048.

Paola Caponetto can be reached in Toronto or Winnipeg.

In Toronto, I can be reached by mail at 1205-6 Assiniboine Road, Toronto, ON, M3J 1L3, Tel: (416) 650-4375. In Winnipeg, I can be reached by mail at 503-1650 Pembina Hwy. Winnipeg, MB, R3T 1G2; Tel: (204) 275-1510.

Consent Form

I, (Last name & First name) , agree to participate in this study on children with autism and their socialization and consent to be interviewed by Paola Caponetto. I agree to have the interview tape-recorded and transcribed verbatim to be utilized for her Masters' of Education thesis. I have read the attached information sheet with this letter of consent, and I understand that I will participate in an in-depth interview, and that a second follow up interview may be required. Therefore, I understand that the first in-depth interview will take approximately one hour and thirty minutes and that a second thirty-minute interview may be required for clarification of some of my responses or the researcher's initial interpretations.

I understand that my child's anonymity and my anonymity will be ensured and that the audiotapes will be erased or disposed of after they have been transcribed. I also understand that I can with no penalty, decline to answer any question, end the interview, or withdraw from the study at any time should I feel it necessary.

I am aware that immediately following the interview, the interviewer will be available in the event that I have any questions or concerns as a result of the interview. I am also aware that I can request a copy of the study's major findings by indicating my request in this letter, or by personally contacting the researcher

by mail or telephone. I also understand that I may ask the researcher to review the interview transcript right after the interview has been transcribed.

--

Participant's Signature in ink

Date

I request a copy of the study's major findings: (Yes or No)

Researcher's Signature in ink (Paola Caponetto)

Date

Department of Educational Administration,

Foundations, and Psychology

University of Manitoba, Winnipeg, MB

Carta de informacion para Parents (Spanish Version)

Carta de Permiso para los Participantes

Querido padre o guardian legal:

Yo, Paola Caponetto, voy a conducir un estudio para completar los requerimientos de Masters en Educacion degree especializandome en Psicologia de Escuela, en la Universidad de Manitoba. El estudio va a ser acerca de las experiencias y los puntos de vista de padres que tienen niños con autismo. El objetivo de este estudio es obtener un resumen de las perspectivas de padres acerca de la socializacion de sus hijos. Socialización, en este estudio, es definida como un complejo proceso de interaccion entre el niño y otras personas en su medio social. El complejo proceso de interacción o socialización afecta a ambos el niño y los que se relacionan con él o ella. Por eso, yo quiero invitar a usted a participar de este estudio.

El estudio focalizará en los reportes de sus experiencias viviendo y relacionandose con su niño o niña. Le preguntaré acerca de sus vivencias sociales cotidianas con su niño(a), y en particular, como el o ella interactua y reponde a usted. En este estudio, sus opiniones en como su niño(a) se relaciona o interactua con otras personas y como otras personas se relacionan con él o ella van a ser explorados, tambien le preguntaré acerca de el lugar que usted juega (si alguno) en las relaciones de su hijo(a) con otras personas.

Con esta propuesta en mente, yo quisiera entrevistar en detalle a usted, y si es posible y necesario una segunda entrevista puede ser necesaria para aclarar sus respuestas y mis primeras interpretaciones. Las entrevistas van a ser grabadas por audio y van a ser transcritas palabra por palabra verbalmente. En el caso que la entrevista es conducida en español, la traduciré a la entrevista en inglés lo mejor posible.

Yo anticipo que la primera "in-depth" entrevista va a durar aproximadamente una hora y treinta minutos, y la segunda entrevista (si necesaria) durara aproximadamente treinta minutos. Por eso en total dos horas sera necesario. El lugar y la fecha mas conveniente para usted las que las entrevistas seran conducidas. Usted puede sin ninguna penalidad, reusar contestar una pregunta, terminar la entrevista, o decidir no participar del estudio en cualquier momento.

