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Parent involvement in the assessment and diagnosis of autism

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Ryerson University

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**PARENT INVOLVEMENT IN THE ASSESSMENT AND DIAGNOSIS OF
AUTISM**

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by

Deborah Saunders

Bachelor of Science McMaster University, 2005

A Major Research Paper

Presented to Ryerson University

in partial fulfillment for the degree of

Master of Arts

in the Program of

Early Childhood Studies

Toronto, Ontario, Canada, 2009

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PARENT INVOLVEMENT IN THE ASSESSMENT AND DIAGNOSIS OF AUTISM

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Master of Arts
Early Childhood Studies
Ryerson University

Abstract

Currently, parents of children with autism are dissatisfied with their experience of the assessment and diagnostic process. This study examined the experiences of parents and families surrounding the assessment and diagnosis of their child. It also explored ways of how parents would like to be involved in the assessment process. A feminist approach governs this investigation, and thematic analysis methodology is used to analyze participants' responses. Semi-structured interviews were conducted with four mothers. The sample was drawn from three different organizations serving children with autism. Six categories emerged and were compiled into three broad themes: (1) delays in obtaining a diagnosis, (2) involvement in the process, and (3) recommendations and support. The implications of this study suggest that parents would like to be more involved and more informed throughout the process of assessment and diagnosis.

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CHAPTER 1

INTRODUCTION

1.1 Definition of autism

Kanner (1943) described autism as: “a pathognomic, fundamental disorder in children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life” (p. 242). His introductory studies have contributed to what we now understand about the disorder, and created a strong core for research conducted over the last 60 years. Since then, researchers have built on Kanner’s definition of autism and the disorder is now defined as a syndrome involving the disturbance of social relatedness, communication, language, and modulation of sensory inputs (Schopler, 1994, as cited in Jacobson & Mulick, 2002).

According to the DSM-IV-TR (American Psychological Association, 2000) and the ICD-10 (World Health Organization, 1993), autism is a developmental disorder which is often detected before three years of age. Although early intervention and specialized treatment lead to a better prognosis (Pérez, González, Comí, & Nieto 2007), autism is a lifelong disorder. It is part of a spectrum of related disorders called Autism Spectrum Disorders (ASDs), and thus is considered a dimension rather than a distinct category (McConachie & Diggle, 2006). The spectrum includes disorders such as Rett’s Disorder, Asperger’s Syndrome, and PDD-NOS (pervasive developmental disorder-not otherwise specified). Individuals with autism exhibit difficulty in three key areas: social interaction, restricted or repetitive behaviours, and communication.

Our increasing knowledge about the characteristics of autism and the ASDs has enabled parents, health professionals, and teachers to better detect the signs of these

disorders (McConachie & Diggle, 2006). As a result of our growing knowledge the rates of diagnosis are also increasing. According to Autism Society Canada (2005), the current prevalence rate of autism is estimated to be one in every 165 children. Despite the advances in etiology, neuroscience, genetics, assessment, and diagnosis, researchers are still trying to solve the pieces to this puzzle.

1.2 Statement of the problem

Assessment and diagnosis play a pivotal role in determining the future of children and their families (Bagnato, Neisworth, & Muson, 1997). At present, parents of children with autism are dissatisfied with their experiences of the assessment and diagnosis of their child (Goin-Kochel, Macintosh, & Myers, 2006; Moore, McConkey, Sines, & Cassidy, 1999; Silkos & Kerns, 2007). This is evident in the high percentages of parents across nations who are dissatisfied. Goin-Kochel et al. (2006) conducted an international study with parents of children with an ASD, and included participants from the United States, Canada, England/Ireland, and Australia/New Zealand. They found that approximately 40% of parents were not satisfied with their diagnostic experience, 35% were moderately satisfied, and only 24% were extremely satisfied. The National Autistic Society also reported on issues of diagnosis and found that 43% of parents were dissatisfied with their diagnostic experience, and of this number 22% were very dissatisfied (NAS, 1999).

Sources of dissatisfaction

One source of dissatisfaction stems from how a child's disability is first communicated. Disclosure is the first communication about a child's disability to parents. According to Hansat and Graves (2000), this initial communication is critical for families

and can determine parents' level of satisfaction. The way that a child's disability is first communicated can affect parents' adaptation to the disorder (Sloper & Tuner, 1993) and can influence how parents interact with the child and treat the child (Hansat & Graves, 2000). Studies have shown high levels of parental dissatisfaction with the services that parents receive from professionals at the time of their child's diagnosis (Sloper & Tuner, 1993). Quine and Rutter, 1994 (as cited in Baker, 2004) found that 58% of parents reported dissatisfaction with the communication of their child's disability. Quine and Rutter's study indicates dissatisfaction with delays in receiving information, accessing information, and the context in which the information was given. It has been reported that how parents experience the initial diagnostic assessment can influence the ongoing relationship that develops between parents and professionals (Baker, 2004).

Another source of dissatisfaction comes from the hardships that parents experience in obtaining a diagnosis for their child (Goin-Kochel et al., 2006; Silkos & Kerns, 2007). Some of these hardships are due to the delays in the assessment process (Silkos & Kerns, 2007). It has been reported that there are gaps between the age of a child when parents' first show concern, the age of the first assessment, and the age of the final diagnosis (Robins, Fein, Barton, & Green, 2001). Siegel, Pliner, Eschler, and Elliot (1988) reported that parents expressed their initial concerns to paediatricians and sought a diagnostic evaluation when their child was 2.5 years old, but did not receive an official diagnosis until age 4.5. In another study, by Howlin and Moore (1997), it was found that 63% of 1200 families obtained a diagnosis for their child after the third visit with a professional. The National Autistic Society (1999) concluded that more than 40% of parents had to wait over 3 years for a diagnosis, 15% had to wait 5-9 years, and 10% had

to wait more than 10 years for a diagnosis. In this study, the mean average time to receive a diagnosis was approximately 2.5 years. The results of these studies show that parental satisfaction can be related to the age at which a child receives a final diagnosis. Another reason for delays may be due to the reluctance of making a diagnosis at an early age before seeing if a child would typically develop (Baranek, 1999). This reluctance can be related to the fact that the early predictors of autism are negative symptoms—failure of normal behavioural systems to mature—rather than positive symptoms that can develop later (Robins et al., 2001). Additionally, early autism diagnosis is limited by the lack of early screening instruments (Bryson, Rogers, & Fombonne, 2003).

Early diagnosis is crucial since it leads to earlier treatment and intervention, which in turn leads to better long term results for the family and the child. Studies have shown that intervention before age 3^{1/2} is more effective than if a child begins after age 5 (Wetherby et al., 2004). Furthermore, children with autism or PDD who develop language and symbolic play before the age of 5 have better outcomes the earlier they begin intervention (Robins, Fein, Barton & Green, 2001).

Still another source of dissatisfaction comes from the number of professionals that parents visit to obtain a diagnosis (Goin-Kochel et al., 2006). Goin-Kochel and colleagues found that parents whose child received a diagnosis at an early age and visited fewer clinicians, were more satisfied than parents who visited a number of clinicians and received a diagnosis at a later age. It was also reported that the reason parents viewed their diagnostic experience as negative was that more doctor visits meant more hassle, additional costs, and a longer wait before receiving an official diagnosis. Visits to multiple professionals can lead to vague diagnoses.

In addition to these hardships, parents are often given unclear diagnoses such as “autistic tendencies” or “atypical autism” which lead to frustration and further dissatisfaction (Silkos & Kerns, 2007, p. 10). It is clear from the literature that parents experience difficulty in obtaining an autism diagnosis. Based on these findings, there is reason to believe that parental involvement during assessment and diagnosis can alleviate some of these hardships and improve satisfaction. Parental inputs such as allowing parents to offer feedback to clinicians or interpret their child’s behaviours may lead to a more solid diagnosis upon the initial visit rather than a vague diagnosis after multiple visits.

With this context in mind, the purpose of the current study was to explore parents’ and families’ experiences of the assessment and diagnostic process. The study also aimed to research ways of how parents would like to be involved in this period of evaluation. The premise of this study relied on a feminist approach to research. A qualitative approach was used to investigate parents’ experiences, and semi-structured interviews were used to elicit this information. A thematic analysis methodology was also used throughout to analyze participants’ responses.

1.3 Definitions

Assessment: The formal evaluation of a child to achieve an official diagnosis.

Involvement: Refers to active participation from the parent in the assessment and diagnostic stages. That is to say, involvement through play interaction with the child, interpretation of the child’s verbal and non-verbal behaviours, simple observation with the practitioner(s), or observing and offering feedback to the other team members.