Por favor considere o tenga en cuenta que, a veces, hablar acerca de nuestras experiencias personales puede causar algunos sentimientos inesperados, como de tristeza o timidez, sobre los cuales usted puede decidir hablar con alguien. Por esa razon, como una experienciada consultora o facilitadora que he trabajado con niños con "Pervasive Developmental Disorders" y sus familias, yo me ofresco a estar a su disposición inmediatamente despues de la entrevista para

hablar de cualquier sentimiento o preocupación que usted pueda tener como resultado de la entrevista o de alguna pregunta.

Para asegurar la privacidad y confidencialidad de su niño(a) y de usted, yo no usare sus nombres reales o ninguna otra información personal que pueda identificarlos. Yo substituiré sus nombres reales con pseudónimos en toda mi colección de información, analisis, y tesis. Solo yo voy a tener acceso a las gravaciones, las cuales seran transcriptas y despues borradas o destruidas. Las transcripciones anónimas seran analisada solo por mi y con excepción de mi, solo mi supervisora y dos miembros de mi comité de thesis tendran acceso a ellas.

Por favor indique abajo, o comuniquese conmigo, en persona, por telefono, o correo si usted quiere recibir una copia de el resumen de los resultados de este estudio. Si usted lo recuesta, yo le enviare el resumen de los resultados despues que haya completado el estudio.

Si usted desea recibir mas información o discutir esto con mi supervisora, por favor contacte a la Dr. Riva Bartell. Desde ya le quiero agradecer su colaboración, por favor no deje de contactarme si usted tiene cualquier pregunta o para pedirme el resumen de los resultados si no indico su deseo en esta carta.

La Dr. Riva Bartell puede ser contactada en la Facultad de Educacion, University of Manitoba, Winnipeg, Manitoba, R3T 2N2; No de Telefono: (204) 474-9048. Paola Caponetto puede ser contactada en Toronto o Winnipeg.

En Toronto, puede encontrarme por correo a 1205-6 Assiniboine Road, Toronto, Ontario, M3J 1L3; o por telefono al (416) 650-4375.

En Winnipeg, puede encontrarme por correo a 503-1650 Pembina Hwy, Winnipeg, MB., R3T 1G2; o por telefono al (204) 275-1510.

Permiso

Yo, primer nombre y apellido _____, acepto participar en este estudio en niños con autismo y su socialización y dejo ser entrevistada por Paola Caponetto. Yo acepto que la entrevista va a ser grabada con un grabador y que sera traducida en ingles y transcripta para ser utilizada en el su Masters of Education thesis. Yo he leído toda la información que esta incluida aqui y entiendo que voy a participar de una in-depth entrevista y que una segunda corta entrevista puede ser requerida. Entonces, yo entiendo que la primera entrevista va a durar una hora y treinta minutos y que la segunda entrevista durara unos treinta minutos aproximadamente con el proposito de aclarar algunas de mis respuestas o las interpretaciones iniciales.

Yo entiendo que la anonimidad de mi hijo(a) y mi propia anonimidad sera asegurada y que las grabaciones seran borradas o destruidas despues de ser transcritas. Yo tambien entiendo que puedo sin ninguna penalidad, reusar a responder a cualquier preguntat, terminar la entrevista, o dejar de participar en el estudio en cualquier momento si yo creo que es necesario.

Yo se que imediatamnete despues de la entrevista, la investigadora va a estar dispuesta si en algún caso yo tengo alguna pregunta o preocupación como resultado de la entrevista. Yo tambien se que puedo pedir una copia de el resumen de los resultados si lo indico en esta carta o si me comunico con la investigadora

personalmente o por telefono. Yo tambien entiendo que puedo pedirle a la investigadora leer o revisar la copia de la trancripcion de la entrevista cuando esta a sido completada.

Firma en tinta de el participante

Fecha

Quisiera una copia de el resumen de los mayores resultados: (Si o No)

Firma de la investigadora (Paola Caponetto)

Fecha

Departmento of Educacion Administracion,

Foundaciones, y Psycologia,

Universidad de Manitoba

Winnipeg, Manitoba

(Una copia para el participante y otra copia para la investigadora.)