Parent: Refers to an individual, who is the primary caregiver or sole provider for the child, this includes the mother, father, grandparent, or foster parent.

CHAPTER 2

LITERATURE REVIEW

2.1 Purpose of assessment and diagnosis

Siegel (1996) concludes that there are two purposes for a diagnosis. The first and most important is that a diagnosis leads to a label. It means that what is wrong is a recognizable problem and can be treated. Labels may appear like a step back in terms of moving away from systems that label children. However, when considering the ASDs in particular, it is best to have a label because of the provision of services that follow (Wall, 2004). The second purpose is that a label or diagnosis gives individuals access to services. Having a label is often the determining factor in receiving these services; hence, diagnosis leading to a label is essential. In Ontario for example, families are not able to apply for or receive publicly funded treatment or supports for their child until they receive a diagnosis of autism or an ASD (Autism Society Canada, 2005). According to Lord (2007), the main purpose of a diagnosis is to get families into intervention programs.

Despite the recent research in neuroscience that aims to identify genetic characteristics in individuals with autism, to date, there are no known biological manifestations. Thus, autism diagnosis relies heavily on the interpretations and clinical judgement of professionals (Lord, 2007). For this reason, the diagnosis of autism is subjective, and so there is room for other interpretations, such as those of parents and family members. Parent interpretations of their child, for example explaining how behaviours with a clinician differ from the behaviours displayed at home, may provide more information for the clinician to draw conclusions from and make a solid diagnosis.

Since the diagnosis of autism is determined not only by the presence of abnormal behaviour, but also by the absence (or limited presence) of normal behaviour, parent interpretations can have significant effects on diagnostic judgment (Lord, 2007).

Assessments may be conducted for a variety of reasons. The four most common reasons according to Perry, Condillac, and Freeman (2002), are as follows:

1. To help understand the individual. Clinically it provides useful information about the person that will help in selecting appropriate interventions.
2. To obtain or clarify an initial diagnosis.
3. To document diagnostic status necessary for access to services or funding.
4. To obtain information for program evaluation or research purposes (p.61-63).

Autism assessment should follow “best practice” procedures (p. 63). These are specific measures used throughout the assessment that carefully relate to the most recent literature and should be consistent with relevant legislation, regulations, standards, ethics, agency policies, and other relevant guidelines such as those set out by the CPO (College of Psychologists of Ontario) (Perry et al., 2002).

2.2 Traditional diagnosis and assessment

Autism assessment generally makes use of standard measures such as the Checklist for Autism in Infants and Toddlers (CHAT), the Screening Tool for Autism in Two-Year-Old (STAT), the Autism Diagnostic Interview Revised (ADI-R), and the Childhood Autism Rating Scale (CARS). The CHAT (Baron-Cohen, Allen, & Gillberg, 1992) is the most well known screening tool for young children suspected to have autism (Kabot et al., 2003). The CHAT is used to identify the early signs of autism by assessing a child’s attainment of developmental milestones (Robins et al., 2001). If the CHAT suggests that a child has autism, an in-depth assessment is recommended. If the CHAT does not suggest autism, further evaluations are recommended (Kabot et al., 2003). The

CHAT may incorrectly identify some children or miss those whose symptoms are mild, but, it is considered to be the best available screening tool (Kabot et al., 2003).

The STAT (Stone & Ousley, 1997) is designed for use by professionals involved in early identification and intervention (Kabot et al., 2003). The STAT is an interactive measure that was developed as a “second-stage screening instrument to differentiate children with autism from children with other developmental disorders” (p. 29).

The ADI-R (Lord, Rutter, & LeCouteur, 1994) is tied to current diagnostic criteria (Kabot et al., 2003). The ADI-R may be the most useful tool as part of a more in-depth assessment of children suspected to have autism (Kabot et al., 2003).

The CARS (Schopler, Reichler, DeVellis, & Daly, 1980) is the most widely used standardized instrument to aid in autism diagnosis (Kabot et al., 2003). The CARS is easy to administer and can be used in a variety of settings (Kabot et al., 2003). This tool includes a severity rating, which is used to periodically monitor children with autism and assess long term outcomes (Kabot et al., 2003).

The above instruments are designed to be used by practitioners. Of these tools, the CHAT and the CARS are the only ones used by both practitioner and parents together. With the CHAT, parents are involved by answering a few binary questions. The first section of the CHAT is completed by the parent, while the latter section is completed by the practitioner. Whereas parents are required to answer yes/no questions about their child, the practitioner is responsible for setting up simple pretend play situations and observing, noting, and commenting on the child's behaviours (Wall, 2004). The CARS on the other hand was designed to be used by a professional, but can be administered by a parent or an early childhood educator. The CARS involves a behaviour rating scale in a

questionnaire format, along with parent reports and direct observation from a professional.

2.3 Issues faced by parents and families of children with autism

In addition to the lack of involvement and the delays in obtaining a diagnosis, parents and families experience other difficulties surrounding their child. Families from different cultures can be faced with stress during the initial stages of diagnosis due to conflicting views between parents and professionals (Wall, 2004). It has been reported that there are discrepancies and uncertainties between professionals and families who are from different cultures, regarding the etiology of autism and the effectiveness of interventions (Prelock et al., 2003). Discrepancies can also stem from different views about assessment and diagnosis, differences in how one interprets atypical behaviour, or differences in views about parent-professional partnership. Cultural inconsistencies in the early stages of assessment and diagnosis can add to parents' dissatisfaction with the overall diagnostic process.

An additional issue faced by families is the factor of inconvenience. Assessments often take place in traditional locations and times that may be inconvenient for both parents to attend. Occasionally, assessment and diagnosis occur with only one parent present in the room (Wall, 2004). The other parent must obtain information about the diagnosis second-hand. This can be frustrating for both parents as one may still be coming-to-terms with the diagnosis and may not be comfortable relaying accurate information. On the other hand, the parent who was absent may feel that they did not gain a sound understanding of their child's diagnosis based on this second-hand information.

For this reason, assessment and diagnosis should be conducted at convenient times when both parents are available.

Wall (2004) explains that problems exist around securing the diagnosis. This can be a result of visiting multiple professionals before obtaining an official diagnosis (Goin-Kochel et al., 2006). The more professionals that parents visit, the more difficult it becomes to obtain a solid diagnosis. Because autism diagnosis can be conducted by different clinicians, and is based on the judgment and interpretation of those clinicians, it is likely that they may not all have the same interpretation. Rutter and Schopler, 1994, (as cited in Baker, 2004) state that there is considerable variation among clinicians in their approach to the diagnosis and classification of autism. With the above issues in mind, professionals should be aware of the dynamics of a child, and responsive to the many factors that can affect families during the period of assessment.

2.4 Family-centered practice and parent-professional partnership

In 1920-30 the involvement of practitioners with families was rooted in the compensatory mode, which emphasized the importance of practitioner involvement (Fitzgerald, 2004). Traditional approaches to early intervention were expert-driven, deficit-oriented, and child-centered, and there was no recognition of the impact of family on a child's development (Therese, 1998). More recently, as noted, greater emphasis is placed on parent and family involvement in the education and early intervention of young children. A growing amount of literature suggests that parental involvement has many positive impacts on children's learning and success (Dunlap, Newton, Fox, Benito, & Vaughn, 2001; Prelock, Beatson, Bitner, Broder, & Ducker, 2003; Wall, 2004). Through active participation, family-centred practices embrace parent involvement and are based

on recognizing families as contributors to all aspects of services concerning their child. This approach to working with children focuses on the priorities defined by the family and allows families to be involved in the plans for intervention throughout the assessment and diagnostic process.

Despite the recent shifts in assessment that would better define autism in a social-developmental domain, the disorder remains in the medical field. As a result, some practitioners still follow an 'expert-driven', 'deficit-oriented', and 'child-centered' approach. Professionals who view autism through a medical lens fail to appreciate the importance of parent-professional partnership that accompanies family-centered practices. According to Lawson (2003), practitioners need to have a shared sense of what is meant by the term partnership; the process of information sharing and communication. At the same time, it cannot be assumed that the stakeholders (practitioners) have the same view as the consumers (parents) (Fitzgerald, 2004). On one hand practitioners may view partnership as simply sharing information with parents and family members in a way that they still hold their role as the expert and all power rests with them. However, parents may view partnership as more than just sharing information. They may perceive partnership as being comprised of equal roles in discussions about their child, especially because they are the ultimate expert on their child.

One can see how issues of power imbalance can arise between parents and practitioners during parent-professional partnerships, particularly because partnership involves a blurring of roles between both parties (Edwards & Knight, 1997, as cited in Fitzgerald, 2004). The professional must step down from his/her role as an authority figure and expert and bring himself/herself to the level of the parent who is in need of

service. While the parent, must put aside his/her role as a consumer and bring his/her knowledge to the assessment and establish the role as the expert who is there to teach the practitioner about their child. In order to equalize the power between parent and practitioner, Whalley (2001) suggests that creating an environment in which parents are encouraged to question, challenge, and make choices about their needs is vital. In contrast, Todd and Higgins (1998) suggest that equality may not be the most important part of parent-professional partnership, instead, it may be recognizing the different perspectives of power that each party has. Even with the problems that may arise in attempting to establish parent-professional partnerships, the positive impacts override the difficulties, thus, partnership in one form or another is recommended during the assessment process.

2.5 Traditional vs. non-traditional approaches to childhood assessment

In traditional approaches to childhood assessment there are some practices that can be considered problematic and should be avoided. Greenspan and Meisels (1994) note four specific practices that professionals should consider avoiding during the assessment of a young child or a child with a disability. First, professionals should not force the separation of a child from his or her parent/caregiver. Practitioners likely want the child to be relaxed and comfortable, and a strange situation, location, and person does not allow for this. They note that there is no value in causing distress by forcing separation and that more information is gained when the child is not distracted by the absence of their caregiver. Second, assessment should avoid a strange examiner to test young children since one cannot expect them to co-operate and perform for a stranger as they would for someone who is more familiar. When a child is anxious or unwilling to

cooperate, this can influence the results of the assessment and may not be an accurate representation of what he or she is capable of. Third, assessment should not be limited to easily measurable developmental skills, such as isolated cognitive, motor, and language skills. These do not give insight to how a child organizes his or her world or how they prepare themselves to act and react in their environment. For example, if an assessment test looks at the child's ability or inability to build a tower, make a puzzle, or catch a ball, and the practitioner simply notes "capable" or "in-capable" then recognition of the child's other skills will be left out. Such skills may include, the child's problem solving skills, imaginary play, social skills, and how he or she uses these tasks in the context of his or her life. Last, the focal point of an assessment should not be the scores on the test and how well or poorly a child performs on these tests. Greenspan and Meisels (1994) note that there is a tendency to treat test scores as more important than other sources of data, such as observations, or parent/caregiver reports. There is a tendency to believe that formal tests provide information that cannot be discovered through observation, interactive play, and functional analysis of the child's behaviours.

There are other practices that professionals can adopt in order to improve assessment of young children with and without disabilities. Greenspan and Meisels (1994) suggest the following:

1. Adopting an integrated model of child development.
2. Use of multiple sources of data and assessment techniques to gather information about the child. Use of sources that are most readily available—parents.
3. Parent involvement throughout data gathering and throughout the initial stages of assessment.
4. A sound understanding of child development (both typical and atypical development).
5. Emphasis on the child's functional capacities and how he or she organizes his or her world, rather than focusing on isolated abilities.

6. Acknowledgement that the assessment is an ongoing process that continues to occur throughout intervention.
7. Collaboration that includes family members and all assessors.

Many non-traditional assessments follow the above practices and provide opportunities for active participation from parents. These methods use a team of experts, which includes parents, to conduct the assessment. Some common non-traditional methods include, *multidisciplinary*, *interdisciplinary*, and *transdisciplinary* assessment. In a multidisciplinary approach, each professional on the team participates separately by using the procedures and outlook unique to his or her discipline. This approach gathers information from several sources, instruments, settings, and occasions to produce the most valid assessment of the child. It blends qualitative and quantitative information about a child, their environment and the family (Bagnato, Neisworth, & Muson, 1997).

An interdisciplinary approach makes use of parent-professional partnership. Parents are regarded as an important element in the assessment process and are embedded in the process right from the start. Parents and family are active participants and a strong effort is made to provide them with information, guidance and support during and after the assessment. Typically, parents are involved in parts of the assessment such as home observation and videotaping, parent/sibling/child interaction, and some parents observe alongside the practitioner as they collect data. Family-centered care provides the theoretical foundation for this assessment model (Prelock, Beatson, Bither, Broder, & Ducker, 2003).

The initial assessment of the child takes place in a face-to-face meeting at the child's home or in a location that is convenient for the family. This initial meeting is used to gather background information on the family and to guide the assessment. The actual

assessment is conducted with an interdisciplinary team who interact with and observe the child. The team is also responsible for interviewing family members and community providers that are involved in the child's life. After the assessment is complete the team meets with the family and community providers to review the results of the assessment and brainstorm recommendations to meet the priority needs of the child and the family. A report is then created based on the input of the interdisciplinary team, and is reviewed for accuracy by the family and the community providers. The final stage of this process involves providing the family and community providers with a book of resources to increase their knowledge about autism, intervention plans, and community contacts (Prelock et al., 2003).

A transdisciplinary approach involves a team of professionals from multiple disciplines who simultaneously conduct the assessment. This simultaneous assessment is often referred to as an arena assessment because of the physical setting of having multiple professionals assess a child at one time (Myers & McBride, 1996). This approach includes parents in assessment and programming decisions. In this type of assessment, one professional interacts with the child and the family and carries out the assessment, while the rest of the team observes and determines the skills and abilities of the child using developmental checklists (Myers & McBride, 1996).

A familiar mode of assessment among these non-traditional methods is the *transdisciplinary play based assessment* (TPBA), which include parents at many levels. Parents can act as observers, play facilitators, or interpreter of the child's behaviours. As a play facilitator the role of the parent is to encourage the child and try to elicit the highest level of play and communication (Linder & Newman, 1995). If both parents are

present, one parent may facilitate play while the other sits with the professional and explains what they are observing. Parents can also describe how the child's behaviours are similar to or different from what is seen at home. According to Linder and Newman (1995), play is a powerful paradigm for assessing a young child because during play a child's abilities, motivations, thoughts, and strategies are displayed. Play also illustrates the child's cognitive abilities, such as early object use, imitation, or problem solving. This mode of assessment looks at functional skills and the processes that lead to those skills. TPBA is a holistic approach that looks at all domains of development and how each influences the other. Although the results of TPBA are different than scores and measures of standardized tests used in traditional modes of assessment, it is very useful and provides valuable information about a child.

Increasing numbers of professionals are using TPBA in conjunction with, or instead of, standardized methods of assessment (Bagnato & Neisworth, 1994, as cited in Myers & McBride, 1996). This growth in TPBA use may be due to the desire for family involvement in the assessment process (Myers & McBride, 1996). TPBA provides opportunity for parents to facilitate the child's behaviours by physically supporting the child (if required), eliciting behaviours, or explaining the child's behaviours. Following the assessment, there is opportunity for parent-professional partnership, communication and collaboration that help in developing and implementing intervention.

One drawback to non-traditional assessment is the time commitment required from all parties involved. Such forms of assessments require all involved parties to attend meetings throughout the entire assessment and attend post assessment meetings to summarize the results. These assessments can also be expensive since multiple

professionals are simultaneously present and focussed on one child for an extended period of time. Nevertheless, through extensive communication and collaboration with parents and family members, together they formulate the best recommendations regarding the diagnosis and early intervention services for the child, thus the rewards are substantial (Benner, 2003).

2.6 Autism in Ontario

Based on current research evidence of neural plasticity and the effectiveness of early intervention, Ontario has been focussing more on early intervention for young children with autism (McCain and Mustard, 1999, as cited in Perry, 2002). In 1999, the Ontario Ministry of Community and Social Services, now called the Ministry of Community Family and Children's Services, introduced an initiative to provide IBI (Intensive Behavioural Intervention) to children with autism 2-5 years of age (Perry, 2002). As a result, children in Ontario within this age category now receive funding for the services that they require.

Programs specific to children with autism in Ontario are called "Autism Intervention Programs". They provide IBI and associated services, such as child and family supports, and transition programs for children and their families. The program is intended for children with a diagnosis of autism or an ASD towards the severe end of the autism spectrum. These services are provided by nine regional service providers across the province of Ontario (Government of Ontario, 2005). According to the Ministry of Children and Youth Services (2006), diagnostic and assessment information provided in the referral process of the Autism Intervention Programs should be used to determine

eligibility, intensity, setting and duration of IBI therapy. If the information is not adequate or available, additional assessments may be required.

Currently, “Child and Youth Mental Health” programs are also offered in Ontario to provide services and supports to children and their families. The purpose of such programs is to alleviate social, emotional, behavioural, and/or psychiatric problems that may arise with having a child who has been diagnosed with a disability. In addition, there are specific services to enhance early identification, intervention, and treatment for children up to age six, in sixty-four community-based transfer payment agencies. These programs include activities that focus on but are not excluded to: early identification and assessment, preventing family breakdown, improving parent coping skills, parent education and support groups, treatment services, and linking parent and caregivers to other community services (Government of Ontario, 2005).