Appendix B

Interview Guide

*** Questions were adjusted according to the individual. Some questions may not be required or may not apply to the individual's situation.**

- 1) Tell me a little bit about what it is like to live with your child (name of child)?**
- 2) Please describe how parenting (name of child) has been for you?**
- 3) Difficulties with social interaction are a prime deficit in autism, is this true of your child? How and when did you start to notice delays or difficulties in your child's social interactions? What were they?**
- 4) How did your child respond to you as an infant? For example, what did he/she do when you tried to hold or cuddle him/her, what about when you smiled at him/her?**
- 5) How does your child respond to you now? Does he/she look at you when you talk to him/her? How does he or she communicate with you and with others?**
- 6) How does (name of child) interact with you now? Please describe some of your social interactions with your child? Is there any difference in how your child interacts with other familiar adults (teacher, aid, grandpa or grandma)?**
- 7) What does (name of child) do when you hug or kiss him/her? Does he/she seek physical contact and comfort with you: how? when?**

- 8) Does (name of child) initiate interactions with you? What kinds of interaction and when? How do you respond to these initiations? Can you give me some examples?
- 9) Does your child seem concerned when you are distressed or upset?
- 10) How does (name of child) interact with his/her siblings?
- 11) How do your other children interact with (name of child) as a sibling?
- 12) Does (name of child) involve himself/herself in social games with siblings?
Please describe how?
- 13) Generally, how does your child respond to or interact with his/her peers in school? Does (name of child) have "special peers" he/she prefers? How does he/she show his/her preference?
- 14) Do you sometimes facilitate interactions between your child and other children or other adults? How?
- 15) Does your child seem to understand how others are feeling? How does he/she show his/her understanding?
- 16) What, if any, interventions and supports have helped your child to become more socially inclined? What are they in the home, classroom, peer-group, and community?

- 17) Over the years have you noticed any strategies that help your child with his or her social interactions? What supports and help have you received to facilitate your child's social development?
- 18) What elements are important to keep in mind when interacting with your child? What would you advise other people to do to involve your child more in social interactions?
- 19) Is there anything else that you would like to add or discuss?

Guia de la Entrevista

*** Preguntas sera modificada de acuerdo con la situacion del participante. No todas las preguntas seran hechas si no son necesarias.**

- 1) Cuente un poco como es para usted vivir con su niño (nombre del niño).**
- 2) Por favor describa como es para usted ser el padre de su hijo(a)?**
- 3) Dificultades con interacciones sociales son unos de los mas identificados problemas con el autismo, es esto cierto o verdad de su hijo(a)? Como y cuando usted empezo a notar retrasos o dificultades con la forma de socializarse de el o ella? Cuales eran esas dificultades?**
- 4) Como respondia su hijo(a) a usted cuando el era un bebe o infante? Por ejemplo, que hacia el/ella cuando usted trataba de alzarlo, abrazarlo y que hacia cuando usted trataba de besarlo o acariciarlo/a?**
- 5) Como responde el/ella a usted ahora? El/ella mira cuando usted le habla? Como se comunica el/ella con usted y con otras personas?**
- 6) Como se relaciona el/ella a usted ahora? Por favor describa sus relaciones sociales con su niño(a)? Hay alguna diferencia en como el/ella se relaciona con otras personas y como se relaciona con usted (otras personas como la maestra, asistente, abuela, o abuelo)?**
- 7) Que hace cuando usted trata de besarlo/a o abrazarlo/a? El/ella trata de acercarse fisicamente a usted? El/ella busca calidez en usted?**

- 8) **El/ella trata de iniciar relaciones o interacciones con usted? Que clase de interacciones? Como responde usted a esas iniciaciones? Puede darme algunos ejemplos?**
- 9) **El/o ella se dan cuenta cuando usted esta enojado/a o angustiada/o?**
- 10) **Como se relaciona con sus hermanas o hermanos?**
- 11) **Y como responden los hermanos y hermanas a el/ella?**
- 12) **Su hijo o hija interviene con sus hermanos en juegos sociales? Por, favor describa como?**
- 13) **Generealmente, como responde su hijo/a con otros ninios de su edad en la escuela? Tiene algunos companieros preferidos? Muestra el especial interes y cuales son sus preferencias?**
- 14) **Usted aveces facilita interacciones entre su hijo/a y otra persona, ninios o adultos? Como?**
- 15) **Le parece que su hijo/a sabe interpretar emociones de otros? Como demuestra su entendimiet?**
- 16) **Que intevecciones, si alguna sirvio para que su hijo/a se incline mas socialmente? Cuele son en la casa, escuela, en grupos, y en la comunidad?**
- 17) **Con el tiempo noto usted algunas intervenciones o cosas que sirvan mas que otros? Que estrategias le sirvieron mas y porque?**