Part of the objective of the autism program in Ontario is to ensure that children with autism receive an accurate diagnosis as early as possible (Perry, 2002). This is because, as stated previously, early diagnosis leads to early treatment and intervention and better long term results for the family and the child affected by autism. However, according to Autism Society Ontario (2005), families can be on waiting lists for years to receive diagnostic assessments. This is due to the lack of qualified professionals both trained and willing to make an ASD diagnosis. Since children are not receiving early diagnoses, the objective of the autism program in Ontario has not been met. Through centralized provincial training and education initiatives, Ontario is developing greater professional expertise in early identification and diagnosis (Perry, 2002); however, more research is needed in this area.

2.7 Research questions

This qualitative study aims to examine the experience of parents and families, surrounding the assessment and diagnosis of their child. A small sample was obtained from three different organizations serving children with autism, within a large metropolitan area in Ontario. Parents' experiences were gained through semi-structured interviews, and interpretations of the interviews were made from the perspective of the researcher.

The following questions were the focus of this investigation:

- (1) What are parents' and families' experience of the assessment and diagnostic process?
- (2) How do parents and families want to be involved in the assessment and diagnosis of their child?

CHAPTER 3

METHODOLOGY

3.1 Theoretical frameworks

This study is governed by a feminist approach to research. A feminist lens brings into focus particular questions and issues that have been under-researched. According to Creswell (1998), feminist research aims to study the topics that have not been studied. This investigation embraces the voices of those individuals affected by autism who are not often heard, and whose opinions have been under-researched. These individuals include parents (specifically mothers) of children with autism (Howlin & Moore, 1997, as cited in Midence & O'Neill, 1999).

As it stands, most power lies in the opinions of the professionals who work with children with autism, conduct the assessments, and provide the diagnosis. The voices of mothers have been ignored, and this leads to a power imbalance between females (mothers) and professionals (mostly males). For decades mothers have been the ones to advocate for their child with a disability and push for services. Unfortunately, this type of advocacy for services, assessments, and diagnoses, still exist. The feminist approach taken in this study will hopefully empower mothers to express their opinions and share their experiences.

According to Lather (1991), the goal of feminist research is to correct the invisibility and misrepresentation of women's experiences. The current study attempts to empower participants in order to hear their silenced voices. It has been reported that many mothers of children with autism are not taken seriously when they first approach a professional concerning their child's development. Parents often find themselves in the

position where they must convince the professional that there is a need for an assessment (Goin-Kochel et al., 2006). Past studies on parents' views of the diagnostic process, have indicated that some professionals actually dismiss parents' concerns about their child's development, and are told to wait for their child to "grow out" of their problems (Goin-Kochel et al., p. 440). It is clear that mothers' voices have been silenced and that their concerns have not been taken seriously.

Feminist researchers are usually attuned to the way that they shape their research questions (Hesse-Biber & Yaiser, 2004). The research questions in this study are guided by a qualitative lens using in-depth interviews. In-depth interviews allow feminists to access the voices of other women (Hesse-Biber & Leavy, 2007) and gain a detailed account of their experiences.

3.2 Research design

The purpose of this investigation was to examine the experiences of parents and families surrounding the assessment and diagnosis of their child. According to Howlin & Moore, 1997 (as cited in Midence & O'Neill, 1999), minimal research has been conducted on parents' experiences of autism. The few studies which have been conducted used standard questionnaires; however, this method does not provide a comprehensive understanding of parents' experiences (Midence & O'Neill, 1999). Furthermore, a questionnaire does not allow for the discussion of what makes an experience positive or negative, nor does it allow for the collection of sufficient information to determine how parents would like to be involved in the assessment process. For this reason, the use of a more in-depth method of obtaining information was required; this was through the use of face-to-face semi-structured interviews.

A quantitative approach, such as a questionnaire, yields data in the form of numbers that can be easily interpreted by some professionals in the field of autism. A qualitative approach on the other hand yields straightforward data that can be interpreted by all professionals in the field. Qualitative researchers concentrate on capturing an inside view and providing a detailed account of how participants understand events (Newman, 2006). Hence, results from an interview provide more details than results from a questionnaire. Researchers have the ability to probe answers in ways to better understand the meaning of participants' responses. This design also gives flexibility for altering questions to follow the flow of the interview.

Semi-structured interviews have the advantage of both structured and unstructured interviews. This method offers the flexibility that unstructured interviews offer, and gives the researcher room to build a rapport. Semi-structured interviews elicit more information about a topic than would a structured interview since the researcher is able to use their judgement and probe answers (Craig, 2004). Although structured interviews are the most reliable, they overlook idiosyncrasies, restrain the topic being discussed, and reduce rapport between researcher and participant (Craig, 2004). Structured interviews are rigid and do not allow for flexibility. The interviewer is often detached from the interviewee and is unable to build a rapport or form a connection. But, building a rapport is important during an interview, since it creates a level of comfort that will allow respondents to unreservedly share information with the researcher. From a social-constructivist approach the researcher-participant relationship is essential to conducting qualitative research.

3.3 Recruitment

The sample was drawn from three different organizations within a large metropolitan area in Ontario. To protect the identity of the participants, these organizations will be referred to as: Organization-1, Organization-2, and Organization-3.

Recruitment began in the summer of 2008 and lasted through the fall of 2008. In all conditions I contacted the organizations and made a request to post a flyer on the research section of the website, as well as in the foyer of the center. Since the response rate was low, I also wrote a letter which was sent to parents that briefly explained the details of my study and request for their participation (Appendix I). Volunteers were asked to contact me through e-mail and simply indicate “yes I am interested” in the subject of their e-mail. I replied with details of when and where the study would take place.

3.4 Sample

Four volunteers participated in the study. Two were from Organization-1, one participant from Organization-2, and one participant from Organization-3. All participants were female, more specifically mothers of a child with an ASD. All volunteers had a child who had been formally diagnosed with autism and who was in an early intervention program. Participants' children were between the ages of 5 to 5years7months and had been diagnosed from 5months to 4 years prior to the date of the study. All of the mothers in this study were married. One mother was a homemaker, while the other mothers had full time or part time jobs. Three of the four mothers had children in addition to the child who had been diagnosed with autism. All children, including the child with autism were male. The majority of the mothers were Caucasian,

and one mother was East-African. The following table illustrates the demographic profile of each participant:

Table 1: Demographics of participants

Participant	Gender of participant	Age of child	Age when diagnosed	Number of years in therapy	Gender of child	Cultural background of participant
P1	Female	5yrs 7mths	1yr 11mths	3 ^{1/2} yrs	Boy	Caucasian
P2	Female	5yrs 3mths	4yrs 10mths	1yr 2mths	Boy	Caucasian
P3	Female	5yrs	3yrs	4yrs	Boy	East African
P4	Female	5yrs	4yrs	2 ^{1/2} yrs	Boy	Caucasian

3.5 Procedures

After volunteers contacted me, I set a date, time, and convenient location of where the interview would be conducted. Two interviews were carried out in coffee shops, one was carried out at the school where the participant worked, and one interview was completed in the participant's home. After meeting with parents, I explained the purpose of the study and what it entailed. I briefly explained the details that were laid out in the consent form (Appendix II) and offered the opportunity to ask questions before we began the interview. Before obtaining signed consent, it was made clear that the interview would be tape-recorded for transcription purposes. I explained that if they were not comfortable with this procedure, they could withdraw at any time and their responses would not be used in the final report.

Feminist researchers are concerned with eliminating the power imbalance between the researcher and the participant; thus, it is important for the researcher to build a rapport, by sharing identities and stories with the participant (Hesse-Biber & Leavy, 2007). I made certain to build a rapport with volunteers before beginning the interview.

Due to the sensitive nature of the topic, I showed empathy throughout the investigation. I understood that it may not have been easy to retrospectively recall and analyze a difficult period in the participants' life, that is, the period when their child was assessed and diagnosed with an ASD. I began each interview with small-talk to help build a rapport. I shared information about myself, such as my academic background and work experiences. I then asked participants to tell me about themselves. This included sharing their cultural background, their views on parent-professional partnership, and their views on being the expert about their child. Small-talk helped to get a two-way conversation started, and it became apparent that participants had a lot to share about their experiences.

3.6 Data Collection

Six open-ended questions were asked in the interview (Appendix III). Each question was designed to provide information that would aid in answering the overarching enquiries of this investigation: What are parents' and families' experiences of the assessment and diagnostic process? How do parents and families want to be involved in the assessment and diagnosis of their child? The interview questions were as follows:

- (1) Tell me about your family.
- (2) What went well for you and your family when your child was diagnosed?
- (3) What challenges did you and your family face during the assessment?
- (4) What changes would you like to see in the assessment process?
- (5) How would you have like to be involved in the assessment process?
- (6) What insights did you receive from your experience?

The first question was presented to build rapport so that participants would feel comfortable sharing their experiences. Questions 2 and 3 were asked to determine the positive and negative aspects of parents' experiences respectively. Question 4 related to specific changes that could be made to increase parent and family involvement. Question 5 pertained to how parents would like to have been involved in the process. The purpose of question 6 was twofold: to obtain information that would help to build on the current methods of parent and family involvement during assessment and diagnosis, and to end on a positive note.

Each interview lasted approximately one hour. I used probes only when it was necessary, for example, if parents were confused (based on their facial expression) or if they explicitly asked "What do you mean by that?" Probe questions included: What was the most positive part of your experience? Were there challenges due to emotional stress? Were there challenges due to other children? As suggested in Newman (2006), probes were used to clarify ambiguous answers, or to obtain a relevant response. A complete copy of the interview and probe questions can be found in Appendix III.

Throughout the interviews, I remained as objective as possible as I did not want my biases to influence parents' responses. According to Newman (2006), interviewer bias can be due to expectations about respondents' answers based on other answers. Since I had conducted four interviews in total, there were obvious similarities that emerged between participants' responses. Because of this, I made certain to be neutral with my interpretations of every interview and each answer.

All interviews were tape recorded for accuracy and for the purpose of transcribing the data. Recording the interview allowed me to listen intently to participants' responses

while only writing brief notes to facilitate analysis. Hesse-Biber and Yaiser (2004) emphasize the importance of listening in feminist research. It is noted that when women interview other women they help each other develop ideas and construct meanings together. The point form notes that I created consisted of key phrases and words made by the respondents, and questions that I formulated based on responses that I did not understand. For example, one mothers' response when asked about the insights that she received from her experience was: "it was like taking a shot in the dark". I assumed that this was with regards to the overall assessment process, but I made a note to question her on exactly what she meant. Immediately after the interview, I reviewed the tapes and my notes to ensure that everything made sense and to clear-up any ambiguities or uncertainties.

3. 7 Data analysis

All interviews were transcribed from micro-cassette tapes to text documents. The tapes were reviewed multiple times for clarification before beginning transcription. This gave an overview of common themes that arose between participants and with the literature.

Thematic analysis was used to analyze participants' responses. Coding was used as a form of categorizing the data into common themes. This method is the analytic process through which data are fractured, conceptualized, and integrated to form theory (Strauss & Corbin, 1998). While reviewing participants' answers I analyzed one sentence at a time and made side notes of similar responses. For example, if a mother responded: "The fact that we found out that we weren't just crazy", I made a side note indicating that there was a feeling of relief. If another mothers' response was similar, such as: "Finally

knowing what it was felt like a relief”, I also made a side note indicating that there was a feeling of relief. I highlighted these similarities with the same colors and compiled common responses into a new document. Six different categories emerged and they are as follows: (1) disclosure about the diagnosis, (2) delays in obtaining a diagnosis, (3) level of involvement, (4) knowledge about autism (5) feedback about the assessment, and (6) recommendations and support. At one point or another during the interview, all of the mothers mentioned how they felt when they first heard the diagnosis of autism. Whenever I heard the words “it was like...” in relation to hearing the diagnosis, I grouped those responses into the category about disclosure. For example, “It was like finding out about a death”, or “It was like getting a rock dropped on your head”, both of these responses were grouped under the same category. There were numerous times throughout the interview that participants mentioned that there were delays in obtaining a diagnosis. Whenever participants mentioned anything relating to time and obtaining a diagnosis, such as “There was a lot of lost time because of the waiting” or, “You spend so much time running around trying to figure things out”, I grouped these responses under the category relating to delays. Some mothers felt involved, some mothers who were involved did not feel as involved as they would have liked to be, and one mother felt uninvolved. Regardless of the level of involvement, whenever I heard “involvement”, all responses with this term were grouped under the same category. One mother felt informed about autism as she had read books prior to her child’s assessment, while the other mothers were not as knowledgeable about the disorder. Whenever mothers used the terms “know”, “did not know”, “heard of” or, “never heard of”, responses with these words were grouped under the category about knowledge of autism. Responses with the

term “feedback” were grouped under the category of feedback about autism. For this category, I looked at responses that related to feedback during and after the assessment. Finally, most mothers mentioned something about the support that they received after the diagnosis, so when I heard the terms “support”, “lack of support”, “recommendations”, or “services”, I grouped responses with these terms under the category pertaining to recommendations and support.

Based on recurrent participants’ responses these categories fit into three broader themes: (1) delays in obtaining a diagnosis, (2) involvement in the process, and (3) recommendations and support. These themes alone would not suffice to capture the richness of participants’ responses since they included plenty of data. Therefore, separating the data into the above categories was required for a better understanding of mothers’ experiences. Since responses about disclosure of the diagnosis preceded or was followed by discussions about delays in obtaining a diagnosis, categories 1 and 2 were grouped together. It was clear from participants’ responses that most mothers felt that involvement meant being involved before and throughout the process, therefore categories 3, 4, and 5 were grouped under one umbrella. After sorting answers into one of the above themes, I labelled the responses with the number 1 or 2 depending on the research question that it was related to. An example of how these themes emerged can be found in Appendix IV.

CHAPTER 4

FINDINGS

All mothers were enthusiastic about completing the interview and about sharing their experiences. They had a lot to say and were pleased that someone was interested in their opinions on the topic of their child's assessment and diagnosis. This was the first time that these mothers had shared their feelings about the process with a researcher, and seemed to enjoy the experience. One parent even said that the interview was "enlightening". Based on participant responses, I was able to obtain a detailed and comprehensive account of parents' experiences of the assessment and diagnostic process. Although there were only four respondents, the information was sufficient to answer the overarching questions of this investigation:

- (1) What are parents' and families' experience of the assessment and diagnostic process?
- (2) How do parents and families want to be involved in the assessment and diagnosis of their child?

The results are organized under six sections: disclosure about the diagnosis, delays in obtaining a diagnosis, level of involvement, knowledge about autism, feedback about the assessment, and recommendations and support.

4.1 Disclosure about the diagnosis

Three of the four mothers experienced mixed emotions upon hearing the diagnosis for the first time. Since all participants in this investigation experienced delays in obtaining a diagnosis, there were feelings of "relief" for most mothers when their child was eventually diagnosed. One mother said: "Finally knowing what it was felt like a

relief” (P1). Another mother said: “I’m really glad she diagnosed him with autism...we got this diagnosis and we focused on autism, which we would have never done” (P2). For another mother, receiving an autism diagnosis confirmed her suspicions about her child’s abnormal development.

we found out that we weren’t just crazy. That at least there was something to...some sort of label, which isn’t a nice word, but there was...so just to hear that I’m not crazy made me feel a little better and that there was actually something that I could start doing.” (P4)

P2 had a negative experience with the process and was not happy about the way her child’s diagnosis was communicated. This is apparent in the following response:

There was nothing positive about the experience...she [clinician] wasn’t even sure of the diagnosis...she said....I can’t tell you for a hundred percent, but I think he might be slightly autistic...those were her words. (P2)

On the other hand, one mother had a positive experience about the process despite having to wait for a diagnosis. When asked about her experience of when her child was finally diagnosed, she replied:

By the time he was diagnosed he’d already been nearly a year in speech therapy and nearly a year in occupational therapy...Dr. [name] was worth the wait... By the time we had gotten there, we had kind of been through most of the challenges. (P3)

Despite the feeling of relief that most mothers experienced, three of the four mothers also mentioned feeling shocked when they first heard that their child had autism. P3 was also shaken when her child was first assessed, in spite of her positive experience. The following quotes illustrate shock in participants’ responses: “Well, the impact of the diagnosis, it was like finding out about a death” (P1) and “It was like getting punched in the stomach” (P4). Another mother described her experience in a little more detail, but her response still reveals a feeling of shock.

It took me about five minutes to get [child] into the room, and then it took another three to four minute to get him into the chair. He [clinician] looked at him [child] and said to me “How long has he been showing autistic tendencies?”...from a parents’ perspective that’s like getting a rock dropped on your head...and that was the first time any professional had said something was wrong. (P3)

When I asked P2 about her experience of when her child was first diagnosed, she mentioned that she did not know much about the disorder and that she did not feel informed. This was clear in the following response:

The only thing I knew about autism at that point was that it was something to do with a neurological disorder. I knew it was not normal and that it was going to be all his life...I did not feel informed at all. (P2)

4.2 Delays in obtaining a diagnosis

Three of the four mothers said they had experienced delays in obtaining a diagnosis for their child. A couple of the mothers had to “push for a diagnosis”. There were feelings of frustration due to these delays. One mother even felt that her initial concern for her child was not taken seriously.