- 18) Que elementos son mas importantes para cuando otros quieren relacionarse con el o ella? Que consejo le daria a la gente para poder relacionarse mejor con el/ella?
- 19) Hay algo mas que quiciera aunmentar o decir?

Appendix C

Letter for Recruiting Agencies
503-1650 Pembina Hwy.
Winnipeg, MB R3T 2G3
Tel: (204) 275-1510
E-mail: pvalentie@usa.net

Or

1205-6 Assiniboine Rd.
Toronto, ON M3J 1L3
Tel: (416) 650-4375

Autism Society of Manitoba

Dear (name of secretary):

As I discussed with you previously, I would appreciate your help in recruiting parents to participate in my study. I will be conducting a research study on the socialization of children with autism to fulfil the requirements of my Masters' of Education from the University of Manitoba. Therefore, I need to recruit 5 parents of children with autism to conduct informal in-depth interviews about the socialization and social interactions of their children. The children need to be between the ages of 6 and 12, diagnosed with autism for more than three years, and have attended mainstream schools for over one year.

As you suggested, please let parents know about my study and how to contact me, or, to ask if I can contact them as soon as possible. I would also appreciate if you post a recruitment advertisement in your newsletter and in a readily visible place in your office. The advertisement includes a non-technical description and purpose of the study, as well as the requirements for participation in the study.

Find enclosed two copies of the advertisements. I will contact you in a couple of days to see if you need anything else. Please do not hesitate to contact me by telephone or e-mail if you have any questions.

Yours truly,

Paola Caponetto

Advertisement to Recruit Participants

To: Autism Society of Manitoba and/or Autism Society Ontario

Re: Masters' Thesis

Children with Autism and their Socialization from the Perspectives and Experiences of Mothers

Dear Parents:

I, Paola Caponetto, will be conducting a research study on the socialization of children with autism to fulfil the requirements of my Masters' of Education from the University of Manitoba. Therefore, I need to recruit 5 parents of children with autism to participate in my study.

Participants are required to have children aged 6 to 12, who have been diagnosed with autism for more than three years, and have been attending mainstream schools for more than one year. Participants can be single, married, or divorced; one or both parents of a child can participate in the study.

The study will focus on the reports of parents regarding their experiences of daily living and social interaction with their children. The purpose of the study is to gain an understanding of parents' views and perceptions of the socialization and social interactions of their children, based on their own parent-child interactions. Therefore, I will be conducting informal in-depth interviews with each parent which will be transcribed verbatim for future analysis.

After the participants are fully informed about the study, they will be asked to sign a letter of consent to participate in an individual interview and if needed, a second follow-up interview. The first interview will take approximately one hour and thirty minutes, and the second follow-up interview will take thirty minutes. The place and time for conducting the interviews will be arranged with each participant.

The participants will be informed about the kind of information they will be asked to share in the interview. Participants' anonymity will be ensured, and they can decline to answer any question, end the interview, or withdraw from the study at any time with no penalty. Participants also have the right to request and obtain a summary of the major findings of the study after the study is completed. Therefore, at the end of this study, I will send a summary of the major findings to the participants who request it.

Please if you are interested in participating in this study do not hesitate to contact me at your earliest convenience. I really appreciate your consideration and collaboration. I, Paola Caponetto, can be reached by telephone or e-mail. (Toronto Tel:(416) 650-4375 or Winnipeg Tel: (204) 275-1510), E-mail: pvalentie@usa.net

Yours truly,

Paola Caponetto