I think that if parents come to them [professionals] with a concern, they should take it seriously and right away get an assessment, a developmental assessment. Take it seriously!...Our regular paediatrician didn’t take the time...My husband pushed for a diagnosis. (P1)

This mother also mentioned the time lost during the period of waiting: “There was a lot of lost time because of the waiting...We felt like we were swimming upstream...It was a wait-and-see attitude for me and for a lot of parents” (P1). Another mother visited multiple professionals before obtaining the final diagnosis for her child. She spoke about the time that her child had lost that could have been spent in intervention.

The first professional, aside from a family doctor that [the child] saw was [Dr...], he was an idiot, [he said] “don’t worry he’ll grow out of it”...my family doctor was quite supportive and she actually felt quite horrible....because she had missed things....she sent us to [an organization], but there was nothing coming from that that I could take anywhere and say “see we need an assessment.” (P3)

Toronto Pre-School Speech and Language wouldn't touch us with a twenty foot pole the first time I contacted them...I was jumping up and down saying there were problems...It took me over a year to get him on...to even get someone to pay attention to put him on the list...it was a year wait, that's not so bad, no...it took over a year to get him on the list....so we're looking at two years now...that's ridiculous, he wasn't four years old yet, and they wasted two years of his life. (P3)

P4 explained that her child's assessment was broken into three different parts with a two-to-three week interval between each assessment. This mother would have preferred that the assessments were conducted all at once:

I don't think I would have liked such a long period of time...instead do it all in one week or something, it's not going to change anything...it just takes longer to get a diagnosis...I just thought it was a long time. (P4)

4.3 Level of involvement

Whereas one mother felt quite involved from the beginning of the assessment process, she explained that getting there was very difficult: "Once you finally get into the assessment process, the parents I think are pretty involved, the issue is getting there in the first place" (P3). On the contrary P2 did not feel involved throughout the diagnostic and assessment process, and felt that her attempts to be involved were discouraged. This is evident in the following responses: "When I questioned his diagnosis, she really got upset", "It would have been helpful if she listened to my feedback [but] she would not hear it" and, "I wish she had taken my input a lot more because I work with him, I know him". She also said the following:

We weren't allowed to look at him...he kept turning around and looking at me to see...you know "should I answer?" kinda thing, and I wasn't allowed to interact with him. I wasn't even allowed to nod at him. Anytime he looked at me it got to a point where she [clinician] got mad at me for looking at him...I may as well have not been in the room. (P2)

some of the words he [child] was saying were in my mother tongue and she didn't get it...I would automatically jump in and translate to English for her....she

would snap at me for jumping in. (P2)

During one assessment, P2's husband was asked to play with the child while she and the clinician observed. This mother did not agree with her husbands' level of involvement. This is clear in the following response:

She [clinician] was talking to me and she was watching him [child] play with my husband, but she has to realize that if she's going to have me listen to her, my husband wants to hear as well, and so my husband wasn't really playing with my son... my husband was ignoring him...she took it as 'he's not interacting with your husband'...my husband is ignoring him because he wants to listen to what you are saying...I wish if she would have had us [parents] participate then she should have had us paying attention to him and see how much attention is he giving to us. (P2)

The other two participants' felt somewhat involved, however, they were not involved in the way that they would have liked to be:

Once we got a developmental paediatrician then I felt involved, but the process should have been more family friendly...I would have liked to have constant dialogue with the professionals, I wanted to feel like I can question them. (P1)

instead of afterwards being handed a bunch of paper work on what autism is, I would have want to be briefed on what autism is and what testing they would have been doing, and what his responses would tell them...what they were looking for. (P4)

I would have liked to be involved by them giving me a little briefing of the type of things you might ask...maybe if I was to play with toys or something like that...Maybe if I understood more of what I was trying to do, then sure I'd like to be involved, but I really wasn't aware of what was going on. (P4)

One mother mentioned an experience pertaining to culture, and felt strongly that her effort to participate and interpret her child's responses was discouraged. This mother would have liked the opportunity to translate her child's responses from her home language into English. This is clear in the following response:

Some of the words that he [child] was saying was in my mother tongue and she didn't [accept it] ...he would say something and I would automatically jump in and translate into English for her...she would snap at me for jumping in, and I would

like “but I’m just translating” (P2)

4.4 Knowledge about autism

Two of the four mothers did not have much knowledge about autism. This is clear in the following responses:

the only thing I knew about autism at that point in time was that it was something do with a neurological disorder. I knew it was not normal and that it was going to be all his life. (P2)

We never really heard of autism....My husband had never heard the word before in his life...I had only heard it in passing....I didn’t know anything about it...How it’s assessed. Nothing! (P2)

P4 said: “I really didn’t know anything...even now it confuses me” (P4). The other two mothers were a little clearer about the disorder. One mother worked in an elementary school as a teacher, and had seen a few children with autism over the years. The other mother had done extensive reading prior to her child’s assessments and understood the disorder by the time her child was diagnosed.

4.5 Feedback about the assessment and the diagnosis

Mothers were given adequate material after receiving the diagnosis. However, two of the four mothers explained that they did not understand the material that was given to them and had to interpret it on their own. In addition, these mothers did not receive a copy of the report even after making a request for it. Throughout the assessment, some of the mothers were not given feedback to help them understand the assessment and what the clinician was testing for. One mother said: “We were given a non-comprehensive sheet from the neurologist” (P1). Here are other common responses:

The biggest issue with this particular doctor...she wont give me the report. I asked her “let me just read it in your office” and she said “no”...I wish I could have gotten a copy of the report. (P2)

a lot of the stuff that she was testing for, I was wondering if he's not doing it because he doesn't understand or because, he's not comfortable...or is he not doing it because he's never been exposed to it...how much of it is exposure? (P2)

A similar circumstance was experienced by another mother: "I tried to contact the doctor afterwards [to access the report] and she never returned my e-mails" (P4). What is more is that this mother did not understand the results of the assessment and did not feel informed. This is clear in the following response: "The diagnosis didn't really describe much to me...I could have written it myself for the most part...it didn't really tell me why or what equals autism" (P4). She explains in more detail exactly what it was that she did not like, and the questions that she had that were left unanswered:

the challenges we faced were basically trying to understand what it was they were testing for...during the testing, wondering 'ok he did this, as a response to what? and is that positive or negative? Is it a sign of autism or something else'....no feedback... not knowing what they wanted him to do... really not understanding autism at all. (P4)

P3 had read many books on autism, including books on methods of autism assessment, therefore she did not mention whether she obtained feedback about the assessment and diagnosis, or whether the information obtained was sufficient.

4.6 Recommendations and support

Three of the four participants pointed out that they did not receive sufficient recommendations from the clinicians, including information about autism, support, services, treatment options, and information on what steps to take next. The following responses illustrate the lack of recommendations and support from clinicians:

We felt alone...there should have been some sort of agency....My husband and I did a lot on our own. We had to figure out how to go through the procedures, but would have liked an agency that would hold our hands. (P1)

She [clinician] should have known where to send us. My husband and I felt very strongly about this. She should have known about [Organization-1], she should have known about Autism Ontario, she should have known all of these resources.....she had no excuse not to give us resources. (P2)

One thing I think that would help immeasurably is after the diagnosis, recommend books....books should be given because we would have been a year ahead. (P3)

One mother received some recommendations to inform her about autism, including an informative course that also acted like a support network with other mothers of children with autism. This mother was also provided with treatment options for her child; therefore, support after the assessment was not an issue for this particular mother.

CHAPTER 5

DISCUSSION

The present study aimed to explore parents' and families' experiences of the assessment and diagnostic process and explore ways of how they would like to be involved. The first part of the findings describes how parents experienced the disclosure about their child's disability. The fact that all of the mothers reported strong negative emotional feelings upon hearing the diagnosis shows that there are major socio-political implications that can be drawn from this study. First, it demonstrates how our thoughts about disability have been shaped in a way that it is viewed through a negative lens. When there are parents who describe their initial reaction of hearing about a disability to a tragedy such as "death", it shows that there is a major problem with how society views disability. We have been conditioned to think that when an individual has been diagnosed with a disability, they cannot lead "normal" and independent lives. But with a disorder like autism, where the prognosis varies for each individual, it is quite possible for such individuals to lead normal lives. Many people would argue that disability is a social construct based on individual differences and the social environment in which the individual lives. With this in mind, disability should not be viewed as a major defect or abnormality, but rather it should be viewed as a neutral difference that can and should be embraced.

Another socio-political implication is the illustration that there must be treatment or a cure for individuals with a disability. As stated earlier, a diagnosis of autism leads to a label and a label permits access to treatment. In the current study, most mothers were not happy with the fact that their child had been labelled; however, they all pushed for a label

in order to receive treatment. What we often fail to realize is that treatment for individuals with a disability aims to normalize these individuals so that they can “fit-in” to society the way that society want them to “fit-in”. What is so wrong with a child who flaps his/her hands because he/she is excited? Or a child who only likes to eat red Smarties because the other colors are not to his liking? This is not to say that some disability-related problems do not require some forms of care or analysis. But, perhaps the overall care for disability is a change in the way that society interacts with individuals with disability.

The final socio-political implication is the illustration that the agents of remedy are the professionals who assess and diagnosis individuals with disability. Professionals are seen as the “gate-way” between the individual and society, but this is not always the case. The agents of remedy can be the individuals who are constantly, advocating, lobbying, and fighting for their child. Often, these individuals are parents, more specifically mothers.

In using a feminist approach as the framework for this investigation, it is clear that mothers did not feel as though they were the agents of remedy for their child. Power differentials exist between mothers and the professionals who conducted the assessments. Often, this power imbalance occurs when the professionals refuse to accept the parents as the expert. Many mothers expressed feelings of being disempowered because they were not included in the assessment of their child. Based on participants’ responses, it is clear that mothers did not feel involved because they were not informed throughout the process. As described above, one mother felt disempowered when the clinician

discouraged her from translating her child's responses from her home language to English.

In conducting in-depth interviews I was able to capture a detailed account of participants' experiences. Hesse-Biber and Leavy (2007) note that if the participant and the researcher are of the same gender (such as in the current study) then "open dialogue" is quickly established, and it provides "maximum opportunity" for the voices of the participants to be heard (p. 140). In the current study, there was an advantage due to gender and professional background of the researcher. Both characteristics enhanced the research as this connection allowed for a deeper rapport to be formed with participants.

Feminist research especially from a qualitative approach allows the researcher to effectively study the lives of women and investigate their range of experiences (Hesse-Biber & Yaiser, 2004). Whereas quantitative research yields data that can be replicated and replaced, qualitative research yields data that is unique to the participants in a particular study and cannot be directly replicated. What is most important is that qualitative feminist research, such as this, aims to produce data on the voices that have been silenced.

Although the sample size was small in this study the results add support to the findings in the literature, which suggest that parents are dissatisfied with the assessment and diagnostic process (Goin-Kochel et al., 2006; Silkos & Kerns, 2007). The findings also suggest that parents would like to be more informed and more involved in the assessment and diagnosis of their child. Autism assessment and diagnosis is an on-going procedure that can take a considerable amount of time to complete (Kabot et al., 2003). Diagnosis is based on the clinicians' judgement as well as on reliable reports of current

and past information about the child (Whiteley et al., 1998, as cited in Baker, 2004). This information is obtainable and most accurate when it comes from parents and other family members who know the child best. The mothers in this investigation felt that their initial concerns about their child were not taken seriously the first time that they approached a professional. Mothers viewed themselves as the expert on their child, therefore, when they first approached professionals and the professionals had a “wait-and-see” attitude (Silkos & Kerns, 2007, p. 11) it caused frustration, particularly because this response leads to delays.

Based on participants’ responses, there were major delays in completing their child’s assessments and in obtaining a final diagnosis. After long wait-lists, and visits to multiple professionals, it was evident that parents experienced difficulty in obtaining an autism diagnosis. These results are similar to the findings in the literature (Silkos & Kerns, 2007). All participants felt that waiting for a diagnosis lead to wasted time that could have been used in intervention programs. However, as mentioned earlier, children can not apply for or receive funded treatment until they receive an autism diagnosis (Autism Society Canada, 2005).

The literature on autism shows that early assessment and diagnosis leads to better long term results for the child (Robin et al., 2001; Wetherby et al., 2004). Intervention before the age of 3^{1/2} is more effective than if a child begins after age 5 (Wetherby et al., 2004). Three of the four participants’ children in the current study, were diagnosed after the age of 3 and began intervention after the recommended age of 3^{1/2}. Because autism diagnosis is limited by early screening tools (Bryson et al., 2003) and by the lack of qualified professionals who are willing to make early diagnoses (Autism Ontario, 2005),

it is difficult for children to obtain a diagnosis as early as parents would like. It is also difficult for parents to know that there is a problem with their child and that intervention programs can alleviate the problem, but accessing these programs is lengthy and cumbersome. Given the effects of early identification and early intervention, one can see how frustrating waiting can be for parents. In the initial stages of coming-to-terms with the idea of having a child with a disability, delays can be a major stress.

Mothers were also dissatisfied with their level of involvement throughout the assessment process. Despite the fact that three of the four mothers were somewhat involved, two of the three were unhappy with their level of involvement. It was clear that for the mothers in the current study, involvement was not merely active participation, as suggested in the literature (Linder & Newman, 1995; Prelock et al., 2003), they wanted to be verbally informed by the clinicians about what was taking place during the assessment. Mothers wanted to know what the clinicians were testing for, what the meaning of the tests were, and what the defining characteristics that lead to the diagnosis of autism were. This was evident in participants' responses to interview question-5, which related to how parents would have like to be involved.

Despite the high prevalence of autism (Autism Society Canada, 2005), parents may still be unfamiliar with the details surrounding assessment and diagnostic procedures of autism. The mothers in this investigation reported that they were vaguely familiar with the disorder and had only "heard the term in passing". Because autism does not have biological manifestations and diagnosis relies on the clinicians' judgement (Lord, 2007, as cited in Pérez et al., 2007), parents may require more information that would provide them with a clearer understanding of what they cannot see.

Parents come to the assessment with many questions and concerns. Even throughout the assessment, questions come up. Some mothers felt confused during the process and did not understand what their child's responses to the tests meant. They would have preferred that every step of the assessment be described. This includes explanations about the behaviours and responses that made their child "autistic". Even the mother who had a positive overall experience was unclear about the prognosis of autism. Based on parents' responses, it was obvious that involvement included being informed of what was happening. Many of the mothers mentioned that it would have been helpful if feedback was given throughout the assessment rather than material that they had trouble understanding following the assessment. Furthermore, mothers did not appreciate the lack of support after the assessments were completed and the diagnosis was given. Many of them had to make sense of the disorder on their own or with their husbands.

Feedback, ongoing support, and follow-up appointments are assessment qualities that are important to parents (Sloper & Turner, 1993). Most mothers reported that ongoing support and recommendations were not part of their child's assessment. Parents reported that they had to "advocate" and "push" for their child to gain access to intervention and services, and reported that they felt "alone" during the process. One mother mentioned that the clinician did not know where to send her after receiving the diagnosis and felt strongly that the clinician should have known. Piper and Howlin (1992) found that parent satisfaction was lower one year after their child's assessment than directly after the assessment. This was probably because parents had time to digest and analyze the details of their experiences. The parents in the current study may have

experienced a similar decrease in their level of satisfaction. It is clear that parent satisfaction about the assessment is not only dependent on the assessment itself, but it is also dependent on services received after the assessment.

The purpose of assessment is to obtain a diagnosis that gives individuals access to services (Siegel, 1996). These services include programs to alleviate the problems that may appear with having a child with a disability. Such programs include, parent education groups, support groups, and coping skills programs (Government of Ontario, 2005). Although families are eligible for services once their child has received an autism diagnosis (Autism Society Canada, 2005), the procedure of accessing these services is stressful. With the exception of one participant, it was evident from mothers' responses that little effort was made by clinicians, to connect parents to these services. This collaboration could lead to greater satisfaction about the assessment process. Of course the process of advocating for one's child is not an easy task, especially when the results can take years (Howlin & Moore, 1997). Mothers already experience the stress of time commitments, other children, and marital pressures due to having a child with a disability (Havens, 2005; Wall, 2004).

The logic behind qualitative research deals with gaining an in-depth understanding and often involves a small sample size (Hesse-Biber & Leavy, 2007). Unfortunately, this was also the greatest limitation of this study (sample size N=4). Another limitation was the restrictions in the method of recruitment. This study sought participants whose child was between 3-5 years of age and who had been formally diagnosed with autism. If participants had a child within this age bracket, this meant that their child had been diagnosed 2-3 years prior to the date of the study. Although these parameters helped to

produce up-to-date data surrounding autism assessment and diagnostic procedures, they also restricted the number of volunteers who chose to participate. With the diagnosis occurring just a couple years prior to the study, parents may have still been coming-to-terms with the idea of having a child with a disability and some may have even been in a state of denial. These could be reasons for the low number of participants. Furthermore, the recruitment was restricted to organizations serving children with autism. If the recruitment source comprised of different types of organizations, including parent support groups or parent education programs, the study could have included a wider range of participants.

CHAPTER 6

CONCLUSION

The study revealed the experiences of a small group of mothers. The findings are comparable to the literature, which suggests that parents of children with autism are dissatisfied with the assessment and diagnostic process. The implications of this study suggest that parents would like to be more involved in the assessment process. Involvement includes being more informed throughout the procedure so that parents can better understand what is taking place.

Parents should be briefed about autism and the relating disorders prior to the assessment. Clinicians should also discuss the assessment and diagnostic procedures that will be used. This briefing may lessen the impact of the shock upon hearing the diagnosis for the first time. Parents should also be informed throughout the assessment, and be encouraged to ask questions and collaborate with the clinician. Clinicians should explain what they are testing for so that parents feel informed and are equally involved in the process. Parents should also be debriefed after the assessment so that they understand what leads to the diagnosis of autism. Parents should be encouraged to question practitioners (Whalley, 2001) as this leads to a more family-friendly assessment. This type of collaboration is central to family-centered practices (Fitzgerald, 2004). Miller and Hanft, 1998 (as cited in Baker, 2004) suggest that the most important factor in creating a positive assessment experience is the presence of a strong parent-professional partnership. In addition, Sloper and Tuner (1993) emphasize that there is a need to give parents clear and accurate information and to acknowledge their initial concerns.

As suggested in Greenspan and Meisels (1994), professionals should realize that assessment is an ongoing process that continues to occur even throughout intervention. Professionals should adopt assessment practices such as those suggested by Greenspan and Meisels. Professionals should work with parents every step of the way making sure they are well informed, and are provided with details of the assessment afterward. Additionally, families should be provided with books of resources to increase their knowledge not only about autism, but also about intervention plans, and community contacts (Prelock et al., 2003).

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Appendix I: Letter to volunteers

Hello, my name is Deborah Saunders; I am a graduate student at Ryerson University, and am conducting a study as part of the requirement for a Master's of Arts in Early Childhood Studies.

This study is about the assessment and diagnosis of autism. The purpose is to investigate the perceptions of parents and families of children with autism.

I am looking for parent(s) or family members of children 5-6 years of age who have been formally diagnosed with autism within the last 2-3 years. You will be asked to complete a short (15-minute) survey about your perceptions of the assessment. At the end of the survey you will also be asked if you would like to participate in a more in depth face-to-face interview. Only a few randomly selected parents will be chosen to participate in the interview.

I am aware that this may be a sensitive topic for some individuals; therefore, I will make a strong effort to build a comfortable and relaxed atmosphere. I would like to inform you that participation in this study is completely voluntary and your responses will be kept confidential. Your participation will not influence future relations with Ryerson University or affect provision of services to you or your child. This research has been approved by the Ryerson Research Ethics board.

If you are interested in participating in this study please contact me, Deborah Saunders via e-mail and simply indicate "yes I am interested" in the subject of your e-mail or give me a call at the number below.

Thank you for your time,

Deborah Saunders
MA candidate
Early Childhood Studies
Ryerson University
deborah.saunders@ryerson.ca
(416) 931-9245

Appendix II: Consent form

Ryerson University Consent Agreement

Parent Involvement in the Assessment and Diagnosis of Autism

You are being asked to participate in a research study. Before you give consent, it is important to read the following information.

Purpose of the Study: This study is part of the requirement for the completion of a Master's of Arts in Early Childhood Studies. The purpose is to investigate the perceptions and experiences of parents and families when their child was assessed and diagnosed with autism.

Investigator: Deborah Saunders

Under the supervision of Dr. Elaine Frankel, Professor, Master of Arts in Early Childhood Studies, School of Early Childhood Education, Ryerson University, efrankel@ryerson.ca, (416) 979-5000 ext. 7651

Description of the study: Families who volunteered to participate were asked to complete a short survey. At the end of the survey you were asked if you would like to also participate in a more in-depth face-to-face interview. The purpose of the interview is to gain a better understanding of your responses. You will be posed open-ended questions which will give you the opportunity to elaborate on your perceptions and experiences.

Some sample questions include:

- *What went well for you and your family when your child was diagnosed?*
- *What challenges did you and your family face during the assessment of your child?*
- *Would you have preferred to be more involved in the assessment of your child?*

Confidentiality: Your responses will be protected throughout the process of this investigation. Your responses will only be discussed anonymously with the project supervisor; Dr Elaine Frankel. Individual responses will not be released in a way that will permit a link between your specific information and your specific responses. The data collected from this investigation will be presented only in aggregate forms (e.g., percentages, means, etc.). Furthermore, you will not be identified in any written or oral report.

Voluntary nature of participation: Participation in this study is voluntary. Your choice of whether you would like to participate will not influence your future relations with Ryerson University or affect provision of services to you or your child. If you choose to participate, know that you are free to withdraw your consent at any time without penalty.

Questions about the study: If you have any questions about the research now, please ask. If you have any questions later you may contact

Researcher: Deborah Saunders, deborah.saunders@ryerson.ca

Project Supervisor: Dr. Elaine Frankel, efrankel@ryerson.ca,

(416) 979-5000 ext. 7651

Agreement: Your signature below indicates that you have read the information in this agreement. Your signature also indicates that you would like to participate in the study and are aware that you can change your mind or withdraw consent to participate at anytime. It also signifies that you agree to have the interview audiotape recorded.

You have been given a copy of this consent form to keep.

You have been informed that by signing this consent form you are not giving up any of your legal rights.

Signature of participant

Date

Signature of researcher

Date

Audio-taping agreement: Your signature below indicates that you are aware that this interview will be tape-recorded for transcription purposes. It also indicates that at anytime throughout the interview if you do not feel comfortable and would like to withdraw you may do so. If this occurs the interview will be discontinued and your information will not be used in the final report.

Signature of participant

Date

Signature of researcher

Date

This research has been approved by the Ryerson Research Ethics Board. You may contact them at anytime if you have any questions regarding the ethics of this investigation.

Ryerson Research Ethics Board
Ryerson University,
350 Victoria Street Rm. YDI 1154
Toronto, Ontario
Canada M5B 2K3

Chair: Nancy Walton (416) 979-5000 ext. 6300 nwalton@ryerson.ca
Ethics Coordinator: Alex Karabanow (416) 979-5000 ext. 7112
alex.karabanow@ryerson.ca

Appendix III: Interview

INTERVIEW QUESTIONS

(Small talk)-conversation to build rapport

1. Tell me about your family

Probes: What is your cultural background? From your perspective, tell me your views on parent-professional partnerships? From a cultural perspective, tell me your views on parent-professional partnerships? Do you feel like the expert of your child? How? Do you feel that professionals are experts on your child? How?

2. What went well for you and your family when your child was diagnosed with autism?

Probes (only if necessary): What was the most positive part of the experience? Was there anything in particular that stood out? Time? Location? Involvement? Did you feel well informed of what was happening throughout the process?

3. What challenges did you and your family face during the assessment of your child?

Probes (only if necessary): Were there any fears? Were there challenges due to emotional stress? What about challenges due to time commitment? Or challenges due to other children?

4. What changes would you like to see in the assessment process?

Probes (only if necessary): More parental or family involvement? More opportunity to speak with professionals? Change in the location of the assessment (for example in your home)?

5. How would you have liked to be involved in the assessment process?

Probes (only if necessary): Interpreter of child's behaviours? Facilitate play or other activities with your child? Sit with and listen to clinical team? Being present in the room with your child? Observing from a two-way mirror? Giving feedback to clinical team?

6. What insights did you receive from your experience?

Probes: What did you learn? Were there any rewards?

Appendix IV: Categories and themes

Research questions:

- (1) What are parents' and families' experiences of the assessment and diagnostic process?
- (2) How do parents and families want to be involved in the assessment and diagnosis of their child?

Participant response	Category	Theme	Research question
"My husband pushed for a diagnosis."	Delays in obtaining a diagnosis	Delays	1
"There was a lot of lost time because of the waiting."	Delays in obtaining a diagnosis	Delays	1
"When I questioned the diagnosis she got really upset."	Level of involvement	Involvement	2
"I really didn't know anything even now it confuses me."	Knowledge about autism	Involvement	2
"We were given a non-comprehensive sheet from the neurologist."	Feedback about the assessment	Recommendations and support	2
"We felt alone, there should have been some sort of agency"	Feedback about the assessment	Recommendations and support	2